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Family Presence During Resuscitation: A Randomised Controlled Trial Of The Impact Of Family Presence

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Abstract

Introduction: This study was undertaken to determine effects on relatives of family presence in an emergency resuscitation room during resuscitation.

Methods: This study was undertaken using a randomised controlled trial using survey methodology. The setting of the study was the emergency department of a major tertiary referral teaching hospital in Queensland. Participants were relatives over 18 years of age, related to patients meeting the inclusion criteria. Relatives were randomly assigned to the experimental or control group. The control group followed the established procedure of placement in the relatives' waiting room, while the experimental group was given the option to be present during the resuscitation with a supportive officer for assistance.

Results: An association was found between those who were present (and their relative survived) and their belief that their presence was beneficial to the patient. Demographic data identified characteristics of the relatives.

Conclusions: This work has identified that relatives find it beneficial to be present in the resuscitation room. Their presence helped with communication between staff and family, and helped relatives to cope with the situation.

Keywords: resuscitation; family presence; relatives; randomized controlled trials

Introduction and aim

It has been established practice in most Emergency Departments (ED) in Australia to exclude the relatives of critically ill patients from the resuscitation room during resuscitation. Over years of clinical practice, two clinician researchers found many situations where the interests of the patient and the relatives seemed to be better served by them not being excluded. The authors could find no Australian research available on the subject of family presence during resuscitation. Most overseas literature was anecdotal with little structured research having been undertaken on the subject.

A three-year research project was undertaken to examine three main areas:

1. Is there a difference in staff attitude to relatives' presence in resuscitation after the implementation of the project?
2. What were staff attitudes to relatives' presence in resuscitation immediately post resuscitation?
3. What are relatives' attitudes to being present during resuscitation?

This report describes the findings of the third area of the research, the relatives' attitudes to being present during resuscitation. Relatives whose family member was resuscitated, were randomised on arrival to the ED and surveyed one month after the resuscitative event. Findings of the other phases will be described elsewhere in the literature. This research was undertaken to establish a starting point for a body of scientific evidence related to this area of clinical practice in the ED.

Literature review

A search of the literature was undertaken using database, citation and hand searching methods. The database searches of CINAHL and MEDLINE are commonly used search engines in medicine and allied health. A citations search was under-taken using collated articles and ISI Web of Science. Hand searching was undertaken for the most common emergency journals including *Journal of Emergency Nursing, Australian Emergency Nursing Journal, Accident and Emergency Nursing Journal, Emergency Medicine* and the *Journal of Accident and Emergency Medicine* (renamed *Emergency Medicine Journal).*

Doyle *et al.*[1] first documented the Foote Hospital emergency department's program of Family Participation During Resuscitation. Since then, publications relating to the topic area fell into two broad categories, research-based and opinion-based. All but 28 of the articles found were opinion-based, editorial or personal accounts of experiences. Of the 28 articles, the majority of the publications relating to relatives presence during resuscitation and invasive procedures focussed on staff opinions and feelings.[2—13] One was excluded as it focussed on the patient,[14] one was excluded as it examined staff-parent interactions[15] and a further six were excluded as they focussed on young children, their parents and the definition of invasive procedures was very broad and included insertion of intravenous cannulae or lumber puncture with little or no reference to presence during resuscitation.[16—21]

Only seven research-based articles were based on the experiences of the relatives.[1,22—26] One Australian publication was found to be tangentially related to the topic. Once again, it was a descriptive review and not a research article.[27]

Doyle *et al.*[1] surveyed relatives about their experiences in the emergency department during their relatives resuscitation. Seventy-two percent indicated they would have liked to be present during the resuscitation. A program was developed to allow certain members of family into the resuscitation room and they were surveyed after their experience. This study showed that family presence during resuscitation can be conducted without disruption to medical care. The relatives in this study were usually present after the arrival of the patient and the initial invasive procedures were completed. The relatives were also asked to leave if other invasive procedures needed to be performed. Although this study was selective in its participants and their presence did not usually involve witnessing invasive procedures such as intravenous insertion it was the initial study that began the change in care for relatives of critically ill emergency patients.

Barratt and Wallis[23] surveyed bereaved relatives to determine their opinions on being present during the resuscitation of the relative and their experience and knowledge of cardiopulmonary resuscitation. Relatives were contacted by phone after their visit to the emergency department and then sent a survey. The results indicated that family would like the opportunity to be present during resuscitation.

Retrospectively, Meyers *et al.*[24] found relatives would have wanted to be present if they had been given a choice. Meyers' research team continued their research prospectively to examine relatives' attitudes after they have been present during resuscitation. Meyers *et al.*[25] conclusions overwhelmingly indicated that relatives want to be present, that the presence of relatives had positive outcomes and that they believed it was their right to be present.

Robinson *et al.*[26] used a randomised, controlled trial method to evaluate whether relatives would like to be present during the resuscitation of their relative and whether witnessing the

resuscitation had any psychological impact on the relatives. Robinson *et al.*[26] found little difference in their levels of distress compared to those not present.

Hanson and Strawser[22] revisits the Foote Hospital family presence program nine years after the program began. While this article provides some experiences that have occurred in the nine years of the program, it does not provide any new research data evaluating relatives' presence during resuscitation.

Finally, Weslein[28] conducted semi-structured interviews with 17 family members to explore their experiences with cardiac arrest. This study looked at three aspects of the cardiac arrest event: the initial event with the patient, when emergency medical services arrive and when staff take over at the hospital. Of these 17 relatives, only two followed the patient into the resuscitation room on arrival at the emergency department. This study had a small sample with a wide range of experiences and provides some insight into the family experience with cardiac arrest. It does not provide a comprehensive view of family presence during resuscitation once they arrive at the hospital.

The Emergency Nurses Association (ENA), based in the United States of America, first released their position statement supporting the presence of relatives during resuscitation in 1994[29] with an 84-page education package that provide guidelines to assist organisations implement the practice within their unit.[30] The American Heart Association in collaboration with the International Liaison Committee on Resuscitation (ILCOR) released within their 2000 Guidelines a section on the Ethical Aspects of CPR and Emergency Cardiovascular Care.[31] These guide-lines discuss the presence of family during resuscitation efforts and encourage staff to offer the opportunity to enter the room during resuscitation. The guidelines also recommend, in line with ENA Guidelines, the allocation of one staff member to the family as a support person to "answer questions, clarify information and offer comfort" [31, p.10].

Methodology

Due to the dominance of opinion-based publications about relatives, a randomised, controlled trial method was chosen to provide structure in this topic area. Relatives of patients meeting the inclusion criteria were randomised to either the control group or experimental group. The control group continued with usual practice of sitting in the quiet relative waiting room. The experimental group were invited to be present in the resuscitation during the resuscitation. Demographic and contact details were obtained before the relative(s) left the department and were followed up by a research assistant independent of the emergency department one month later.

Inclusion criteria for the resuscitation patient

The inclusion criteria for patients to meet the resuscitation criteria are: patients in Triage Category 1 or 2, with or without altered level of consciousness (a Glasgow Coma Scale reading of 13 or less), hypotension, respiratory distress or the need for cardiopulmonary resuscitation. Trauma cases were excluded to provide for consistency between the control and experimental groups.

Inclusion criteria for relatives/significant others

The relatives had to meet the inclusion criteria to be part of the study. This included the relatives of those patients that met the criteria for inclusion above, those who were over 18 years of age, immediate family or significant other, the obtaining of written consent, the presence of a trained support person and the relative must not be disruptive to the treatment.

Randomisation process

The relatives of patients who fit the criteria, were randomly assigned to either the experimental group or the control group. A group of identical envelopes, containing randomly allocated control or experimental group were developed on a ratio of 40:60. The higher ratio of experimental to control was to allow for relatives who did not consent to be a part of the study and enter the room. The randomisation process is outlined in Fig. 1 following recommendations outlined in the CONSORT Statement.[32]

Sample size determination

At the time the sample size was determined, there were minimal studies undertaken on relatives. As a result a power calculation was not possible. Based on the existing non-randomised studies, sample sizes varied.[10,22] The research team aimed to have at least 30 recruited in each group. The research team wanted to allow for an attrition rate of 10% per group. Anecdotally, the staff felt there would be an increased attrition to the experimental group due to their reactions. A further 30% attrition was included to the experimental group. Rounded up, the sample size aimed to be 40 for the control group and 60 for the experimental group.

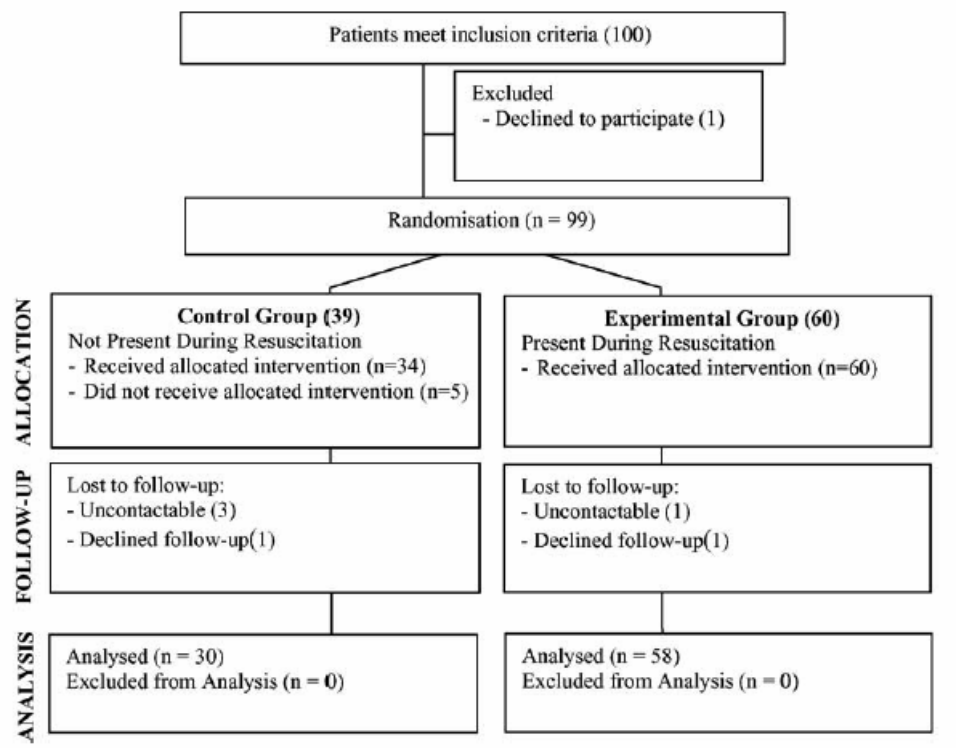

Figure 1 Participant flow diagram through the project.

Data collection

Consent from relatives was obtained prior to the commencement of each subject inclusion. Demo-graphic data including contact details for follow-up was collected prior to the relatives leaving the department. A reminder letter was sent out one month later with the

questions to be asked during the phone interview attached. A research nurse independent of the emergency department then undertook a follow-up phone call to collect the data using the survey tool.

Relative's Questionnaire

Were you asked if you would like the opportunity to be present during your relative's resuscitation period? Y/N

If yes, did you go in and observe the care of your relative? Y/N

If no, would you have liked the opportunity to be present during the resuscitation? Y/N

Were you involved in any resuscitation procedures prior to your relative arriving at hospital? Y/N If yes, please explain

Have you ever had any experience with resuscitation prior to this event? Y/N If yes, please explain

* Did you feel pressured to be with your relative during the resuscitation? Y,'N

* Did the staff communicate with you during the resuscitation process? Y/N

+ Did the staff communicate with you about your relative whilst you waited for the doctor to inform you of your relative's condition? Y/N If yes, please explain

+ Would you have preferred to be present in the resuscitation room during the resuscitation? Y/N If yes, please explain

What are your feelings about being present in the resuscitation room?

*What can you remember about the resuscitation?

* Are you glad you were present in the resuscitation room?

* Do you feel that your presence in the resuscitation room assisted you to come to terms with the loss of your relative Y/N

+ Do you feel that your presence in the resuscitation room would have assisted you to come to terms with the loss of your relative? N/N

Did you feel you were given adequate support by staff (e.g. Doctors, nurses, social worker and chaplains) during and following the resuscitation procedure? Y/N If yes. please explain

Were you given any follow -up support in the weeks following your family crisis? Y/N If yes, please explain

Do you have any further comments on the presence of Relatives in the resuscitation room during resuscitation?

* Questions specific to the experimental group
+ Questions specific to the control group

Figure 2. Outline of questionnaire used with relatives.

Survey tool

Survey questions were developed to provide continuity between the control and experimental groups of subjects with a variation in the questions to reflect the outcome of the patient. That is, questions were worded to suit the relative of the patient who lived or was deceased. An outline of the questions in the tool are in Fig. 2. Demographic data relating to age, previous experiences and gender were collected. Survey questions based upon the experiences of the clinical staff and the review of the literature were developed for each

phase of the project. All questions were dichotomous or open-ended in nature. During the early development of the tool, the project team asked clinical staff to comment on the questions and how they would answer them if they were a relative. Due to the delicate nature of the tool, it was difficult to test the tool prior to the commencement of the project so the tool was piloted on the first 10 relatives participating in the project. As data was collected via phone interview, the research team validated the questions with the participants during the interview. The research team analysed the responses for content validity and the survey remained unchanged. To ensure reliability, education was undertaken on how to collect the data with the research team and research assistant. Reliability was measured by degree of agreement. Where possible, the same research assistant was used.

Demographic questions included age and relationship to patient. During the development of the tool, the multidisciplinary team felt the results from relatives may be influenced if they worked in a health care field. As a result, a question asking if they worked in a health care field and if so what the occupation, was included.

Relatives were asked if they were invited to be present during the resuscitation. When the answer was yes, they were then asked whether they went into the resuscitation room. If they were not invited, they were asked if they would have liked to go in. Data was gathered in relation to the participation in the resuscitation prior to the arrival to the hospital and previous to this event. Relatives who were present were asked if they felt pressured to go in during the resuscitation. Relatives were asked if they were communicated with during the resuscitation process relevant to their location, either within the room or in the relatives' waiting room. Relatives who were present in the resuscitation room were asked about what they remembered of the resuscitation and how they felt about being present. The support of staff in the emergency department and the service provided was also evaluated. Finally, an open question relating to any other comments completed the interview.

Ethical considerations

The researchers conformed to the ethical guide-lines set out by the National Health and Medical Research Council's National *Statement on Ethical Conduct in Research Involving Humans.*[33] The Human Research Ethics Committee of the hospital approved the research project. There were many ethical issues to be considered during this project. The consent of both staff and patients was obtained prior to entry to the resuscitation room. After long deliberations with staff, it was decided that although it could potentially bias the results of the project, if staff did not wish to participate in the resuscitation room with the relative/s present, their decision would be respected and they would be replaced in the area for the duration of the resuscitation.

There was consideration given to the potential for traumatic consequences on staff as a result of the relatives' presence. A major education program in the ED was undertaken at the beginning and at strategic periods throughout the project. The education program included peer-support, debriefing and dealing with grieving relatives. At the end of each resuscitation, the nurse-in-charge informally debriefed staff and initiated follow-up for-mal debriefing as required. A bereavement follow-up program was initiated to ensure relatives were followed up independently of the project. This included giving contact details of the support person/nurse involved to relatives for any later questions. Follow-up contact was offered prior to relatives leaving the department.

Results

The results of the findings have been divided into three areas of questions for reporting here. The three areas of questions were related to: demographics, relatives' experiences and support

while in the emergency department. Statistical analysis of the findings of the surveys consisted of descriptive statistics only.

Demographics

Table 1 reports the relationship to the patient and age group of the respondents for experimental and control groups. For both groups the majority of relatives were either the spouse/partner, 55.2% for experimental and 51.7% for control group and over the age of 50 years, 50.9% for experimental and 64.3% for the control group.

When asked if the respondents worked in a health care field, the experimental group identified 22.8% work in the health care field while the control group identified 31%. A total of 11 respondents were nurses distributed across both groups. Carers were also well represented with six. Other health care workers included an ambulance officer, social worker and administration staff. A complete description of respondents working in the health care field is shown in Table 2.

Table 1 Demographics of relatives

	Experimental (n = 58) (%)	Control (n = 30) (%)
Relationship		
Wife	39.7	27.6
Husband	12.1	10.3
Daughter	20.7	17.2
Son	6.9	3.4
Parent/s	12.1	17.2
Sibling	3.4	6.9
Grandchild	1.7	0
Partner	3.4	13.8
Family friend	0	3.4
Age group (years)		
20—25	7	0
26—30	1.8	0
31—35	8.8	3.6
36—40	14	3.6
40—50	17.5	28.6
>50	50.9	64.3

Table 2 Relatives who work in healthcare

	Experimental (n = 58) (%)	Control (n = 30) (%)
Yes	2.8	31.0
No	66.3	33.7
Types of occupations		
Carer		Carer
Nursing		Nurse
Administration officer		
Red cross volunteer		
Domestic		
Payroll officer		

Experiences

A total of 58 families in the experimental group were present during resuscitation. Only 12% of relatives in the experimental group and 10% of the control group were involved in the

patient's resuscitation prior to their arrival at hospital. Respondents experience with resuscitation prior to this event was 14% for the control group and 24% for the experimental group.

From the findings of the open-ended questions, experiences were also described. The most common responses made by relatives on their feelings of being present were: "I preferred to be present"; "I was worried about being in the way"; "it's a personal choice"; and "I was very scared and emotional". Memories of the resuscitation mainly focussed on the activity, how fast and how much was being done for the patient and how reassured and cared for the family felt.

Support

None of the respondents felt pressured to be present and 43% preferred to be present. The control group was asked if they would prefer to be present and 67% responded yes. Of those relatives that were present during the resuscitation, 100% were glad they were present during their relative's resuscitation. Both control and experimental groups reported staff communicated with them during the resuscitation. The comments made by each group however showed the difference in the type of the communication. The control group were informed of condition on arrival and were allowed to see patient and told everything after the resuscitation. The experimental group always had someone with them, staff explained things as the resuscitation went along, and staff offered support and allowed questions to be asked during the resuscitation.

The experimental group was asked if they thought their presence in the resuscitation room assisted them to come to terms with the patient's outcome from the illness. Ninety-six percent felt their presence assisted them to come to terms with the patient's outcome. When asked whether their presence in the room would have helped them cope with the outcome better, 71.2% of the respondents from the control group felt their presence in the room would have helped them cope more with the outcome.

The relatives of patients from the experimental group that was revived during resuscitation were asked if they thought their presence was beneficial to the recovery of their relative. The experimental respondents had overwhelming responses on this question with 85% feeling their presence was beneficial to the patient's recovery. Comments relating to this included: "We were able to calm him"; and "as a result, my father became less frightened".

The experimental group responded well when asked if they had adequate support during their visit to the emergency department with 92% feeling they received adequate support. The control group made only five responses to this question, but all of these five respondents felt they were given adequate support. Some of the comments from both groups included: "they made us feel part of the process"; "we were not in the way and could ask questions"; "doctor was really sorry husband was sick and I was very appreciative of this"; "staff explained what was happening"; "medical officer kept coming in and explaining our relative was comfortable"; and "nurse and chaplain stayed with us for hours and anything we required was arranged quickly".

The follow-up support was also discussed with the respondents. Fifty-eight percent of the experimental group stated they received follow-up sup-port while only 18% of the control group reiterated this comment. The most common comments from the respondents for both groups related to the category of staff member conducting the follow-up and that the relatives felt they did not need follow-up.

Other comments made by the relatives included "a wonderful idea"; "well cared for"; "helped with grieving process"; and "we liked how we were allowed to walk in and out of the room". The most negative comment made by relatives was "memory of tubes, etc. will stick in my head, but I was glad to be there".

During the phone interview, two negative comments were made pertaining to general

administrative issues within the department. Permission was received for these to be reported to the Nurse Practice Coordinator for review.

Discussion

The findings of this research have provided a preliminary, structured analysis of the issues surrounding the complexities of encouraging the presence of relatives in resuscitation. Our findings show that many family members are grateful for the ability to be present during the resuscitation of their relative.

The trial originally was to have been completed over a 12-month period. There were a variety of circumstances however, that extended the study to over three years. The major reason related to the surprising number of patients for resuscitation presenting without relatives or significant others.

The demographic data showed inconsistent results between the health care occupation of the relative and their experience of resuscitation prior to the event. The major indicator of this was the relative with nursing qualifications with little resuscitation experience. Although clarification of the type of qualifications versus area of nursing experience was not recorded, one reason for the inconsistency could be that health care experience does not necessarily correlate to resuscitation experience.

While perceptions of staff both within the emergency department and the literature[25,34] indicated concern about relatives critiquing staff performance during the resuscitation, the results indicate relatives are more focussed on the support provided and not the procedures being undertaken.

During the study, changes to staffing and environmental factors impacted on the success of the follow-up program as indicated by the number of relatives actually followed up. This requires further study focussing more specifically on this area. No conclusions can be drawn from the available data. During the phone interview, comments relating to the project were overwhelmingly positive. Negative comments were so rare that all of them have been reported within this article.

Implications for practice

The research supports the relative's presence during resuscitation. This project also highlights the important need for the support person in the over-all care of the patient and their relatives in the emergency department. The research has also high-lighted the importance of giving the caregiver the confidence in including the relatives during the care of the patient and making them part of the team.

This project used the United States ENA's *Presenting the option for family presence* program[30] educational booklet as part of the implementation process, which proved to be invaluable.

Conclusions

These findings relate to relatives' opinions and feelings on being present during resuscitation. Further research needs to be developed within this area that relate to psychological effects of relative presence during resuscitation and relative follow-up support. Overall, relatives valued the opportunity to be present during resuscitation. There has been no known adverse events from relatives being present and in fact relatives have felt they were more able to cope with the final outcome of their relative, by them being present. These findings add an Australian perspective to the international literature in this area that overwhelmingly supports the judicious use of the presence of relatives in the resuscitation room.

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