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REVIEW / *DERLEME*

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Preferences and Experiences of Family Members Witnessing Cardiopulmonary Resuscitation: A Systematic Review

Kardiyopulmoner Resüsitasyona Tanık Olan Aile Üyelerinin Tercihleri ve Deneyimleri: Sistematik Derleme

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ABSTRACT This systematic review aimed to examine the preferences and experiences of family members who had witnessed cardiopulmonary resuscitation.
Electronic searches were performed on Cochrane, JBI, Ovid, PubMed, Scopus, and Web of Science. We included studies conducted among adult patients and family members that were published in peer-reviewed journals in English between 2013-2018. The studies were summarized by the researchers independently. Then, the summaries were compared, and a consensus was established among the researchers. A total of nine studies were included. Family members expressed that they wanted to witness the cardiopulmonary resuscitation and expected to have that decision respected by healthcare professionals. Although the number of studies were limited, family members who had witnessed cardiopulmonary resuscitation experienced less anxiety, depression, post-traumatic stress, and grief. Further comparison studies are needed to identify the positive and negative experiences of family members who witnesss cardiopulmonary resuscitation.
Keywords: Family witnessed resuscitation, family presence, family members' preferences, family members' experiences

ÖZ Bu sistematik derlemenin amacı, kardiyopulmoner resüsitasyona tanık olan aile üyelerinin tercihlerini ve deneyimlerini incelemektir. Cochrane, JBI, Ovid, PubMed, Scopus ve Web of Science elektronik veri tabanlarında taramalar yapıldı. Sistematik incelemeye 2013-2018 yılları arasında yetişkin hastalar ve aile üyeleri ile yürütülen ve hakemli dergilerde İngilizce olarak yayınlanan çalışmalar dahil edildi. Kapsama alınan makaleler araştırmacılar tarafından bağımsız olarak özetlendi ve fikir birliği sağlandı. Toplam dokuz çalışma dahil edildi. Aile üyeleri kardiyopulmoner resüsitasyona tanık olmak istemekte ve bu karara sağlık profesyonelleri tarafından saygı gösterilmesini beklemektedirler. Sınırlı sayıda çalışma olmasına rağmen, kardiyopulmoner resüsitasyona tanık olan aile üyelerinin daha az kaygı, depresyon, travma sonrası stres ve keder yaşadığı belirlendi. Kardiyopulmoner resüsitasyona tanık olan aile üyelerinin olumlu ve olumsuz deneyimlerini belirlemek için daha fazla karşılaştırmalı araştırmalara ihtiyaç vardır.
Anahtar Kelimeler: Aile tanıklı resüsistasyon, aile varlığı, aile üyelerinin tercihleri, aile üyelerinin deneyimleri

Introduction

Although the presence of the families is not desired during the cardiopulmonary resuscitation (CPR), family presence during resuscitation (FPDR) has been recommended as an interdisciplinary intervention due to its importance within the recovery process (1). FPDR refers to the intervention of CPR to the patient with the presence of his or her family (2,3) or by ensuring that the family is in visual or physical contact with their loved one during CPR (3).

FPDR is consistent with family-centered care model (4) and considered a very important component (5). Creating patient and family-centered care policies would ensure the day-to-day interaction of healthcare professionals as well as the structuring of facilitating designs (4,6). Furthermore, this model has been reported to have positive effects, such as the improvement of healthcare outcomes, effective utilization of resources, patient satisfaction, and patient family satisfaction. It is important to include families in the healthcare process when the patients are intubated in

intensive care and emergency units where they cannot be involved in decision-making regarding themselves as they are not able to speak. FPDR in these units contributes to the partnership of healthcare professionals, patients, and families within the care process (6). Therefore, many professional organizations, such as the American Association of Critical-Care Nurses and Emergency Nurses Association, support the idea of family-witnessed CPR due to its benefits for patients and families and have published guidelines on their implementation (1,3). In addition, the European Resuscitation Council guidelines emphasize that patients' relatives should be offered the option of being present during CPR, and cultural and social differences regarding these decisions should be respected (7).

Studies have shown that family-witnessed CPR has positive effects on patients, family members and healthcare professionals (8). However, research results still suggest that this issue is a very controversial, underutilized, and unusual practice (9,10).

When examining the literature, there is a lack of sufficient studies on the subject. Listed among existing studies are a systematic review examining the impact of training provided to support FPDR implementation by healthcare professionals (11), a meta-synthesis in which qualitative studies of patients, families, and nurses are combined (6), a review of the literature on barriers related to using FPDR in the emergency department (12,13), and an integrative review on the behaviors and experience of nurses and physicians (14). However, there are no systematic reviews in the literature regarding the preferences and experiences of the families of adult patients regarding FPDR itself. Therefore, this review aimed to bring these studies together and share their results.

Materials and Methods

This systematic review aimed to examine the preferences and experiences of family members witnessing CPR. A literature review was done by using a systematic approach. Sackett (1997) framework, known as Population, Intervention, Comparison, and Outcome, was used to elicit insight into the current body of evidence (15). The following framework was used; Population: patients and relatives who were 18 years or older; Intervention: family members who had witnessed CPR practices; Comparison: family members who had witnessed CPR and those who had not; Outcome: preferences and experiences of family members.

Cochrane, JBI, Ovid, PubMed, Scopus and Web of Science databases were searched using the keywords "CPR," "support", "witnessed resuscitation", "family-witnessed resuscitation", "family presence", "family members' preferences", "family members' experiences", and "impacts on family members". Studies concerning adult patients and families published in English in peer-reviewed journals between 2013 and 2018 were included in the study, while studies in languages other than English and those concerning child patients and families were excluded. A total of 1,317 articles (Web of Science: 503, Scopus: 328, Cochrane Library: 259, PubMed: 105, Ovid: 107, JBI: 15, other sources: 3) were transferred to the EndNote program. After 119 duplicate articles were removed, 671 articles published within the given dates were transferred to the program, and a separate file was created. Then, the headlines and abstracts of the 671 articles were evaluated. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram was used to guide article inclusion, and a total of nine studies meeting the PRISMA research criteria were included in the sample. A total of 662 studies not meeting the PRISMA research criteria were excluded because these studies were about different healthcare professionals' or students' experiences, or scale development studies or the sample of the research comprised children and their families regarding FPDR (Figure 1).

Data Analysis

To summarize the data, researchers developed a Data Summarization Form, evaluated the data according to it and summarized each article independently. Then, the summaries were compared, and consensus was established among the researchers. Because the type of research and measurement methods of the studies included in this systematic review were different from each other, it was aimed to present any relevant data without performing a meta-analysis.

Results

The final data set consisted of nine articles: two randomized experimental studies, four qualitative studies, one cross-sectional study, one descriptive study, and one multivariate, comparison prospective study. While seven of these studies were conducted with family members, one concerned patient family and nurses and another concerned patient, family members, and healthcare professionals

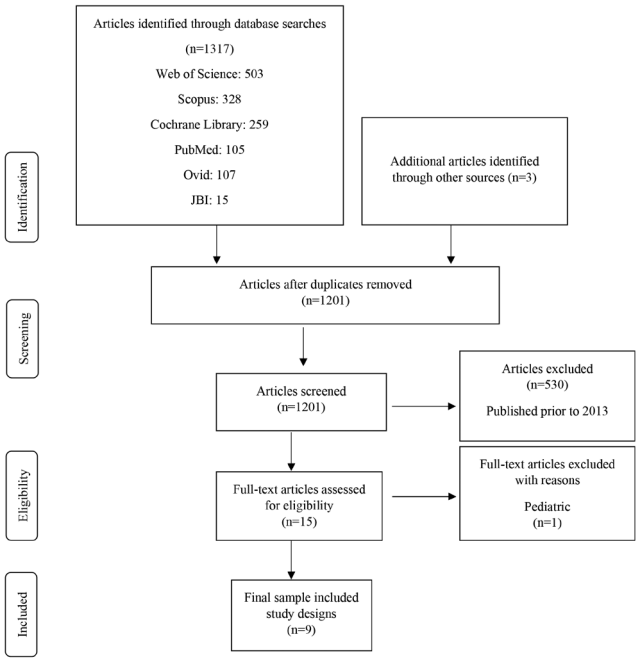

Figure 1. Summary of the data collection

(physicians, nurses, and paramedics). In these two studies, only the results obtained from the family members were taken into consideration. The study included papers from France (3 papers), United States (2 papers), Australia (2 papers), Finland (1 paper), and Iran (1 paper). The titles, designs, sample characteristics, findings and suggestions of the papers are given in Table 1.

In the two randomized controlled studies, conducted by the same authors using the same sample group, a total of 570 family members present or not present during CPR were compared. A trained psychologist collected the data using a scale during telephone interviews 90 days after the resuscitation in the first study and one year following the resuscitation in the second study. In both studies, post-traumatic stress syndrome-related symptoms, the Hospital Anxiety and Depression scale, or the Major Depressive Episode scores were found to be significantly higher in the control group (16,17). In addition, Jabre et al. (16) (2014) also studied complicated grief status, finding it to be higher also in the control group. Furthermore, another study (experimental: 70, control: 70) identified that FPDR had reduced the anxiety and stress in the families as well as fostered reports of well-being in the family (18).

Four of the studies included in the systematic review had been planned as qualitative research, of which three were conducted with family members (1,19,20) and one with family members, patients, and healthcare professionals (21), with sample sizes ranging from 12 to 30. Giles et al. (21) (2016) examined in detail the factors affecting family members' decisions to accept or reject FPDR. Family members regarded caring for their loved ones and being present with them as their fundamental rights.

De Stefano et al. (19) evaluated the experiences of family members during CPR, also. The findings indicated that active participation during resuscitation was very important in terms of supporting the loved one emotionally and observing the efforts of the healthcare professionals to save the patient, ensuring effective communication between the family and healthcare professionals, increasing satisfaction from the efforts of the resuscitators, and making death and loss easier to accept. Furthermore, this study indicated the central role that family presence played in accepting death and relieving the pain of death based on the experiences and reactions of the families who witnessed CPR, the feeling of participation at this important moment, and the communication between the family and the healthcare team.

Leske et al. (1) emphasized the importance of collaboration among the family and healthcare team in his study. In Sak-Dankosky et al.'s (20) study, aiming to determine the preferences of the family members regarding FPDR, concluded that there were gaps in the presentation of family-centered care in intensive care units, that the families desired more involvement in patient care during CPR, and that healthcare professionals should be more attentive and respectful during CPR.

In the descriptive study of Zali et al. (22) (2017), randomly selected nurses and family members were asked to evaluate the positive and negative aspects of witnessing CPR. Family members shared the opinion that it was helpful to be with their loved one to see that everything was being done for them and to provide spiritual support.

In the population-based study using a cross-sectional design (23), 1,208 individuals were contacted by phone in order to evaluate the level of the social support given to families present during CPR and to determine whether or not opinions had changed in the case that the patient was a child, adult, or themselves as well as to identify effective factors. The study concluded that younger adults (18-25 years) had strong desires to be present during CPR and wanted their family members to be present during CPR.

Table 1. Analyzes of included articles (by years)						
Author\Year	**Title of Article**	**Design of Research**	**Sample**	**Method**	**Study Findings**	**Suggestions**
Jabre et al. (17) (2013)	Family presence during CPR	The prospective, cluster-randomized, controlled trial.	First-degree relatives of patients who presented to 15 hospital emergency medical services with cardiac arrest at home and was implemented resuscitation between November 2009 and October 2011.	Experimental group was offered the chance to witness resuscitation. Control groups were not offered this proposal, standard communication was maintained and their requests to monitor CPR were asked. Because 211 of the 266 individuals in the experimental group (79%) and 131 of the 304 family members in the control group (43%) stated they would like to witness CPR, the comparisons were made on these individuals. Data were collected 90 days later by a trained psychologist. IES and HADS were used. PTSD, anxiety, depression findings and the effects of the family presence on the healthcare professionals were evaluated.	PTSD-related symptoms in the control group were higher than those in the experimental group. Anxiety and depression rates were higher in those who did not witness CPR. Relatives witnessing CPR did not affect the resuscitation procedure, survival rate of the patient, nor level of emotional stress in the healthcare professionals, so it did not result in any malpractice cases.	The presence of family members during CPR of adult patients at home and in emergency units were found to benefit both the family and healthcare team.
Leske et al. (1) (2013)	Experiences of families present during resuscitation in the emergency department after trauma	Descriptive qualitative design	Sample size was 28 family members (one family member per patient who was 18 years or older, visited the patient in the surgical intensive care unit, spoke English, and had only one critically injured patient in the family).	Open-ended interview format was used (three open-ended questions).	Two main categories were as follows: the role of the healthcare professionals to treat the patient and the role of the family to protect and support the patient. Family members stated that the experience of being present in the trauma room lessened their anxiety. In addition, FPDR helped family members to build trust in the healthcare team, fulfilled information needs, allowed family members to gain proximity to the patient, and fostered family members to support the patient emotionally.	Study results supported a family partnership with the healthcare team. Further research is needed with other populations for both the patient and family perspectives to clarify the meaning of FPDR in these role contexts.

Table 1 contiuned

Jabre et al. (16) (2014)	Offering the opportunity for family to be present during CPR: 1-year assessment	The multi-center randomized controlled trial.	570 family members who applied to the 15 emergency units between 2009-2011 and whose relatives had had cardiac arrest at home	Experimental group (n=266) was provided with the opportunity to witness CPR and not offered to the control group (n=304). At one-year post-resuscitation, a trained psychologist unaware of the group allocation asked family members to answer a structured questionnaire over the telephone. The IES, the HADS, the Inventory of Complicated Grief, and the Structured diagnosis of Major Depressive Episode were used.	In the evaluations made at the end of the first year, PTSD-related symptoms were higher in the control group. PTSD, HADS, complicated grief and depression diagnostic inventory were higher in the control group.	Due to the psychological benefits of FPDR, family members should be given the opportunity to witness CPR.
Dwyer (23) (2015)	Predictors of public support for family presence during cardiopulmonary resuscitation: A population-based study	Cross-sectional design.	1,208 randomly selected people over the age of 18	To determine public perceptions in general, researchers interviewed i ndividuals by telephone, collecting the data by a questionnaire. The data collection form recorded demographic data and the data concerning the attitudes and behaviors of families during CPR.	Only 20% of participants had previously experienced CPR in their families. Of the participants, 52.5% stated they would like to witness CPR, and this should be asked to the families. The reasons for not wanting to be present during CPR were that the healthcare professionals could be distracted (30.4%), it would be very upsetting to watch their relatives in this way (30%), and fear and uncertainty (19%). Gender, prior experience, and being an adult or child were effective factors ($p<0.05$).	It is important that healthcare professionals receive family support during decision-making. It is useful to share experiences and give information about family-witnessed CPR.

Table 1 contiuned

Giles et al. (21) (2016)	Original research: Empirical research - qualitative	Constructivist, grounded theory design-qualitative	Using purposeful sampling, 25 individuals in acute care settings, including healthcare professionals (registered nurses, doctors, paramedics), family members, and patients who desired the presence of their families or whose families were present during CPR.	A flexible interview guide was used to reveal the experiences of individuals. The data were collected through face-to-face interviews, telephone calls, and three follow-up interviews. The interviews lasted 25-65 minutes.	The study's themes are summarized as follows: Caring for his/her patient/ relative (perception that being with their loved one is the most important right and making decisions on their behalf as well), being provided the opportunity, valuing family presence, prioritizing preferences and rights, evaluating the ability of the individual to cope with process in terms of the competence of the individual (first reaction they display when inviting, etc.), determining the boundaries by healthcare professionals (preparing the family with support staff and postponing the participation of the family until a suitable environment is provided), and protecting others and self (some of the healthcare professionals tried to protect families from emotional and psychological impacts of observing disturbing resuscitation scenes).	Increasing awareness about FPDR and application of recommended clinical protocols have become the starting point of addressing inconsistencies and differences in practice. Future practices need to be guided by evidence and standards for the safety and well-being of healthcare consumers rather than their individual preferences and values.

Table 1 contiuned

De Stefano et al. (19) (2016)	FDPR: A qualitative analysis from a national multi-center randomized clinical trial.	Sequential explanatory design-qualitative	Purposeful sampling method with 30 randomly selected family members who had and had not witnessed CPR. Survivors after CPR were excluded from the sampling.	Relatives of patients who had agreed and had not agreed to be present during CPR were classified as the experimental and control groups. They were contacted on the phone three months after the CPR, and the semi-structured interview form was used. PTSD, depression, and anxiety levels of individuals were determined.	Four themes were identified: (1) choosing to participate actively in CPR; (2) communication between the family and emergency care professionals; (3) perception of death, acceptance of loss; (4) experiences and reactions of relatives who witnessed or did not witness CPR. The presence of the family during the transition from life to death, the feeling of being present at this important moment, and communication between family and emergency care professionals played a central role in accepting death and alleviating the pain of death.	Witnessing CPR is recommended to the family members because it is protective and prevents helplessness in a traumatic case. It ensures the active participation of the healthcare professionals due to the presence of their families during the resuscitation process.
Zali et al. (22) (2017)	FDPR: A descriptive study with Iranian nurses and family members of the patients.	Descriptive	A total of 177 Iranian nurses and 137 families, who had previously experienced CPR were included.	A 27-question sociodemographic survey about attitudes towards FPDR.	57.2% of family members stated that they had the right to experience FPDR and that witnessing CPR had certain advantages, such as monitoring that everything necessary was done for the patient and having less anxiety. There was a significant difference between the responses of the nurses and families regarding the positive aspects of the application, such as benefiting the patient (family mean score: 2.98; nurses mean score: 2.06), benefiting the family (family mean score: 3.08; nurses mean score: 2.50). There was also a significant difference between nurses and family members in terms of the negative aspects of FPDR.	Attempts to reduce the gap between nurses and families related to FPDR were proposed.

Table 1 contiuned

Leske et al. (18) (2017)	FDPR after trauma .	Multivariate, comparison prospective design.	Adult family members of critically injured trauma patients, speaking and understanding English and having no more than one critically injured patient in the family. They were eligible to participate in the study up to 72 hours after admission to the surgical intensive care unit. Only one family member per trauma patient was enrolled. The study sample size was 70 family members who were present in FPDR and 70 who were not present.	Study instruments included demographi c information, and family strengths were measured using the Family Inventory of Resources for Management scale, Family Crisis Oriented Personal Evaluation scale, and Family Problem Solving Communication index. In addition, family outcomes were measured by using four additional scales: the State-Trait Anxiety inventory, Acute Stress Disorder, Family Well-being index, and Family Satisfaction in the Intensive are Unit scale.	The option to participate in FPDR significantly reduced family self-reporting of anxiety and stress and fostered well-being; however, it was not significant for satisfaction with critical care.	The option to participate in FPDR may help families be better equipped to help the patient during the initial critical care period.
Sak-Dankosky et al. (20) (2019)	Preferences of patient families regarding family-witnessed cardiopulmonary resuscitation: A qualitative perspective of the family members of the intensive care patients.	Descriptive qualitative design; Phenomenological study.	Relatives of 12 patients who had been in adult intensive care for at least two years.	Data were obtained from the relatives of the patient through in-depth interviews and a semi-structured questionnaire form.	The data were classified into two main themes, consisting of four sub-themes: More inclusion in the healthcare process of the patient in CPR and being cared for and treated respectfully during possible CPR.	They stated that there were gaps in the delivery of family-centered care in intensive care units, that the awareness of nurses and patients about the family preferences should be increased, and that system changes were required for the successful implementation of FPDR. It was also stated that further research was necessary to demonstrate the success of family-witnessed CPR.

CPR: Cardiopulmonary resuscitation, FPDR: Family presence during resuscitation, PTSD: Post-traumatic stress syndrome, IES: Impact of event scale, HADS: Hospital anxiety and depression scale

Their opinions were affected by gender, prior experience of witnessing CPR, experiences of relatives, and cases when CPR was conducted on a child, adult, or themselves. The study determined that younger adults had wanted to be present during CPR of a child at the rate of 75%.

Discussion

FPDR is the fundamental component of family-centered care. According to family care nursing theory, health affects all family members, health and illness are family events, and families determine healthcare processes and outcomes (24). For this reason, it is very important for healthcare professionals to provide families with the FPDR option. This review aimed to examine the preferences and experiences of family members regarding FPDR.

Family members wanted to show support by being present with their loved one during CPR and thought this was helpful (22). Family members desired more inclusion during CPR and expected their presence to be understood and respected by healthcare professionals (20). Furthermore, anxiety, depression, post-traumatic stress, and grief experienced by families decreased (16,17). Moreover, witnessing CPR resulted in reports of well-being by the families (25) and played an important role in relieving the pain of family members as well as accepting death (19).

FPDR remains a controversial issue due to medical, social, cultural, ethical, and legal aspects as well as to the psychological and emotional effects it has on the patient's family (26,27). Despite the positive results, studies have reported also that health professionals had differing opinions (14). Some healthcare professionals who look positively upon FPDR think of it as a "patient's right," helping to facilitate the family's acceptance of their loved-one's death and make the grieving process easier (26,27). Negative attitudes included patient safety, emotional responses of family members, performance anxiety, concerns about creating stress in the healthcare environment, and distraction (28,29). In addition, some healthcare professionals look negatively at FPDR from cultural and religious aspects, thinking that it creates stress burden, affects the CPR procedure negatively, and creates trauma on the patient's family. Moreover, healthcare professionals are doubtful toward FPDR due to the lack of formal policy and sufficient studies on the subject (26,27). In a study conducted with 63 healthcare professionals in Turkey, 65.07% of them strongly opposed FPDR, 71.41% stated that the presence of family members negatively affected their performance, and they were concerned about making mistakes during the CPR because CPR requires focus (27). In another study conducted using a randomized experimental design, the anxiety levels of patients' families and healthcare professionals were evaluated. Despite there being no differences in the anxiety levels of the families who witnessed CPR, there were differences in anxiety levels of the healthcare professionals, and it was found that especially physicians who performed CPR with FPDR experienced more stress (30).

Although the history of FPDR dates back many years, it is still not included in routine family-centered nursing practice in healthcare settings (31). That is why, to benefit from FPDR, it is important to raise awareness in healthcare professionals regarding its positive effects.

Strengths and Limitations

The strengths of this systematic review are that many nursing and medical databases were searched extensively. In addition, quality assessment and data extraction in duplicate were done by two separate authors using piloted forms. The limitation of this systematic review was the inclusion of studies published between 2013-2018 in English only.

Conclusion

Although there are few studies investigating the preferences and experiences of family members related to family-witnessed CPR, it has positive effects on families. Family members desire to be with their loved one and support him or her spiritually and want healthcare professionals to respect these wishes. However, further research is needed to explore the positive and negative experiences of family members witnessing CPR.

Ethics

Peer-review: Externally peer-reviewed.

Authorship Contributions

Surgical and Medical Practices: P.K., Ö.D., Concept: P.K., Ö.D., Design: P.K., Ö.D., Data Collection or Processing: P.K., Ö.D., Analysis or Interpretation: P.K., Ö.D., Literature Search: P.K., Ö.D., Writing: P.K., Ö.D.

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