In-hospital family-witnessed adult resuscitation

Perspectives of patients, families and healthcare professionals

Annette Waldemar
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In-hospital family-witnessed adult resuscitation: Perspectives of patients, families and healthcare professionals

Annette Waldemar

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ERRATA
Avhandlingen

**Sid 10.** Första stycket i *Introduktion* saknar referens: 224.

**Sid 17.** Andra stycket stryk: The physician must respect the patient’s right to be informed in every phase of the care process and communicate with the family regarding the patient’s confidentiality [51].

**Sid 22.** Tabell 1. Crowded small rooms saknar referenser: 83, 191, 216.

**Sid 27.** Förrsta stycket stryk referens 59.

**Sid 48.** Under *Descriptive statistics* ska *Mann-Whitney U test (I)* was used for comparisons of continuous variables on the ordinal scale level between different groups flyttas till: Bivariate analyses.

**Sid 49.** Under *Multivariate analyses* stryk: In Study I, multiple linear regression (Enter method) was carried out to determine which of the variables were independently associated with positive attitudes towards FWR.

**Sid 50–51.** Step 2, 3 och 4 ordet *experimental* ska ersättas med *experiential*.

**Sid 69.** Stycke 2 stryk mening: Likewise, self-confidence was boosted by the ability to communicate about the resuscitation effort with the family, to identify spiritual and emotional needs of family members, and to debrief the family after the resuscitation their family member.

**Sid 69.** I Tabell 21 har påståendena kommit i fel ordning och ska vara enligt tabellen nedan.

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre-test</th>
<th>Post-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. I could communicate effectively with other team members during resuscitation efforts with family members present.</td>
<td>4.04 ± 0.99</td>
<td>4.23 ± 0.94</td>
<td>0.050</td>
</tr>
<tr>
<td>7. I could identify family members who display appropriate coping behaviours to be present during resuscitation efforts.</td>
<td>3.13 ± 1.06</td>
<td>3.56 ± 1.01</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>8. I could prepare family members to enter the area of resuscitation of their family member.</td>
<td>3.90 ± 1.06</td>
<td>4.10 ± 0.90</td>
<td>0.038</td>
</tr>
<tr>
<td>11. I could announce family member’s presence to the other team members during resuscitation efforts of their family member.</td>
<td>3.97 ± 0.99</td>
<td>4.18 ± 0.88</td>
<td>0.026</td>
</tr>
<tr>
<td>14. I could encourage family members to talk to their family member during resuscitation efforts.</td>
<td>2.49 ± 1.20</td>
<td>2.91 ± 1.36</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>15. I could delegate tasks to other team members in order for myself to support family members during resuscitation efforts of their family member.</td>
<td>3.20 ± 1.22</td>
<td>3.62 ± 1.15</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

**Sid 93. Conclusion.** Fjärde stycket stryk: The HCP’s self-confidence did not strengthen in areas which were not ad-dressed in the video, such ability to identify family members who are assumed to be present, encourage family members to talk to the patient during ongoing resuscitation and coordinate follow-up after death. These topics needs to be included in when revising to content in the educational video.

**sid 113.** Referens 184 stryk *Rob, R., J.C. Philip, and K. Juho* Rätt: Guo, P. J., Kim, J., & Rubin, R.
Sid 11. Stryk första stycket (dubblett)

Sid 11. I tabell 4 har påståendena kommit i fel ordning och ska vara enligt tabellen nedan.

**Table 4. Comparisons of mean scores in each item included in the self-confidence instrument before and after attending the intervention, using paired t-tests. The pre- and post-tests are presented in mean and standard deviation (±), N=78.**

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre-test</th>
<th>Post-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I could communicate about the resuscitation effort to family members who are present.</td>
<td>4.36 ± 0.76</td>
<td>4.45 ± 0.78</td>
<td>0.211</td>
</tr>
<tr>
<td>2. I could administer drug therapies during resuscitation efforts with family members present.</td>
<td>4.18 ± 1.16</td>
<td>4.36 ± 0.90</td>
<td>0.085</td>
</tr>
<tr>
<td>3. I could perform defibrillating therapies during resuscitation efforts with family members present.</td>
<td>4.49 ± 0.78</td>
<td>4.55 ± 0.80</td>
<td>0.415</td>
</tr>
<tr>
<td>4. I could deliver chest compressions during resuscitation efforts with family members present.</td>
<td>4.60 ± 0.69</td>
<td>4.62 ± 0.72</td>
<td>0.726</td>
</tr>
<tr>
<td>5. I could communicate effectively with other team members during resuscitation efforts with family members present.</td>
<td>4.04 ± 0.99</td>
<td>4.23 ± 0.94</td>
<td>0.050</td>
</tr>
<tr>
<td>6. I could maintain dignity of the patient during resuscitation efforts with family members present.</td>
<td>3.67 ± 1.10</td>
<td>3.86 ± 0.96</td>
<td>0.087</td>
</tr>
<tr>
<td>7. I could identify family members who display appropriate coping behaviours to be present during resuscitation efforts.</td>
<td>3.13 ± 1.06</td>
<td>3.56 ± 1.01</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>8. I could prepare family members to enter the area of resuscitation of their family member.</td>
<td>3.90 ± 1.06</td>
<td>4.10 ± 0.90</td>
<td>0.038</td>
</tr>
<tr>
<td>9. I could enlist support from the other team members for family presence during resuscitation efforts.</td>
<td>3.88 ± 1.06</td>
<td>4.01 ± 0.97</td>
<td>0.248</td>
</tr>
<tr>
<td>10. I could escort family members into the room during resuscitation of their family member.</td>
<td>4.35 ± 0.88</td>
<td>4.42 ± 0.88</td>
<td>0.358</td>
</tr>
<tr>
<td>11. I could announce family member’s presence to the other team members during resuscitation efforts of their family member.</td>
<td>3.97 ± 0.99</td>
<td>4.18 ± 0.88</td>
<td>0.026</td>
</tr>
<tr>
<td>12. I could provide comfort measures to family members witnessing resuscitation efforts of their family member.</td>
<td>3.94 ± 1.11</td>
<td>4.14 ± 0.96</td>
<td>0.052</td>
</tr>
<tr>
<td>13. I could identify spiritual and emotional needs of family members witnessing resuscitation efforts of their family member.</td>
<td>3.49 ± 1.11</td>
<td>3.59 ± 1.07</td>
<td>0.261</td>
</tr>
<tr>
<td>14. I could encourage family members to talk to their family member during resuscitation efforts.</td>
<td>2.49 ± 1.20</td>
<td>2.91 ± 1.36</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>15. I could delegate tasks to other team members in order for myself to support family members during resuscitation efforts of their family member.</td>
<td>3.20 ± 1.22</td>
<td>3.62 ± 1.15</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>16. I could debrief family after resuscitation of their family member.</td>
<td>4.06 ± 0.94</td>
<td>4.22 ± 0.93</td>
<td>0.096</td>
</tr>
<tr>
<td>17. I could coordinate bereavement follow-up with family members after resuscitation efforts of their family member, if required.</td>
<td>3.37 ± 1.20</td>
<td>3.46 ± 1.18</td>
<td>0.451</td>
</tr>
</tbody>
</table>
In-hospital family-witnessed adult resuscitation
Perspectives of patients, families and healthcare professionals

Annette Waldemar

Department of Medical and Health Sciences
Linköping University, Sweden
Linköping 2023
"Att drabbas av ett hjärtstopp kan innebära att både patienten och familjen upplever sig strandsatta. Sjukvårdspersonal bör finnas där för att erbjuda stöd och förse dem med verktyg, som åror och flytväst, redo att våga sätta sig i båten och ge sig ut på livets resa igen”.

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To my family,
Roger, Johannes, Emanuel & Julia!

"Om jag vill lyckas med att föra en människa mot ett bestämt mål måste jag först finna henne där hon är och börja just där"

"If I want to succeed in leading a person towards a specific goal, I must first find him where he is and start right there"
Søren Kierkegaard
## ABSTRACT ................................................................................................................................. 1
## PREFACE ........................................................................................................................................ 5
## LIST OF PAPERS .................................................................................................................. 7
## ABBREVIATIONS .................................................................................................................... 8
## INTRODUCTION .......................................................................................................................... 11
## BACKGROUND .......................................................................................................................... 13
  - Historical perspective of family-witnessed resuscitation ....................................................... 13
  - Guidelines on family-witnessed resuscitation ........................................................................... 14
  - Family-witnessed resuscitation in the light of person- and family-centred care ....................... 15
  - Ethical aspects on family-witnessed resuscitation .................................................................... 17
  - Patients’ perspectives on family-witnessed resuscitation ....................................................... 18
  - Families’ perspectives on family-witnessed resuscitation ..................................................... 19
    - Right to be present and say a final goodbye ........................................................................... 19
    - Traumatic and negative reactions to family-witnessed resuscitation ................................. 19
  - Healthcare professionals’ perspectives on family-witnessed resuscitation ............................... 20
  - Healthcare professionals’ attitudes towards family-witnessed resuscitation in different cultures and contexts ................................................................................................................... 22
  - Educational support for healthcare professionals ................................................................... 24
  - What should education programmes contain? ......................................................................... 27
  - Family support person ............................................................................................................. 27
  - Who should have the family support role? ............................................................................. 29
    - Registered nurses ................................................................................................................... 29
    - Healthcare chaplains .............................................................................................................. 30
    - Counsellors ............................................................................................................................ 30
  - Swedish Register of Cardiopulmonary Resuscitation ................................................................. 30
  - Procedural processes and outcomes of family-witnessed resuscitation .................................... 31
    - Structured follow-up of cardiac arrest survivors’ well-being and coping ............................... 31
  - RATIONALE ............................................................................................................................. 35
  - AIMS .......................................................................................................................................... 37
    - Specific aims of the included studies ..................................................................................... 37
METHOD ................................................................. 39
  Design ........................................................................ 39
  Participants ................................................................. 40
    Inclusion and exclusion criteria .................................. 40
  Setting and procedures ................................................ 40
    Procedure of recruitment ........................................... 40
    Procedure of data collection ....................................... 42
  Data collection .......................................................... 42
    Self-reported questionnaires ....................................... 42
    Registry data .......................................................... 44
    Narrative interviews ................................................ 45
  Development, pilot testing, and evaluation of an educational video .................................................. 46
  Data analyses ............................................................ 48
    Quantitative methods ................................................. 48
    Qualitative method .................................................. 49
  Ethical considerations .................................................. 51

RESULTS ...................................................................... 55
  Prevalence and outcome of family-witnessed resuscitation .......... 55
    Sociodemographic background and clinical data .................. 55
    In-hospital cardiac arrest and family presence .................... 55
    Outcomes of cardiac arrest with and without family presence ...... 56
  Patient and family member experiences of family-witnessed resuscitation .................................................. 57
  Local guidelines about family-witnessed resuscitation .......... 60
  Healthcare professionals’ experiences of family-witnessed resuscitation .................................................. 61
  Healthcare professionals’ attitudes to family-witnessed resuscitation .................................................. 62
  Healthcare professionals’ self-confidence in family-witnessed resuscitation situations .................................. 67
  The impact of an educational intervention on self-confidence and attitudes towards family-witnessed resuscitation .................................................. 68

DISCUSSION ................................................................ 71
  Discussion of the results ................................................ 71
    Prolonged cardiopulmonary resuscitation attempts .............. 71
Patient and family members’ experiences of cardiac arrest and post cardiac arrest care ................................................................. 72
Person-, patient- and family-centred care ........................................ 75
Attitudes towards family-witnessed resuscitation ............................. 77
Self-confidence in managing family-witnessed resuscitation .......... 78
Family support person - who should be given the role? ............... 79
Guidelines .................................................................................. 81
Methodological considerations ...................................................... 82
Design and research approaches .................................................. 82
Participants .................................................................................. 82
Data collection ............................................................................ 85
Data analyses .............................................................................. 87
The choice of pedagogical tool for the intervention ....................... 90
CONCLUSIONS ........................................................................... 93
Clinical implications ..................................................................... 94
Future perspectives ....................................................................... 95
SVENSK SAMMANFATTNING .................................................. 97
ACKNOWLEDGEMENTS .............................................................. 99
REFERENCES ............................................................................. 101
ABSTRACT

Background
Several international organizations recommend family-witnessed resuscitation (FWR) in hospitals, which means that the family should be offered to be present during resuscitation. These recommendations are based on research that shows that it is usually beneficial for the family to be present. The family can see that everything was done for the patient, they can say goodbye, they acknowledge that the patient passed away and the grieving process is facilitated. However, research has yet to examine how FWR affects the patient and family members who were present during the cardiac arrest and what it is like to live on with the shared experience.

Healthcare professionals (HCPs) in general are sceptical of FWR, and current guidelines that recommend FWR have not made a significant impact in healthcare. HCPs believe that FWR could worsen the outcome for the patient and that the family could be psychologically damaged by being present during resuscitation.

HCPs also express uncertainty about how to act during FWR, because they have not received education or training about FWR. There is a need for research concerning the outcomes of FWR in hospitalized adult patients. Research on the experiences, attitudes, and self-confidence of HCPs in Sweden in relation to FWR, as well as the shared experiences of patients and families, is lacking. There is also lack of research exploring whether an educational intervention can have a positive impact on attitudes and self-confidence among HCPs.

Overall Aim
The overall aim of this thesis was to describe the prevalence, processes, and outcomes of FWR; explore experiences and attitudes towards FWR among patients, families, and HCPs; and to further develop and test an educational intervention addressing HCP.

Methods
This thesis includes four studies, where the first study used a cross-sectional design (I), Study II was a retrospective observational cohort study, Study III was a qualitative study, and Study IV used a quasi-experimental design. The sample size ranged between 15-4846 participants across the studies. Data was collected through web surveys (I, IV), registers (II), and narrative face-to-face interviews (III). Descriptive and correlational statis-
tistics were used in the quantitative studies (I-II, IV) and interpretative phenomenological analysis (IPA) in the qualitative study (III). A 10-minute educational video was developed, pilot tested, and used as intervention in Study IV. The video was based on previous research covering the prevalence and outcome of FWR, attitudes among HCPs, patient and family experiences, and FWR guidelines.

**Results**

It was significantly more common that a family member was on site if the cardiac arrest occurred in acute settings such as emergency departments and intensive care units than in hospital wards (44% vs. 26%, p<0.001). In total, 395 patients (12%) had family on site when the cardiac arrest occurred, in 186 of these cardiac arrests the family chose to witness resuscitation. (II). The mean time from initiation to termination of resuscitation was significantly longer if a family member was present (17.7 vs. 20.7 minutes, p=0.020) (II). There were no significant differences in survival rate between FWR and non-FWR, neither immediately after resuscitation (57% vs. 53%, p=0.291) nor in 30-day survival (35% vs. 29%, p=0.086) (II).

HCPs reported a wide range of experiences regarding FWR (I, IV). More nurses (70%) than physicians (49%) expressed positive experiences in Study I, while in Study IV, the proportions were the opposite, with 52% of physicians and 33% of nurses reporting positive experiences.

Regarding attitudes, the results from Study IV show a more positive attitude towards offering the family the opportunity to be with the patient during CPR compared to Study I. In Study IV, 77.1% of nurses and 58.1% of physicians reported a positive attitude towards FWR, while in Study I, 58.7% of nurses and 29.2% of physicians were positive.

Performing defibrillation, administering drug therapies, and providing chest compressions during FWR were not considered to be a problem for either physicians or nurses. Nevertheless, being able to identify family members who demonstrate appropriate coping behaviours was more difficult, and 27% of nurses and 37% of physicians reported that they had no confidence in performing this task. Furthermore, 52.7% of nurses and 69.4% of physicians were not comfortable encouraging family members to talk to the patient during resuscitation (IV). In Study I, none of the included hospitals reported having local guidelines about FWR, while 18.6% reported that they had guidelines seven years later when Study IV was performed.

The results suggest that the educational intervention had a positive influence on HCPs’ self-confidence during FWR (3.83±0.70 to 4.02±0.70,
Abstract

p<0.001) and their attitudes towards FWR (3.38±0.49 to 3.62±0.48, p<0.001) (IV).

Patients and families describe powerlessness in the face of life's fragility, but also faith in life after experiencing and surviving a sudden cardiac arrest together. Even though the participants felt exposed and vulnerable in the care relationship and lacked a sense of control and continuity, they had hope and re-evaluated life, lived in the moment and saw the value in everyday life. The love they felt for people who were important to them and the gratitude for life increased after the cardiac arrest. The desire for freedom and independence also increased (III).

Conclusion

Surviving as well as witnessing an in-hospital cardiac arrest is a critical event making patients and family members vulnerable. To meet their needs, HCPs should routinely invite the family to witness resuscitation if it is deemed to be safe. HCPs need to show compassion and evaluate how family members are coping during the process and provide support and information during and after resuscitation. Processes and outcomes do not seem to be negatively affected by FWR, even though there is some resistance to FWR among HCPs. These obstacles must be considered when planning for the implementation of FWR in daily practice. A short online educational video can be a way to improve the self-confidence and attitudes towards FWR among HCPs. This will likely result in increased compliance with national and local guidelines that recommend FWR.
Family members with heart problems is something I grew up with. My grandfather had a major heart attack when he was 50 years and died of severe heart failure. My grandmother died young, which was also related to heart failure, after several heart attacks. My grandpa died in our home when I was a teenager due to a cardiac arrest. When I graduated as a nurse in 1995, it felt natural to work in cardiac care. I was driven by the thought that I might be able to improve the care and treatment of cardiac patients. I soon started working in the cardiac intensive care unit, and after a few years, I started in the heart failure and arrhythmia outpatient clinic, where I still work.

In 2012, my colleague Maria Pettersson and I were preparing to write a bachelor thesis. We wanted to write something about cardiac arrest and searched through the PubMed database. We found an article about family-witnessed resuscitation. We had never talked about or practiced family-witnessed resuscitation at my workplace. Who can write about such a thing, we asked ourselves. It turned out there were about 800 articles touching on the subject from different angles. How was this possible? How could there be so much research that we did not know about? We decided to write our bachelor thesis about family-witnessed resuscitation, which for us was a controversial topic. Families were not allowed to be present during resuscitation at our workplace, as we felt it was quite traumatic for them to witness resuscitation. Our actions towards families during resuscitation were not based on evidence, only the opinions of healthcare professionals. We realized that our thinking and actions did not at all agree with the research, which showed that families often want to be invited in and to be with their family member.

We also discovered that there were both national and international guidelines that said that family members should be offered to be present during resuscitation. After I had finished my bachelor thesis, I was convinced: “Now we must start offering family members to be present during resuscitation”, and I spoke strongly in favour of introducing family-witnessed resuscitation. But there was a lot of resistance. Even though I was able to show a lot of evidence and pointed out that there were in fact guidelines in place, I got little response.

A few years later, in the heart failure outpatient clinic, I had a new visitor, a woman aged 55. I saw that the woman was sad and asked why. “It's
In-hospital family-witnessed adult resuscitation

my husband”, she replied. I asked: “What happened to your husband”? She told me: “My husband became ill, and I called an ambulance. When we got to the emergency department, he had a cardiac arrest. I was so relieved and grateful that we were in the hospital. They placed me on a chair outside the emergency room where they worked with my husband. I sat and waited. The longer the time went by and the more staff that ran into the emergency room, the more confident I became – nothing can go wrong. After 30 minutes, they opened the doors and told me, ‘You can go in’. I was so excited and happy to go in and see, hug, and talk to my husband. But you know, there lies my husband, DEAD-stone dead, he’s even cold!!! What had they been doing for 30 minutes? They couldn’t have done everything for my husband”. The woman did not get the opportunity to say goodbye to a warm body or see that the staff had done everything they could and that was not possible to resuscitate her husband. The woman was on sick leave due to post-traumatic stress and difficult grief work. What if the staff members had followed the current evidence-based guidelines and invited the woman into the room where she would have seen with her own eyes that everything had been done and been close to her loved one and said a final goodbye?

How is it possible that we as healthcare professionals are allowed to act on our own accord, ignoring guidelines based on our preconceived notions, depriving the family of this important, perhaps final moment together? Decisions that cause people to suffer for years. What are the underlying experiences and attitudes of Swedish healthcare professionals, and is it possible to strengthen their self-confidence during family-witnessed resuscitation? The encounter with the woman awakened something in me, and in 2017 I became a PhD student with the intention of getting a more objective picture of family-witnessed resuscitation in Sweden seen from the patients’, families’, and healthcare professionals’ perspective.
LIST OF PAPERS

This thesis is based on the following papers, which will be referred to by their roman numerals (I-IV).


IV. Waldemar, A., Bremer, A., Strömberg, A., & Thylén, I. Family presence during in-hospital cardiopulmonary resuscitation: effects of an educational online intervention on self-confidence and attitudes of healthcare professionals. Accepted October 2023.
In-hospital family-witnessed adult resuscitation

ABREVIATIONS

CPR Cardiopulmonary Resuscitation
FWR Family-witnessed Resuscitation
HCP Healthcare Professionals
IPA Interpretative Phenomenological Analysis
PROM Patient-reported Outcome Measures
PTSD Posttraumatic Stress Disorder
USA United States of America
INTRODUCTION

Cardiovascular diseases are the most common cause of death in the Western world, and cardiac arrests are thought to account for approximately 50% of all cardiovascular deaths in the general population [1]. Cardiac arrest is generally sudden and usually unexpected [2], but cardiac arrest is also part of the natural dying process [3]. Commonly, the cause of cardiac arrest is cardiac-related conditions, such as myocardial infarction, arrhythmia, or heart failure, with a prevalence of approximately 50% to 60%.

Cardiac arrest is often categorized into two separate groups depending on the location of the arrest: out-of-hospital cardiac arrest and in-hospital cardiac arrest [4]. The in-hospital cardiac arrest population is older and has more comorbidities and other health-related problems [5], and is the population of which this thesis is focusing upon. Worldwide, the annual incidence of in-hospital cardiac arrest is between 1.2 and 10 per 1,000 hospital admissions[6]. Annually in Sweden, about 2,400 persons suffer an in-hospital cardiac arrest[7].

Globally, one-year survival for in-hospital cardiac arrest with a cardiac-related cause is about 39% and 11% in patients with a non-cardiac cause [8]. The in-hospital cardiac arrest survival rate among adults in Sweden has risen from the turn of the millennium through 2020, reaching about 35% in 2020 [9]. Without rapid action the cardiac arrest progresses to sudden death [2]. To improve the chance of survival, the “Chain of Survival” was introduced in 1967 [10] and later revised by the European Resuscitation Council (ERC) in 1995 [11]. The purpose of the chain is to ensure that the people involved in resuscitation work systematically and follow the steps outlined in the recommendations to improve the chance of survival. The key elements of the chain are recognition and call for help, provide early CPR including chest compressions and ventilation, early defibrillation, when applicable and immediate attention to potentially reversible causes to help restore normal heart function and stabilize the condition of the affected person. The final step in the chain is to provide post-resuscitation care, which may involve cardiac monitoring, specialized treatment, and coronary angiography [12].

When cardiac arrest occurs outside the hospital, family presence during resuscitation may be unavoidable and family members are commonly involved in the resuscitation process themselves before the ambulance arrives. In hospitals on the other hand, family members are passive observers and attendance may depend on whether the staff offers the family to be
present during resuscitation [13]. Family-witnessed resuscitation (FWR) in-hospital means that one or more family members (i.e. siblings, parents, spouses, children, or close friends) are present in the room where CPR is performed and that they can maintain visual or physical contact with the patient and the care team [14]. Family members generally want to be present if given the choice, which also tends to be the preference of patients [15].

FWR remains highly debated in clinical practice. About 52% of countries in Europe do not practice FWR, and the corresponding percentage worldwide is 69% [16]. Reasons why family members are not included in the resuscitation of an adult in hospital are multifaceted. Healthcare professionals (HCPs) have reported that they are afraid that the family will prevent, interfere, or disrupt the resuscitation. HCPs are also concerned about family trauma and exposure to negative and visually distressing images [13]. In contrast, HCPs that advocate FWR believe that family presence improves coping and facilitates the grieving process if the patient does not survive [13]. Despite global research on the experiences and attitudes of physicians and nurses towards FWR, data from Sweden is scarce.

FWR can also increase stress for HCPs involved in resuscitation and may have negative psychological impacts on the staff, as well as on the team performance [17]. HCPs often feel unsure how to manage the family during CPR; therefore, education, training and local guidelines are needed [18]. Previous research suggests that education plays a vital role in the implementation of FWR. Education and training increase self-confidence among HCPs when caring for family members during and after cardiac arrest. It also makes them more likely to implement FWR [19]. It is therefore important to investigate whether an educational intervention aimed at HCPs can increase self-confidence and promote FWR among adult patients in hospital. Furthermore, previous research on the prevalence, procedural processes, and outcomes of FWR is lacking. Nor has the subsequent impact of FWR been studied in relation to the patient and family members.

This thesis focuses on family-witnessed resuscitation (FWR) of adults in-hospital but is seen from a broader perspective than just the resuscitation of the patient and include the time before, during, and after the cardiac arrest.
BACKGROUND

Historical perspective of family-witnessed resuscitation

The appropriateness of family-witnessed resuscitation (FWR) has been debated for more than 40 years [17]. Already in the late 1970s, it was discussed that when patients are expected to die in hospital, it is important for the family to have the opportunity to be with the patient so that they feel a sense of acceptance, get information, support and comfort from healthcare professionals (HCPs) [20].

Two incidents took place at Foote Hospital in Michigan in the US at the beginning of the 1980s, leading HCPs to begin questioning the policy to exclude family members during resuscitation. In one incident, a police officer was shot and the wife begged to see her husband during resuscitation. The second involved a mother who refused to leave the emergency room while her daughter was resuscitated after a riding accident. Both the wife and the mother were grateful to be present during CPR. Foote Hospital decided to change their protocol and allow FWR [21]. To evaluate the new policy, a survey was conducted with family members showing that 94% of family members would participate again, 76% believed that the adjustment to the death and the grieving process were facilitated by witnessing the resuscitation, and 64% believed that their presence was beneficial to the dying family member [21]. The incidents at Foote Hospital started an ethical debate concerning FWR, and research on FWR increased significantly in some countries [22]. In Europe, an early survey from 2004 showed that 8 out of 20 countries (40%) did not routinely allow FWR [23], and it was still not routinely allowed in 16 out of 31 European countries (52%) in a survey performed in 2017 [24].

The first study of FWR in Sweden was performed in 2003 and included 89 nurses and 86 physicians working in anaesthesiology, cardiology and emergency department [25]. The results showed that there were more nurses (39%) than physicians (8%) who had experienced FWR and more nurses (43%) than physicians (36%) believed that the family should be offered to attend resuscitation [25]. Weslien and Nilstun (2005) later interviewed 17 Swedish family members after an unexpected cardiac arrest of a family member, 15 patients died during resuscitation. The results showed that family members believed that the HCPs involved should guide family members during resuscitation and that it is important that family members
do not feel burdened with guilt. The focus should be on what is best for the individual family member [26]. Participants were also asked about their views on FWR. Two believed that their presence was permitted but the others believed that the healthcare system was opposed to FWR. They also believed that the patient wanted them to be there to provide support or comfort and that the patient did not want to die alone. The family members described their presence as valuable for themselves, the patient, and the HCPs. They were there for the patient and could inform the HCPs about the patient’s illnesses. The family members needed a person who could provide support and strength and who could help them maintain self-control. They felt confident in the HCPs when they saw how skilfully they performed resuscitation [26].

At a conference of the European Federation of Critical Care Nursing Associations in 2002, 235 nurses working in intensive care units were invited to participate in a survey on FWR, whereof 130 (55%) responded. Of the respondents, 12% were nurses from Sweden. The authors found that nurses from the United Kingdom were significantly more positive about FWR than nurses from other countries, who also had less experience with FWR and were more uncertain about its implications [27]. The attitudes and experiences of nurses from Sweden were not specifically investigated.

At three international cardiovascular conferences for nurses in Europe in 2007, questionnaires were distributed asking about experiences of and attitudes towards FWR. Of the 411 respondents, the majority were against FWR, but those with longer nursing experience were more positive. Of the 108 (26%) respondents from Sweden, 52% had experience of FWR, whereof 30% had positive experiences and 22% had negative experiences, 23% had been asked by the family to attend, 21% had invited a family member to attend and 10% reported that their unit/department had a protocol or policy document on FWR [28].

**Guidelines on family-witnessed resuscitation**

The first practical guidelines on FWR were developed in the US in 1993 by the Emergency Nurses Association (ENA), who recommended that family members should be offered to be present during resuscitation [29]. Many international health organizations now endorsed FWR [30-38]. (Figure 1).

The Swedish Council for Cardiopulmonary Rescue guidelines [39] agree with the latest recommendations from the European Resuscitation Council (ERC), it is stated that:
“Resuscitation teams should offer family members of cardiac arrest patients the opportunity to be present during the resuscitation attempt in cases where this opportunity can be provided safely, and a member of the team can be allocated to provide support to the patient's family. Systems should provide clinicians with training on how best to provide information and support to family members during resuscitation attempts” [40](p. 411).

<table>
<thead>
<tr>
<th>British Medical Association Emergency Nurses Association (International professional organization)</th>
<th>American Association of Critical-Care Nurses American Heart Association Emergency Cardiovascular Care (United States of America) Resuscitation Council (United Kingdom)</th>
<th>British Association for Accident and Emergency Medicine Canadian Critical Care Society</th>
<th>European Federation of Critical Care Nursing associations European Resuscitation Council Society of Critical Care Medicine (United States of America) Svenska rådet för hjärt-lung-räddning</th>
</tr>
</thead>
</table>

**Figure 1.** Guidelines on family-witnessed resuscitation since the first one was published in 1993.

**Family-witnessed resuscitation in the light of person- and family-centred care**

Family-witnessed resuscitation is strongly associated with person- and family centred care, which is an approach that involves families throughout the life continuum. Family members can be both active and passive observers. Families can be active in the resuscitation procedure; sometimes the family member has started CPR before arriving at the emergency department and feels that they are a part of the resuscitation process. Family members are also a partner in care and decision-making within the framework of family-centred care [41]. Family-centred care involves considering the psychosocial needs of the patient and the entire family [42]. A consensus definition of family-centred care is lacking, but there are some general principles:

- The exchange of information is open, objective, and impartial.
- The relationship with everyone involved is characterized by respect for diversity, cultural and linguistic traditions.
In-hospital family-witnessed adult resuscitation

- Care takes place in partnership and collaboration where medical decisions are made together with all parties involved.
- The outcomes of medical care plans are flexible [43].

Family-centred care involves families throughout the life continuum. Based on the assumptions of the family-centred care, there is an expectation that regardless of the care context, the patients’ family members should be included and considered in health care [44]. FWR is linked to the family-centred care paradigm, which encourages and recommends the participation of family members in the patient’s care, invasive procedures, resuscitation, and end-of-life decisions [41].

In this thesis, I have the view that the patient is a person with needs and preferences beyond the medical perspective alone and that the person is part of a larger context and another concept for that is person-centred care which is based on the person's biological, psychological, social, and spiritual aspects [45]. Person-centred care is also based on an ethical perspective that emphasizes the need for HCPs to know the person behind the illness in order for the person to be able to engage in care [46]. The focus is the person's life world, experience of illness, consequences of symptoms and treatment and the patient's needs. The person is seen as a valuable and equal partner who is involved in the planning, implementation, and follow-up of their care. Person-centred care is characterized by a partnership between the person, caregivers and family members with a focus on the person's own experiences and situation [47]. The word patient originally meant ‘one who suffers’, a person who is receiving medical care, or who is cared for by a physician [48]. However, the word patient will be used in this thesis in the meaning of a person affected by cardiac arrest or undergoing resuscitation.

The concept of empathy can be used to help clarify the difference between person-centred care and patient-centred care. In patient-centred care, the goal is for the patient to function where the HCP ascertains the patient's emotional state and behaviours to ensure that emotional support is offered to the patient. In person-centred care, the goal is for the person to live a meaningful life and then the meaning of empathy becomes looking beyond the person's specific feelings in the present to the life he or she lives. Person-centred care involves trying to enter the person’s world and assume that there is a meaning to all behaviour, even if it is difficult for the HCP to interpret [46].
Ethical aspects on family-witnessed resuscitation

European Resuscitation Council Ethics guidelines safeguarding autonomy state that physicians should incorporate shared decision. HCP should integrate the patient/family with shared decision, inform about the patient’s condition, involve patients/family members in discussions about care plans and CPR. All patients with an increased risk of cardiac arrest or poor outcome in the event of cardiac arrest should be offered advance care planning [49].

There are ethical codes that describe how healthcare professionals are expected to act [50]. The ICN Code of Ethics for Nurses applies in all settings, roles and areas of practice. Nurses are expected to demonstrate sensitivity, care, compassion, and empathy and ensure that the individual and family receive understandable, accurate, sufficient, and timely information in an appropriate manner [50]. There is also a code of ethics for physicians whose primary duty is to promote health and well-being of patients by providing humane care with respect for patient autonomy and rights. The physician must respect the patient's right to be informed in every phase of the care process and communicate with the family regarding the patient's confidentiality [51]. One way to alert the HCP to the patient's needs in a cardiac arrest situation can be to discuss ethical codes among the staff and reflect on the patients' and family's experiences of a cardiac arrest and try to imagine their situation and needs.

The principles of non-maleficence and beneficence make it difficult when healthcare providers have to take a position on FWR when they do not know the patient's wishes. Most patients who suffer cardiac arrest die, which should mean that the long-term well-being for the family and symptoms that can arise like PTSD, depression and anxiety should decide if FWR should be offered to the family. At the same time there is research showing that some patients do not want the presence of the family due to e.g., concerns about breaches of privacy [52-54] but recently resuscitated hospital patients show the opposite, they prefer FWR [52]. However, there may be situations when the patient would oppose FWR if asked. This may mean that the HCP offered FWR, and the patient must continue to live with the knowledge that things happened against their will during the care period. These ethical dilemmas need not arise if the FWR issue were to be discussed with the patient upon admission to hospital.

Patients have the right to make informed decisions about their care in line with the principle of autonomy [17]. If the patient cannot decide about FWR, the family can make this decision hopefully in line with what they believe the patient wanted.
Patients’ perspectives on family-witnessed resuscitation

The majority of hospitalized patients want a family member to be present during their own resuscitation and believe that it is the family’s right to decide whether they want to be present [52, 55, 56]. Patients believe that they should be asked about their preferences when admitted to hospital [54, 57]. In a study from 2004, patients expressed both the psychological risks and benefits associated with FWR. Negative effects were that the presence of family members could violate the patient’s confidentiality and privacy rights, that FWR could cause anxiety among HCPs, and that families could interfere with the resuscitation team. Positive effects were that FWR could increase professionalism among HCPs and prolong CPR [56].

When it comes to resuscitated patients, younger cardiac arrest survivors tend to be more supportive of FWR than older patients [58, 59], while gender, education and health status do not seem to influence these attitudes [58]. Some resuscitated patients have expressed that there are only certain family members they would like to have present if they were resuscitated [58-61]. Patients have also expressed concerns about family members seeing them naked [54].

In a large study (n=500) conducted in Poland in 2017, only 29% of surveyed resuscitated patients expressed a desire to be present during the resuscitation of a family member [62]. Similar opinions were found by Grice et al. (2004), where 29% of patients supported FWR. The most frequent reasons expressed for not wanting family members present were the possibility that the family would suffer from long-term trauma after resuscitation, because it is too distressing for the family [63]. Despite the knowledge that it can be traumatic for their family member to be present during resuscitation, most patients support FWR and believe that no one should die alone [52, 54, 58, 60, 61, 64].

Furthermore, interviews with cardiac arrest survivors show that a certain percentage were partially awake during a part of the resuscitation. These patients had memories of the resuscitation and remembered whether family members were present [65]. Patients described feeling loved, supported, less alone and afraid when family members were present and that family members could act as their advocates [66, 67]. Patients believed that if HCPs are reminded that the patient is a person with a family, they will make more of an effort to help him or her survive [66]. The presence of family members also encourages the patient to persevere during resuscitation [68]. Patients report that they felt comfort, calm, and support
due to the presence of family members [22, 54]. Other reported advantages of FWR are that family members can pray and talk to the patient during resuscitation [54]. The family would have the assurance of knowing that everything possible had been done for the patient and this would aid in the grieving process if the patient does not survive [13, 54, 69].

Families’ perspectives on family-witnessed resuscitation

Right to be present and say a final goodbye
Most family members believe that they have the right to be present during the resuscitation of a family member [28, 57, 60, 70-72]. FWR increases the feeling of control over the situation and satisfaction with the HCPs’ efforts to save the life of a family member. Additionally, HCPs’ communication with the family facilitates the acceptance of death [57, 70, 72, 73]. It is quite common that family members started CPR out-of-hospital before emergency personnel arrived, and that they feel that they were part of the process from the outset [13].

Families feel that they have information that could be useful to the healthcare team [57, 70], that they can support the patient [57, 60, 70, 71], and that their presence has a calming effect [22]. The family can touch their family member, pray, prevent aloneness, decrease fear and give the patient “permission” to die [70, 74, 75]. Some families also believe that they can provide spiritual support [13, 44, 54, 57, 60, 70, 73, 76, 77].

FWR is an opportunity for family members to see that everything possible has been done [22] and can help them understand the gravity of the situation, to say a final goodbye and facilitate the grieving process [13, 21, 30, 44, 53, 66, 70, 71, 73, 75, 78-81]. FWR can allow the family to say things that need to be said and prevent the feeling of guilt during the grieving process [74]. Allowing family members to be present can prevent a prolonged period of denial during the grieving process [70, 80].

Traumatic and negative reactions to family-witnessed resuscitation
Family members sometimes exhibit different reactions to FWR, such as fainting [82-84], freezing up [85], hysterical behaviour and emesis [83]. Family members themselves describe a fear of losing emotional control [86]. Some family members think that there could be a risk that they will interfere with CPR because of strong emotions [79]. Incidents where family
members exhibit angry or distressed behaviour, thus interfering with resuscitation, seem to be very low (<1%) [60]. Jabre et al. (2013) examined negative behaviours in 266 out-of-hospital FWRs and found family agitation in 8% of the cardiac arrests and aggression and conflict in 1% of cases [85].

The argument that is usually presented by HCPs is that witnessing CPR is too traumatic for the family [87-89]. There is also research showing that FWR has increased the risk of posttraumatic stress syndrome symptoms [90]. Despite the risk of traumatic experiences, families still want to have the opportunity to be present [22, 70, 74]. Some family members feel that the resuscitation attempt was too long and may have been extended for their sake [13]. When family members choose to be present, they frequently cite emotional reasons for doing so. Past experiences of providing support to family members can make them want to support the patient again [70]. The fact that family members report that they would witness the resuscitation again suggests that FWR is not overly traumatic in most cases [13, 91].

Several studies have investigated posttraumatic stress syndrome, anxiety, and grief in FWR. The literature on FWR is mostly based on cross-sectional, quasi-experimental and interview studies. However, five randomized controlled trials have been performed [78, 80, 85, 92-94]. Four out of five studies showed that the FWR group had significantly lower levels of posttraumatic stress syndrome, anxiety and sadness and that FWR had a favourable effect on the grieving process [78, 80, 93, 94]. One study showed no favourable effect of FWR, as all participants demonstrated an overall high level of depression and symptoms during the grieving process [92].

Healthcare professionals’ perspectives on family-witnessed resuscitation

The concept of in-hospital adult FWR remains controversial. There is disagreement among HCPs as to whether families should be allowed to witness CPR on an adult patient [41, 95]. Family members, patients and HCPs have different views on who has the right to decide on FWR. For example, family members claim that it is their right to decide, while some HCPs believe that it is their duty to decide and others believe it is the family’s choice. However, HCPs who believe that it is the family’s right to be present during CPR are more likely to implement this practice [61].
Nurses seem to be more open to FWR than other professionals [57, 61, 96, 97], and nurses see themselves as advocates for patients and their families [30, 61, 98]. Physicians are less enthusiastic about FWR, and FWR can increase the level of anxiety among physicians [99]. Physicians fear that families may request the continuation of futile resuscitation or that they terminate CPR prematurely [100, 101]. Furthermore, physicians fear that family members may interfere with resuscitation or that they will be subject to medico-legal repercussions [61, 89, 96, 98, 102].

Previous positive experiences of family presence make HCPs more likely to implement FWR [44, 61, 103]. On the other hand, previous negative experiences can be a barrier to implementation [44, 61].

For HCPs, FWR can be an obstacle to effectively practicing their profession; for example, HCPs cannot use the same coping strategies during FWR, such as seeing the person as an “object”, as they do not want to see the person behind the patient, because they will not be able to perform CPR as effectively then [97]. One of the most common reasons HCPs do not advocate FWR is fear of litigation, but the literature contains no reports of legal action after FWR. Families seem to be more interested in supporting the patient than monitoring the work of the team [44]. Table 1 summarizes the positive and negative effects of FWR as perceived by HCPs.

<table>
<thead>
<tr>
<th>Positive effects</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Humanized, the patient is not just a diagnosis, but a person who “belongs to someone”.</td>
<td>44, 61</td>
</tr>
<tr>
<td>Cultural and religious needs can be met.</td>
<td>44</td>
</tr>
<tr>
<td>Helpers, family members can perform simpler tasks.</td>
<td>44</td>
</tr>
<tr>
<td>Information source about background and previous medical history.</td>
<td>44, 191</td>
</tr>
<tr>
<td>Dignity is maintained.</td>
<td>61</td>
</tr>
<tr>
<td>Decision-making, the family can facilitate 'decision-making' to end resuscitation.</td>
<td>44, 61, 166, 191</td>
</tr>
<tr>
<td>Communication with family when patient passes away.</td>
<td>44, 61</td>
</tr>
<tr>
<td>Physical contact, hold or touch the patient.</td>
<td>44</td>
</tr>
<tr>
<td>Farewell the family is given the opportunity to say goodbye, and could settle unfinished conflicts.</td>
<td>44</td>
</tr>
<tr>
<td>Understanding and conviction that everything was done that could have been done, to save the patient.</td>
<td>44, 61, 166, 191</td>
</tr>
<tr>
<td>Grief work is facilitated.</td>
<td>44, 61, 191</td>
</tr>
</tbody>
</table>

1 Information about whether there is a family support person available is lacking in the studies.
In-hospital family-witnessed adult resuscitation

Continued: Table 1. A summary of positive and negative effects of family-witnessed resuscitation as perceived by healthcare professionals.1

<table>
<thead>
<tr>
<th>Negative effects</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Traumatic</strong> for the family, it can be interpreted as cruelty by those who are unfamiliar with resuscitation.</td>
<td>19, 87, 57, 61, 89</td>
</tr>
<tr>
<td><strong>Culture and religious</strong> differences.</td>
<td>44, 89</td>
</tr>
<tr>
<td><strong>Crowded and small rooms.</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Stress</strong> for the healthcare professionals because they do not want to be observed and evaluated.</td>
<td>57, 61, 83, 191, 216</td>
</tr>
<tr>
<td><strong>Increase workload.</strong></td>
<td>174</td>
</tr>
<tr>
<td><strong>Distracts</strong> the team because the attention must be in several causes.</td>
<td>44, 57, 167, 191</td>
</tr>
<tr>
<td><strong>Discomfort</strong>, perceived performance anxiety.</td>
<td>61</td>
</tr>
<tr>
<td><strong>Communication</strong> is hampered in the team.</td>
<td>44</td>
</tr>
<tr>
<td><strong>Self-confidence</strong> decreases, difficulty performing technical procedures.</td>
<td>44</td>
</tr>
<tr>
<td><strong>Support person</strong> is missing to care for the family during resuscitation.</td>
<td>72</td>
</tr>
<tr>
<td><strong>Dignity and confidentiality</strong> are a risk of being disregarded.</td>
<td>19, 57, 108</td>
</tr>
<tr>
<td><strong>Resuscitation</strong> will last longer.</td>
<td>13, 19, 44</td>
</tr>
<tr>
<td><strong>Attacked</strong>, fear of being attacked by the family when they do not understand what’s happen and do not accept the death.</td>
<td>61, 96, 164</td>
</tr>
<tr>
<td><strong>Mistakes</strong>, fear of making mistakes in front of the family.</td>
<td>44</td>
</tr>
<tr>
<td><strong>Litigation</strong> against professionals and institutions.</td>
<td>19, 57, 61</td>
</tr>
</tbody>
</table>

1 Information about whether there is a family support person available is lacking in the studies.

Healthcare professionals’ attitudes towards family-witnessed resuscitation in different cultures and contexts

Cultural context affects the attitudes and practices of HCPs [104]. Cultural and educational background also influence attitudes and experiences of FWR among HCPs. There is a difference between countries and cultures around FWR [86]. FWR may be a double-edged sword for HCPs [84]. Although different healthcare systems worldwide have sought to abandon paternalistic attitudes and place the patient at the centre of care, some countries have achieved this better than others [89].

Attitudes towards FWR vary between countries and HCPs (Table 2). Almost all studies that have investigated attitudes of HCPs have been conducted in the emergency departments or intensive care units. Among HCPs in the Middle East, South America, and Asia, negative views towards FWR were the norm. FWR is still controversial in Europe and the Arab world, and HCPs have varying opinions. In general, HCPs in Anglo-Saxon countries (US, United Kingdom, Ireland, Australia, South Africa, and Canada) show greater support for FWR [57]. In Africa, FWR is a rather new concept, but they have welcomed the idea of FWR [105-108].
Table 2. Attitudes towards family-witnessed resuscitation vary between countries and HCP.

<table>
<thead>
<tr>
<th>Author</th>
<th>Country</th>
<th>Year</th>
<th>Participants</th>
<th>Attitude to FWR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yanturali, S., et al.</td>
<td>Turkey</td>
<td>2005</td>
<td>Physicians</td>
<td>X</td>
</tr>
<tr>
<td>Demir, F.</td>
<td></td>
<td>2008</td>
<td>HCP</td>
<td>X</td>
</tr>
<tr>
<td>Günes, U &amp; Zaybak, A.</td>
<td></td>
<td>2009</td>
<td>Nurses</td>
<td>X</td>
</tr>
<tr>
<td>Ganz, F &amp; Yoffe, F.</td>
<td>Israel</td>
<td>2012</td>
<td>Nurses</td>
<td>X</td>
</tr>
<tr>
<td>Mahabir, D &amp; Sammy, I.</td>
<td>Trinidad Tobago</td>
<td>2012</td>
<td>HCP</td>
<td>X</td>
</tr>
<tr>
<td>Sheng, C., et al.</td>
<td>Taiwan</td>
<td>2010</td>
<td>HCP</td>
<td>X</td>
</tr>
<tr>
<td>Leung, N &amp; Chow, S.</td>
<td>Hongkong</td>
<td>2012</td>
<td>HCP</td>
<td>X</td>
</tr>
<tr>
<td>Zakaria, M &amp; Siddique, M.</td>
<td>Pakistan</td>
<td>2017</td>
<td>HCP</td>
<td>X</td>
</tr>
<tr>
<td>Park, J &amp; Ha, J.</td>
<td>South Korea</td>
<td>2021</td>
<td>Nurses</td>
<td>X</td>
</tr>
<tr>
<td>Hayajneh, F.</td>
<td>Jordan</td>
<td>2013</td>
<td>Nurses</td>
<td>X</td>
</tr>
<tr>
<td>Alzawaidah, M., et al.</td>
<td></td>
<td>2023</td>
<td>Nurses</td>
<td>X</td>
</tr>
<tr>
<td>Hosseini, Z., et al.</td>
<td></td>
<td>2022</td>
<td>Nurses</td>
<td>X</td>
</tr>
<tr>
<td>Westen, M &amp; Nilstun, T.</td>
<td>Sweden</td>
<td>2003</td>
<td>HCP</td>
<td>X</td>
</tr>
<tr>
<td>Axelsson, A., et al.</td>
<td></td>
<td>2010</td>
<td>Nurses</td>
<td>X</td>
</tr>
<tr>
<td>Madden, E &amp; Condon, C.</td>
<td>Ireland</td>
<td>2007</td>
<td>Nurses</td>
<td>X</td>
</tr>
<tr>
<td>Axelsson, A., et al.</td>
<td></td>
<td>2010</td>
<td>Nurses</td>
<td>X</td>
</tr>
<tr>
<td>Fulbrook, P., et al.</td>
<td></td>
<td>2005</td>
<td>Nurses</td>
<td>X</td>
</tr>
<tr>
<td>Axelsson, A., et al.</td>
<td></td>
<td>2010</td>
<td>Nurses</td>
<td>X</td>
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<tr>
<td>Monks, J &amp; Flynn, M.</td>
<td></td>
<td>2014</td>
<td>Nurses</td>
<td>X</td>
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<tr>
<td>Magowan, E &amp; Melby, V.</td>
<td></td>
<td>2019</td>
<td>HCP</td>
<td>X</td>
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<tr>
<td>Fallis, W., et al.</td>
<td>Canada</td>
<td>2008</td>
<td>Nurses</td>
<td>X</td>
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<td>Ellison, S.</td>
<td>US</td>
<td>2003</td>
<td>Nurses</td>
<td>X</td>
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<td>Duran, C., et al.</td>
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<td>2007</td>
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<td>X</td>
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<td>Tomlinson, K., et al.</td>
<td></td>
<td>2010</td>
<td>HCP</td>
<td>X</td>
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<tr>
<td>Lowry, E.</td>
<td></td>
<td>2012</td>
<td>Nurses</td>
<td>X</td>
</tr>
<tr>
<td>Goodenough, T &amp; Brysiewicz, P.</td>
<td>South Africa</td>
<td>2003</td>
<td>HCP</td>
<td>X</td>
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<tr>
<td>Emmanuelly, W &amp; Brysiewicz, P.</td>
<td></td>
<td>2018</td>
<td>HCP</td>
<td>X</td>
</tr>
<tr>
<td>Ambelal, M.</td>
<td></td>
<td>2018</td>
<td>HCP</td>
<td>X</td>
</tr>
<tr>
<td>Havugitanga, P &amp; Brysiewicz, P.</td>
<td>Rwanda</td>
<td>2014</td>
<td>HCP</td>
<td>X</td>
</tr>
<tr>
<td>Ramage, E., et al.</td>
<td></td>
<td>2018</td>
<td>HCP</td>
<td>X</td>
</tr>
</tbody>
</table>

Health care professionals = HCP
Educational support for healthcare professionals

Despite numerous international guidelines in support of FWR, there is a need for training and education about FWR [13]. HCPs are requesting more education about FWR, especially how to implement FWR and develop local policies [19, 103, 109]. Training programmes about FWR can increase competence in HCPs and reduce stress and fear [19].

Education can change HCP attitudes towards FWR and empower families to be present [19, 104, 110-113]. Attitudes consist of beliefs and values. An attitude expresses our ideas about what is normal, right and realistic. It is easier to encounter new phenomena that support our understanding of the world than that which opposes what we believe [114]. Attitudes can be learned by imitating others. Positive attitudes can be created through information and exposure; however, a concerted program is required to challenge deep-rooted attitudes. Increasing awareness of what is problematic, for example an attitude that causes harm to the patient or that non-evidence-based care is performed, can often be the first step towards a change in attitude [114].

In the late 1990s, FWR was not as widespread. A study conducted by Bassler (1999) showed dramatic results after an education initiative. The nurses’ support for FWR rose from 56% to 89% and the percentage who wanted to give the family the choice to FWR rose from 11% to 79% [115].

Some HCPs express a lack of self-confidence in performing FWR. Training and education are important for HCPs so that they have the opportunity to practice communication and practical skills [72], increase self-confidence and promote commitment to change [116]. Interventions to improve self-confidence in FWR are supported by social cognitive theory and learning theory. People with high self-efficacy will seek to master rather than avoid difficult situations. The term self-confidence can be used in place of self-efficacy. Self-confidence builds motivation, which is a key factor for learning new skills and daring to use them. It is beneficial to measure self-confidence when developing education initiatives [117].

There are at least 12 studies that have used pre- and post-tests to measure the effect of various FWR educational interventions directed at HCPs. Based on these studies, which show great variation in educational content and length between pre- and post-test, it is not possible to draw any conclusions about which type of education intervention is best or the optimal amount of time between pre- and post-test (Table 3).
Table 3. Healthcare professionals’ attitudes to family-witnessed resuscitation, pre- and post-test after implementation of an intervention.

<table>
<thead>
<tr>
<th>Authors</th>
<th>Participants</th>
<th>Country/Unit</th>
<th>Pre-/post-test</th>
<th>Design</th>
<th>Intervention</th>
<th>Instrument</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bassler, 1999</td>
<td>Nurses 46</td>
<td>USA ED TH</td>
<td>Directly after education</td>
<td>Quasi-experimental</td>
<td>One lecture face to face including perceived obstacles to introducing FWR, families affected both positively/negatively, staff support to family members, possible risks, hospital's policy and how to act when families are present during CPR.</td>
<td>Not described Scales: Not provided Attitudes Experience</td>
<td>Training reduces fear and stress, sense of feeling safe in the situation increased. Before lecture, 11% had positive attitude towards FWR, after training 79% were positive.</td>
</tr>
<tr>
<td>Mian et al, 2007</td>
<td>Nurses &amp; Physicians Pretest 121 Posttest 99</td>
<td>USA ED TH</td>
<td>12 months</td>
<td>Quasi-experimental</td>
<td>One 1-hour lecture which was given by nurse to nurses and physician to the physicians. A video including families experiences of FWR, different opinions from caregivers. FWR guidelines were reviewed. Roleplay after CPR, a staff member played the role of FS, feedback from the patient's family to the resuscitation team.</td>
<td>Self-made Attitudes values, and behaviors, 30-item Likert scale. FWR experience: 12 questions, 4 questions about the education</td>
<td>Nurses reported having a more positive attitude toward FWR after a training program. Physicians showed less support for FWR in post-test, and more concern about practice issues than in the pre-test. Physicians supported that FWR is beneficial to patients' families.</td>
</tr>
<tr>
<td>Holzhausener &amp; Finucane, 2007</td>
<td>Nurses &amp; medical staff Pretest 63 Posttest 36</td>
<td>Australia ED TH</td>
<td>6 months</td>
<td>Quasi-experimental</td>
<td>They measured attitudes before the staff had been involved in FWR. Then the staff had to participate in one or more CA where families were involved. Then the attitudes were measured again.</td>
<td>Self-made survey about attitudes. All questions were dichotomous, open-ended, or a Likert scale</td>
<td>Positive change in staff attitudes: FWR provided quick anamnesis which positively influenced care, staff felt that the patient was comforted by FWR and the family benefited. There were no negative events for staff or family members during the project.</td>
</tr>
<tr>
<td>Feagan &amp; Fisher, 2011</td>
<td>Nurses &amp; Physicians Pretest 94 Posttest 25 nurses</td>
<td>USA ED TH</td>
<td>N/A months</td>
<td>Quasi-experimental</td>
<td>A 40-minute educational PowerPoint program on the pros and cons of FWR and ethical-legal issues. In addition to the PowerPoint presentation, time was set aside for discussion and clarification of the unit's new FWR guideline.</td>
<td>Self-made survey, effects of FWR on patients, family, outcomes, personal comfort, 4-point Likert scale</td>
<td>The mean score improved in favor of FWR. There was a marked difference before and after training indicating that nurses were receptive to evidence-based information, which may have changed their views.</td>
</tr>
<tr>
<td>Nykiel et al, 2011</td>
<td>Nurses, physicians &amp; medical staff Pretest 139 Posttest 113</td>
<td>USA ED</td>
<td>6 months</td>
<td>Quasi-experimental</td>
<td>Implementation of a program to facilitated FWR. The program was meant to improve ED HCP perceptions of their role in providing psychosocial and emotional support to families and improve HCP beliefs offer FWR.</td>
<td>Instrument from ENA 13 items, Likert scale 1 to 5. Two open-ended questions allowed the respondent to write free text</td>
<td>Nurses and staff strongly supported FWR before implementation. Physicians were more comfortable and acceptance of FWR increased after the program. There were no differences between HCPs in terms of providing psychosocial support to families, but positive changes in attitudes towards FWR. The duration of CPR was reduced when FWR was offered.</td>
</tr>
</tbody>
</table>

CA=Cardiac Arrest, CPR=Cardiopulmonary Resuscitation, ED=Emergency Department, ENA= Emergency Nurses Association, FSP=Family Support Person, FPR-BS=Family Presence Risk-Benefit Scale, FPS-CS=FPS-CS=Family Presence Self-Confidence Scale, FWR=Family-witnessed Resuscitation, ICU=Intensive Care Unit, RCT=Randomized Controlled Trial, TH=Teaching Hospital
<table>
<thead>
<tr>
<th>Authors</th>
<th>Participants</th>
<th>Country / Unit</th>
<th>Design</th>
<th>Pre- / Post-test</th>
<th>Intervention</th>
<th>Instrument</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edwards et al., 2013</td>
<td>Nurses &amp; Physicians</td>
<td>USA</td>
<td>Quasi-experimental</td>
<td>12 months</td>
<td>Lecture on background and policy regarding FWR</td>
<td>FWR-BS (Torrance 2008)</td>
<td>Nesting students knowledge, perceptions, and self-confidence positively increased after education.</td>
</tr>
<tr>
<td>Kamprath et al., 2013</td>
<td>Nurses &amp; Physicians</td>
<td>USA</td>
<td>Directly experimental</td>
<td>N/A</td>
<td>PowerPoint presentation on FWR</td>
<td>FWR-BS (Torrance 2008)</td>
<td>Nesting students knowledge, perceptions, and self-confidence positively increased after education.</td>
</tr>
<tr>
<td>Dwyer et al., 2016</td>
<td>Nurses &amp; Physicians</td>
<td>Australia</td>
<td>Quasi-experimental</td>
<td>3 months</td>
<td>One-hour lecture on FWR and a review of the literature</td>
<td>FWR-BS (Torrance 2008)</td>
<td>Education did not increase participants’ intention to offer FWR. Slightly more positive attitudes toward FWR after education. Some participants supported the need for a dedicated FSP.</td>
</tr>
<tr>
<td>Ferrara et al., 2016</td>
<td>Nurses &amp; Physicians</td>
<td>USA</td>
<td>Quasi-experimental</td>
<td>2 months</td>
<td>Three video simulations of FWR</td>
<td>FWR-BS (Torrance 2008)</td>
<td>The intervention had no effect on attitudes.</td>
</tr>
<tr>
<td>Candiola et al., 2016</td>
<td>Nurses</td>
<td>USA</td>
<td>RCT</td>
<td>1 month</td>
<td>PowerPoint presentation on FWR literature.</td>
<td>FWR-BS (Torrance 2008)</td>
<td>There was a statistically significant increase in self-confidence and positive attitudes after education. The control group saw a positive impact on facilitating FWR.</td>
</tr>
<tr>
<td>Powell et al., 2016</td>
<td>Nurses</td>
<td>USA</td>
<td>Quasi-experimental</td>
<td>2 months</td>
<td>PowerPoint presentation on benefits and barriers of FWR</td>
<td>FWR-BS (Torrance 2008)</td>
<td>Increased self-confidence and positive attitudes after education. Journal review: 5% of families were offered FWR before the intervention 100% offered FWR after the intervention.</td>
</tr>
<tr>
<td>Meghani et al., 2019</td>
<td>Physicians &amp; Nurses</td>
<td>Pakistan</td>
<td>Quasi-experimental</td>
<td>1 month</td>
<td>PowerPoint presentation on FWR literature.</td>
<td>FWR-BS (Torrance 2008)</td>
<td>There was a statistically significant increase in self-confidence and positive attitudes after education. The control group saw a positive impact on facilitating FWR.</td>
</tr>
<tr>
<td>Council &amp; Powers, 2022</td>
<td>Nurses</td>
<td>USA</td>
<td>Quasi-experimental</td>
<td>2 months</td>
<td>PowerPoint presentation on benefits and barriers of FWR</td>
<td>FWR-BS (Torrance 2008)</td>
<td>Increased self-confidence and positive attitudes after education. Journal review: 5% of families were offered FWR before the intervention 100% offered FWR after the intervention.</td>
</tr>
</tbody>
</table>

**Notes:**
- CA=Cardiac Arrest, CPR=Cardiopulmonary Resuscitation, ED=Emergency Department, ENA=Emergency Nurses Association, FWR=Family Witnessed Resuscitation, FWR=Family Witnessed Resuscitation, IPC=Fetal Protection Scale, PCS=Family Presence Scale, RCT=Randomized Controlled Trial, TH=Teaching Hospital.
What should education programmes contain?

There is no fixed content in FWR education initiatives, but it is important that all team members are included in the education [118]. Based on the available research and the requests of HCPs, education programmes should contain benefits for patients, families and HCPs [72, 119] and existing FWR unit policies. If no policies are in place, they should be established [72, 118]. Role-play or simulation, where HCPs play the role of family members and a family support person during CPR training, has been shown to have a beneficial effect. HCPs gain a better understanding of what it is like to have family present during CPR and their comfort and confidence increases. It also increases the willingness of HCPs to offer FWR [59, 118]. The family support person’s role involves assessing the family’s ability to attend and manage reactions [18, 120] (Table 4).

Family support person

A critical aspect of the success of FWR implementation is the role of a family support person. Both international and national guidelines recommend that a team member should be allocated to provide support to the patient’s family during and after resuscitation attempts and that the healthcare systems should also provide physicians with training on how to provide information and support to family members [39, 40] (Table 4).

FWR can be stressful for HCPs if they feel that the family is not being supported during resuscitation [121]. Having a family support person reduces stress and anxiety in HCPs when they perform CPR [34, 121]. Having a family support person facilitates the ability of the department to offer FWR. The family support person should be trained to provide support and prepare the family for what they will see so that they are prepared to cope with the experience. The family support person should explain the scenarios, meet the family’s physical and emotional needs, and advocate for the family’s interests in communication with the CPR team [18, 44].

The family support person’s role is to serve as a link between HCPs and the family, provide the family with optimal support, assess the family’s ability to handle the situation, provide information, translate medical terminology, explain the procedures and respond to the family’s reactions in a seemingly chaotic environment, but also to remove potentially aggressive family members from the resuscitation room [18, 19, 22, 44, 84, 121]. The members of the CPR team need to accept a variety of behaviours during
FWR. Lowry (2012) asked emergency nurses to describe what it might be like to practice FWR. To families who are calm, who want to be close to the patient, you may say: "if you want to...hold his hand, tell him that you love him", "tell him not to give up" or "you can go ". Families may also be confrontational, "they get angry with you"; "flopping around, screaming and crying". One nurse said: "you don't respond to their anger...because you know that it just happens". HCPs need to practice handling these situations. If the HCP is trained for FWR, you don't feel distracted by the family and can handle upset family members, "hysterical...but as the code went on...it started sinking in...they were a lot calmer at the end." [122](page 331).

The family support person also cares for family members who decide not to be present during resuscitation. The person is responsible for taking care of the family after cardiac arrest and answers questions and responds to their needs. In this way, stress and anxiety can also be reduced for the HCPs involved in resuscitation [19]. It is beneficial if the family support person use a clear and accessible language to help the family understand. If possible, the family support person should have the same cultural background as the family and the patient [44].

<table>
<thead>
<tr>
<th>Table 4. Family support person role.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Appropriateness</strong></td>
</tr>
<tr>
<td><em>Contraindications</em></td>
</tr>
<tr>
<td>Influence of drugs or alcohol, unwilling to follow instructions, violent behaviour or distracting emotional outbursts [72, 120].</td>
</tr>
</tbody>
</table>

| **Preparation**                     |
| *Before entering the room.*         |
| What they are expected to see and hear, patient's appearance, treatments and equipment used [17, 18, 44, 120, 123]. |

| **Support during and after FWR**    |
| *Simple information*                |
| Without detailed medical explanation, the most important thing is to show empathy [18]. |
| Information about the seriousness of the situation, and that decisions can be made to end CPR [19]. |

| **Security**                        |
| Family members cannot be combative or disruptive or make it difficult for health care professionals or the patient. They may also be asked to leave the resuscitation room [17, 19, 44, 120]. |

| **Assessment**                      |
| How family members cope during family-witnessed resuscitation, give information that they can leave the resuscitation area at any time [18, 19, 44, 120]. |

| **Be close**                        |
| Encourage the family that they may touch the patient if they wish, family support person decides if/when family members can touch and hold the patient [17, 18, 44]. |

| **The number of family members**    |
| Limit the number of family members allowed to attend, ensure safety, often there is a lack of space in the resuscitation area [19, 44, 120]. |

| **Manage reactions**                |
| Different reactions e.g., fainting, vomiting, offer family members to be able to sit on a chair [17, 18, 124]. |

| **Not be left alone**               |
| During or after the resuscitation, the family support person remains with the family to provide emotional and logistical support [18, 19, 44, 120]. |
Who should have the family support role?

The role of family support person is quite undefined and formal education and training programmes are still lacking [18, 125], but the family support person should have the communication skills and knowledge needed to make an initial assessment of the family's wishes for family presence and evaluate the family's readiness to enter the room. The family should be instructed about expected behaviours outside the room so that they do not interfere with the ongoing resuscitation [18].

It is recommended that an experienced HCP is appointed to be responsible for explaining the resuscitation process to the patient's family [18, 44, 84]. It is common to use experienced registered nurses (USA) [13] or chaplains (United Kingdom) as family support persons [123, 126], but other professionals from varying disciplines can serve in the role, including for example counsellors, physicians and anaesthesia technicians [18, 110, 127]. In the Swedish healthcare context, there is also assistant nurses, who often have the role of family support.

Two studies have explored the family support person role. In interviews with nurses, chaplains and counsellors from hospitals in the USA, it was found that counsellors and chaplains sometimes find it difficult to answer questions about what happens during CPR from a medical perspective [123, 126]. Attempts have been made to have family support persons view videos of actual resuscitation attempts to increase their knowledge, even though counsellors and priests are not expected to give medical explanations to the family [128]. A family support person needs support to serve effectively in the role. Despite many years of experience, serving as a family support person is not something individuals get used to [18, 123].

Registered nurses

Registered nurses may be suitable for the family support person role because of their holistic approach. The nurse's competence in nursing makes it possible to support patients and families in making decisions and to act based on the patient's values, culture, beliefs and while serving as a liaison between patients, families and HCPs [129]. Nurses are usually on the scene when cardiac arrest occurs. They also have a good ability to assess the situation and have knowledge of CPR [123, 126]. There are challenges when nurses serve in the role of family support person. It can be difficult to put all the focus on the family if the team also needs help. The shortage of nurses means that it can be difficult to spare a nurse for the task, and nurses do not have specific family support person training [123, 126, 130]. There are no clinical guidelines for nurses who serve as family support persons,
and many feel unprepared to support family members and may be reluctant to step into this role during FWR [18].

**Healthcare chaplains**
Sweden’s population currently consists of multifaceted cultural and religious groups. Individuals may consider themselves spiritual, but not religious. Spirituality is now increasingly seen as separate from religion. Healthcare chaplains in western countries, with their unique experience, skills and training, are well prepared to deal with diverse religious beliefs and can support multiple beliefs and perspectives. This is an important skill during FWR, and the need for HCPs to understand the role of clergy as spiritual caregivers in light of changing perspectives on spirituality and religion [131]. Though HCPs may not always think to call on a chaplain, they can provide support and be an important resource to the family both during and after FWR. Chaplains can be an important resource, for example, when issues arise relating to crisis management, anxiety, anger, religious items and existential questions during cardiac arrest and they are often able to stay after the cardiac arrest and take care of the family [131].

**Counsellors**
Counsellors do not have restrictions linked to religion [110, 126], but are skilled at providing psychosocial support both during CPR and afterwards [123, 126]. In some emergency departments, a counsellor is tasked with supporting patients, family member and staff [132]. Counsellors promote family presence by offering support, giving and receiving information and involving the family in decision-making. In some hospital units, if the family is not present at the time of the cardiac arrest, the counsellor tries to contact them in order to inform them that there has been a change in the patient’s status and that a resuscitation attempt is underway [110, 126]. It can be difficult to enter as a counsellor when a cardiac arrest is in progress. Counsellors have no relationship with the team and may feel unsure of what to do [126].

**Swedish Register of Cardiopulmonary Resuscitation**
The Swedish Register of Cardiopulmonary Resuscitation describes cardiac arrest treated both inside and outside of the hospital. All 74 emergency hospitals in Sweden are currently included in the register [133]. The purpose of the Swedish Register of Cardiopulmonary Resuscitation is to map the
circumstances surrounding cardiac arrest and to provide a detailed description of treatment regarding the duration and effect (i.e. short- and long-term survival) [133].

After cardiac arrest, the nurse who participated in resuscitation reports information related to the cardiac arrest event to the registry. The requested information includes alarm times, witnessed cardiac arrest, ECG rhythm, medication, manual or mechanical cardiac compression, number of defibrillations and whether the patient was alive after CPR [133]. Patients who survived are followed up by telephone 3-6 months after the cardiac arrest event by the locally responsible registered nurse, who collects patient-reported outcome measures (PROM) [134]. PROM data in the registry consists of the EuroQoL-5 Dimension Questionnaire (EQ 5D-5L) [135], the Hospital Anxiety Depression Scale (HADS) [136], and the Life Satisfaction Questionnaire (LiSat-11) [137].

Procedural processes and outcomes of family-witnessed resuscitation

There is a widespread concern among HCPs that FWR could negatively affect the outcomes of CPR because it could make it more difficult to perform technical procedures and communicate in the team [44] and that resuscitation will last longer [13, 19, 44]. When it comes to the return of spontaneous circulation, a small retrospective cohort study from the US of patients in intensive care units (n=323) found that fewer patients regained spontaneous circulation when a family member was present during resuscitation (45% vs. 62%) [138]. It has also been reported that the resuscitation time is shorter (23.5 vs. 30 minutes) [139] or not affected at all when FWR was practiced [138]. However, in a large observational cohort study in the USA involving 41,568 patients with cardiac arrest, there were no differences in the quality of resuscitation, interventions, or potential resuscitation system errors between hospitals with and without FWR policies. Nonetheless, the study found a small but significant reduction in the mean-time to defibrillation in patients (2.1 vs. 2.4 minutes) in hospitals with FWR policies compared to hospitals without such policies [140]. Furthermore, a meta-analysis published in 2015 found that FWR did not influence adult resuscitation outcomes [119], and a more recent umbrella review reported that FWR did not cause interference with resuscitation or procedural processes and did not affect mortality or the quality of resuscitation (duration, repetition, time interval between request and initiation). Family members focused more on the patient than the ongoing procedure [72].
Structured follow-up of cardiac arrest survivors’ well-being and coping

The transition from hospital to everyday life at home can be difficult for cardiac arrest survivors and their families. During the hospital stay, the patient receives highly specialised care and they feel protected from death, but after discharge, many patients feel insecure and vulnerable, where feelings of abandonment, isolation and loneliness can arise [141]. After a cardiac arrest, it is relatively common for a patient to have some form of cognitive impairment, such as memory loss and/or emotional problems, including loss of confidence, personality changes, irritability, anger, frustration and fatigue [65, 142]. In Sweden, about 30% of cardiac arrest survivors experience fatigue [143]. Cardiac arrest survivors have also reported that they can recall actual events that occurred during resuscitation and some also have ‘near-death experiences’ [65]. Existential thoughts are evoked by the fragmented cardiac arrest event and its existential consequences. These are "invisible problems" that are not always noticed by the healthcare system. However, these problems can have a significant impact on both the patient and the family after discharge from hospital.

The sudden, life-threatening and traumatic nature of cardiac arrest means that it is not only the patient, but also the family, that needs support, as the family plays an integral role in the patient’s life before, during and after discharge from hospital. Sometimes the family not only witnessed the cardiac arrest at the hospital, they may also have performed CPR themselves before arriving at the hospital and may have been responsible for saving the patient’s life [142]. Family members of adult cardiac arrest patients report that they often experience significant uncertainty and a persistent psychological burden after cardiac arrest, sometimes even exhibiting higher levels of anxiety compared to the cardiac arrest survivor [144]. Family members may need to manage both their own needs and the patient’s needs, thus complicating the transition to life at home and they may also feel that primary care is insufficient to meet their needs. Family members report that they lack information and support and that they feel ill-equipped to deal with the consequences of cardiac arrest in the patient [145].

Pin Pek et al. (2023) investigated 46,828 out-of-hospital cardiac arrests between 2002-2022 and found that depression, anxiety, posttraumatic stress syndrome and female gender showed significant associations with lower health related quality of life scores. Impaired neurocognitive
function and impaired daily life were also significantly associated with poorer health related quality of life [146].

As described in Table 5, out-of-hospital cardiac arrest survivors have internationally been found to have a higher degree of psychological distress, than the general population [147, 148], with 13%–61% reporting anxiety and 11%–45% having symptoms of depression [149, 150]. In comparisons between in-hospital cardiac arrest and out-of-hospital cardiac arrest, out-of-hospital cardiac arrest survivors are more likely to develop anxiety and depression within six months, whereas in-hospital cardiac arrest survivors develop more symptoms of anxiety and depression over time [5]. Cardiac arrest survivors in Sweden tend to have a better health-related quality of life compared to cardiac arrest survivors from an international perspective [143, 151, 152]. In-hospital cardiac arrest survivors experience more problems with daily activities and mobility compared to out-of-hospital cardiac arrest survivors [151]. In in-hospital cardiac arrest survivors, known risk factors for worse health related quality of life include multiple comorbidities [153]. In-hospital cardiac arrest and out-of-hospital cardiac arrest survivors tend to estimate their health at the same level as the general population [143, 151]. Cardiac arrest survivors in Sweden also tend to have lower psychological distress compared to international patients, with 12%–18% reporting anxiety and 9%–15% symptoms of depression [143, 151, 152]. Furthermore, female cardiac arrest survivors report higher levels of anxiety, posttraumatic stress syndrome and lower health compared to male survivors [152] (Table 5).

Today, a structured follow-up for family members who have lost a family member in cardiac arrest is lacking in Sweden, although many units contact the family member by telephone when some time has passed. However, a structured follow-up within three months after discharge from the hospital is recommended for all cardiac arrest survivors and their family members. During the follow-up, screening should be done for cognition, emotional problems and fatigue. Based on the patient’s history and the results of the screening, the follow-up should be tailored to the patient’s needs. Referral for further specialized care may be needed so that further investigations can be carried out [154-156].
Table 5. Health status and psychological distress of cardiac arrest survivors.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Setting</th>
<th>Year</th>
<th>Participants</th>
<th>Data collection after CA</th>
<th>Depression</th>
<th>Anxiety</th>
<th>PTSD</th>
<th>EQ-VAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wilder et al 2013 Review</td>
<td>Europe, US</td>
<td>1993-2011</td>
<td>683 OHCA</td>
<td>0-72 months</td>
<td>14%-45%</td>
<td>13%-61%</td>
<td>19%-27%</td>
<td></td>
</tr>
<tr>
<td>Yaow et al 2022</td>
<td>Europe, US and Canada</td>
<td>1983-2021</td>
<td>OHCA 186,160</td>
<td>1-18 months</td>
<td>11%-30%</td>
<td>16%-39%</td>
<td>3%-65%</td>
<td></td>
</tr>
<tr>
<td>Chen et al 2023</td>
<td>Europe, US, Australia, Canada and Israel</td>
<td>1983-2021</td>
<td>187,910 OHCA and IHCA</td>
<td>3-12 months</td>
<td>Short-term 18% OHCA 8% IHCA</td>
<td>Short-term 28% OHCA 14% IHCA</td>
<td>Short-term 17% OHCA 30% IHCA</td>
<td>Short-term 24% OHCA 20% IHCA</td>
</tr>
<tr>
<td>Israelsson et al 2017</td>
<td>Cross-sectional study</td>
<td>2013-2015</td>
<td>594 IHCA</td>
<td>3-6 months</td>
<td>13%</td>
<td>15%</td>
<td>-</td>
<td>70</td>
</tr>
<tr>
<td>Djärv et al 2020</td>
<td>Cross-sectional study</td>
<td>2014-2017</td>
<td>1,369 OHCA 772 IHCA</td>
<td>3-6 months</td>
<td>OHCA 13% IHCA 15%</td>
<td>OHCA 12% IHCA 16%</td>
<td>-</td>
<td>OHCA 80 IHCA 70</td>
</tr>
<tr>
<td>Hellström et al 2021</td>
<td>Cross-sectional study</td>
<td>2013-2018</td>
<td>50 OHCA 162 IHCA</td>
<td>6 months</td>
<td>9%</td>
<td>18%</td>
<td>-</td>
<td>OHCA 80 IHCA 70</td>
</tr>
</tbody>
</table>

1 The table summarizes health status and psychological distress in cardiac arrest survivors based on Swedish cross-sectional studies and the most recent systematic reviews which reported the number of patients included and data for depression, anxiety, and posttraumatic stress syndrome or visual analogue scale. CA=Cardiac arrest, IHCA=in-hospital cardiac arrest, OHCA=out-of-hospital cardiac arrest, EQ-VAS=EuroQol-visual analogue scale, PTSD=posttraumatic stress disorder.
RATIONALE

Annually, 1.5–2.8 unexpected cardiac arrests occur per 1,000 hospital admissions in hospitals in Europe and the USA. In Swedish hospitals, cardiac arrest affects approximately 2,500 patients each year. In a cardiac arrest, it is important for the patient’s outcome that routines and teamwork function optimally. In case of in-hospital cardiac arrest, international guidelines recommend FWR, except in situations when the outcome for the patient may be worsened by FWR. However, knowledge is lacking about how often families are offered to participate during in-hospital CPR, to what degree they choose to participate, and survival rates when FWR is practiced.

Having a family member present during CPR may increase stress among HCPs and international studies demonstrate that the majority of nurses and physicians are hesitant about FWR. In Sweden, it is unclear how nurses and physicians view FWR, how they practice FWR and whether there are local FWR guidelines. Mapping what the situation looks like can improve care by reducing the risk of unfavourable experiences for everyone involved during and after a cardiac arrest.

Scientific knowledge of the shared experience of FWR among patients and family members, both in hospital and after hospital discharge, is almost non-existent. In order to be able to develop effective care, knowledge is needed about how cardiac arrest affects persons who survive and their family members, as well as knowledge about how HCPs should meet them in the best possible way. Such knowledge can form the basis for developing hospital care and post cardiac arrest care for both survivors and family members, thus making care more individualized and person-centred.

Finally, existing guidelines state that the healthcare system should provide HCPs with education on how best to provide information and support to the family during and after FWR. However, there is a shortage of educational training aimed at HCPs, as well as a lack of interventions adapted to HCP needs in specific contexts. Consequently, new and innovative solutions are needed to investigate whether education can affect attitudes and strengthen the self-confidence of HCPs in managing FWR situations.

The knowledge gained from this thesis can be used to improve in-hospital cardiac arrest care when a family member is present, thus reducing the risk of adverse experiences for everyone involved and facilitating the grieving process if the patient does not survive.
In-hospital family-witnessed adult resuscitation
Aims

The overall aim of this thesis was to describe characteristics of FWR, explore experiences and attitudes towards FWR and further develop and test an educational intervention for in-hospital FWR.

Specific aims of the included studies

To explore nurses’ and physicians’ experiences and attitudes toward family- witnessed resuscitation in cardiac care units (I).

To describe the prevalence and processes of family-witnessed resuscitation in hospitalised adult patients, and to investigate associations between family-witnessed resuscitation and the outcomes of resuscitation (II).

To explore experiences of in-hospital cardiac arrest and the impact on life it had for the patient who suffered the arrest and the family member who witnessed the resuscitation (III).

To evaluate the effects of an educational online video intervention on nurses’ and physicians’ attitudes towards in-hospital family-witnessed resuscitation and their self-confidence in managing such situations (IV).
METHOD

Design
This thesis includes four separate studies: three quantitative studies and one qualitative study. An overview of the designs, participants, data collection and measurements are shown in Table 6.

| Table 6. Overview of methods, participants, data collection and measurements, studies I-IV |
|-----------------------------------------------|-----------------------------------------------|-----------------------------------------------|-----------------------------------------------|
| Study I                                      | Study II                                     | Study III                                     | Study IV                                      |
| **Design**                                   | Cross sectional multicentre study            | Retrospective observational cohort study      | Qualitative study                             |
| **Participants**                             | Nurses and physicans at the cardiology units at all seven university hospitals (n=189) | Patients with IHCA registered in the SRCPR (n=4,843) | Patients$^a$ who survived IHCA and family member(s)$^a$ who were present during CPR (n=15) |
| **Data collection**                          | Web based self-reported survey 2015          | Registry data 2018–2020                       | Narrative dyad/family interviews 2018–2020   |
| **Study variables**                          | 1. Sociodemographic data                     | 1. Sociodemographic data                      | 1. Sociodemographic data                      |
|                                              | 2. Experiences of FWR                        | 2. Prevalence data                            | 2. The family’s shared experiences of in-hospital FWR |
| **Data analysis**                            | Descriptive statistics: Frequencies, proportions (%), median (Md), quartiles (Q1, Q3) | Correlational statistics: $\chi^2$ tests, Mann-Whitney $U$ test, Qualitative content analysis | Descriptive Phenomenological Analysis (IPA) |
|                                              | Descriptive statistics: Frequencies, proportions (%), means (SD). | Correlational statistics: $\chi^2$ tests including post-hoc tests with adjusted z-scores, Student’s t-tests, linear and binary logistic regression | Descriptive statistics: Frequencies, proportions (%), means (SD) |
|                                              | Interpretative Phenomenological Analysis (IPA) | Correlational statistics: Paired t-test       | Correlational statistics: Sample size calculation |

CPR=Cardiopulmonary resuscitation, ED=Emergency Department, FPS-CS=Family Presence Self-Confidence Scale, FWR=Family-witnessed Resuscitation, IHCA=In-Hospital Cardiac Arrest, SD=Standard Deviation, SRCPR=Swedish register of Cardiopulmonary Resuscitation

$^a$ Patients (cardiac arrest survivors): 4 male, 3 female. Family members, 5 female, 3 male. Age: 19-85.
Relationships: father, mother, daughter, son, grandmother, grandchild, husband, spouse. Age: 30-80
Participants
Participants included in the thesis were healthcare professionals (I, IV), in-hospital cardiac arrest patients (II-III) and their family members (III). The samples in studies I and II were probability samples. The samples in studies III and IV were non-probability samples and purposive samples in studies III and IV (Table 6).

Inclusion and exclusion criteria
The inclusion criteria were as follows: Swedish speaking HCP working in clinical patient care (I, IV), patient ≥ 18 years of age having a reported in-hospital cardiac arrest in the Swedish Register of Cardiopulmonary Resuscitation (II), Swedish speaking patient ≥ 18 years of age and (III), and Swedish speaking family members having witnessed the resuscitation of a next-of-kin in hospital (III).

Exclusion criteria were as follows: communication disabilities, severe cognitive impairment, severe psychiatric illness, or being at the end-of-life (III). Patients with an in-hospital cardiac arrest occurring in the operating theatre, catheter laboratory, or in public areas of the hospital were excluded in studies II and III. For Study II, the sample was also limited to the index event (i.e. the first cardiac arrest registered in the Swedish Register of Cardiopulmonary Resuscitation in each patient during the study period).

Setting and procedures
Procedure of recruitment
All studies (I-IV) were multicentre studies conducted in Sweden. Data was collected in autumn 2015 to spring 2023 (Table 7). In Study I, participants were recruited from all cardiology departments at the seven university hospitals in Sweden. In studies II and III, participants were recruited from the Swedish Register of Cardiopulmonary Resuscitation. An overview of the study cohort in Study II is shown in Figure 2.
Method

Figure 2. Study cohort in Study II. In-hospital cardiac arrests reported in the Swedish Register of Cardiopulmonary Resuscitation from April 2018 to April 2020.

1 Operating theatre or catheter laboratory. Physiotherapy, occupational therapy, public spaces such as corridors outside wards, cafeteria.2 Only the first (index) event was included in the study for each patient during the study period.

Participants in Study IV were recruited from one university hospital, one county hospital and four district hospitals in the eastern middle region of Sweden. The participants were employed at different departments: emergency; general medicine; cardiology; infectious diseases; and orthopaedic, thoracic and abdominal surgery (Table 7).

<table>
<thead>
<tr>
<th>Department</th>
<th>University hospital</th>
<th>County hospital</th>
<th>District hospital</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nurses</td>
<td>Physicians</td>
<td>Nurses</td>
<td>Physicians</td>
</tr>
<tr>
<td>Medicine</td>
<td>62</td>
<td>36</td>
<td>71</td>
<td>81</td>
</tr>
<tr>
<td>Cardiology</td>
<td>40</td>
<td>25</td>
<td>40</td>
<td>25</td>
</tr>
<tr>
<td>Emergency</td>
<td>57</td>
<td>76</td>
<td>43</td>
<td>30</td>
</tr>
<tr>
<td>Infectious</td>
<td>22</td>
<td>20</td>
<td>24</td>
<td>19</td>
</tr>
<tr>
<td>diseases</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>37</td>
<td>50</td>
<td>37</td>
<td>50</td>
</tr>
<tr>
<td>Orthopaedics</td>
<td></td>
<td></td>
<td>37</td>
<td>22</td>
</tr>
<tr>
<td>Thoracic</td>
<td>15</td>
<td>18</td>
<td></td>
<td></td>
</tr>
<tr>
<td>surgery</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>193</td>
<td>200</td>
<td>111</td>
<td>106</td>
</tr>
</tbody>
</table>
**Procedure of data collection**

An invitation to participate was distributed by e-mail to all nurses and physicians together with a weblink to the questionnaire by the heads of the departments (I) and by the research group for Study IV. Five out of seven hospitals in Study I reported the number of HCPs approached, while the remaining two only reported the number of completed questionnaires. In Study IV, 1195 HCPs were approached.

For Study II, an application to access data from the Swedish Register of Cardiopulmonary Resuscitation was sent to the register holder. Before receiving the data, all data was anonymised.

For Study III, 12 patients were identified and informed of the study by local register nurses at a routine telephone follow-up, 3-6 months after the cardiac arrest when PROM data were collected for the Swedish Register of Cardiopulmonary Resuscitation. All patients expressed interest in participating. The PhD student then called potential participants to confirm that both the patient and the family member(s) wanted to participate. Information letters were sent and a follow-up call occurred after two weeks. However, five interviews could not be conducted due to two unexpected patient deaths and two family members and one patient changed their preference. Finally, seven interviews were conducted with 15 participants.

**Data collection**

Study I and IV used self-reported web-based questionnaires for data collection, Study II used registry data, while Study III used narrative interviews for the same purpose.

**Self-reported questionnaires**

There are several questionnaires that measure attitudes to FWR [27, 104, 111, 113, 157, 158], but only one published questionnaire that measure self-confidence in managing such situations [159]. In this thesis, only the two instruments that were used in studies I and IV will be presented [27, 159].

Written permission was obtained from the instrument designers for use of the original scales, as well as for the existing Swedish version of the FWR attitude instrument.

**Attitudes towards FWR**

The questionnaire was initially designed by Fulbrook et al. [27] and used in several studies [83, 160-167]. The instrument has previously been validated on Swedish cardiac nurses [28].
The survey consists of three parts:
1) Sociodemographic background (6 and 8 questions for studies I and IV, respectively).
2) Experiences of FWR (7 questions).
3) Attitudes towards FWR (30 questions).

The questions in the second part are answered dichotomously (yes/no), while the questions in the third part – which is divided into three areas (decision-making, process, outcome) – are answered on a five-point Likert scale, from 1 = strongly disagree to 5 = strongly agree, with a neutral middle answer of 3 = I don't know. The questions are either positively or negatively worded to reduce the risk of mechanical unreflective responses. In order to calculate average values, the Likert scale can be converted to numbers from 1 to 5. When the data is analysed, the rating is weighted so that a higher score means a more positive attitude [27]. There is also an opportunity to express personal opinions regarding FWR in open-ended questions.

In Study I, the Cronbach's alpha was 0.86 for the total scale, 0.43 for the decision-making sub-scale, 0.62 for the process and 0.85 for the outcomes. In Study IV, Cronbach's alpha was 0.90 for the total score and 0.53, 0.78, and 0.86 for the sub-scales, respectively.

Since the questionnaire had neither been tested on physicians nor in a web format, the research group modified the questionnaire by replacing "nurse" with "physician" and vice versa in each statement. It was subsequently changed to a web format and tested in a pilot study. The questionnaire aimed at nurses retained the original text. The head of the cardiology department strategically selected potential participants based on variation in their background variables. These individuals were later asked about participation by the study manager (the PhD student).

The pilot study was conducted by the PhD student and involved five physicians and five nurses. They were instructed to validate each item in the web questionnaire to test the feasibility and usability (i.e. relevance, clarity, comprehensibility and readability as suggested by Polit and Beck (2021) [168] using the "think aloud" technique [169, 170], where the participants were encouraged to verbalize their thoughts and feelings in relation to the web questionnaire. Responses were audio-recorded and participants were encouraged to continue speaking aloud or to answer any follow-up questions [169, 170].

There was good relevance, understanding and legibility of the web-based questionnaire. Minor amendments were made in the introduction to
the questionnaire, but otherwise the questionnaire retained its original form and content. The results from the pilot study are unpublished.

**Family Presence Self-confidence Scale**
The Family Presence Self-confidence Scale (FPS-CS) was originally developed and validated for nurses in the United Kingdom by Twibell, based on the literature and interviews with experts from a variety of clinical areas [159]. FPS-CS has previously been used in several studies [14, 106, 110, 112, 118, 121, 171-180].

It contains a total of 17 questions on a 5-point Likert scale from 1 = *not at all confident* to 5 = *very confident*. The questions focus on how confident the nurse/physician feels in a CPR situation where families are present (e.g. communicating, administering medications, defibrillating and giving heart compressions). Other questions concern how confident a nurse feels about preparing family members to enter a room where CPR is being performed, as well as the ability to maintain patient dignity and integrity, manage family members emotions, help family members talk to the patient during resuscitation and to care for family members after cardiac arrest regardless of the outcome. A higher score indicates a greater level of self-confidence in performing FWR. Mean scoring is used to determine overall self-confidence [159].

The instrument for nurses [159] is not translated to physicians; the research group therefore translated the questionnaire to include the same questions for physicians. The translation followed the recommendations for translation of instruments outlined by the WHO [181] and Valaker et al. (2019) [182], where all the steps in the translation process are clearly described. The questionnaire was then reviewed by peers and researchers for content and face validity, without any further modifications needed. The FPS-CS questionnaire was also tested in a pilot study, as it had not been previously tested on physicians. The pilot study was performed using the “think aloud” technique [170] and showed good relevance, understanding and legibility of the web-based questionnaires. Minor amendments were made in the introductory text, but the questionnaire otherwise retained its original form and content. For Study IV, the total score for Cronbach’s alpha was 0.92.

**Registry data**
At the time of the planning of Study II, The Swedish Register of Cardiopulmonary Resuscitation lacked specific questions about FWR, which led to a
collaboration between the research group and the register holder where five new questions were developed and tested.

The new questions were validated by nurses and physicians using a think-aloud technique [170] and were then included in the Swedish Register of Cardiopulmonary Resuscitation in the second quarter of 2018 as routine questions after in-hospital cardiac arrest. The questions are answered yes or no by the nurse who participated in the resuscitation event (Table 8).

| Table 8. Variables about family-witnessed resuscitation in Swedish Register of Cardiopulmonary Resuscitation and explanations of questions. |
|---------------------------------|------------------|--------------------------------------------------|
| Family* presence                | Yes/No           | Explanations to questions                        |
| Was there a family member visiting the patient when the cardiac arrest occurred? | Yes/No | Yes = there was a family member present, either with the patient or in direct connection with the event |
| Did the family request to be present during CPR? | Yes/No | Yes = the family actively requested to stay with the patient or come into the room where CPR occurred |
| Was the family offered to be present during CPR? | Yes/No | Yes = one of the HCPs actively asked if the family member(s) wanted to be present during CPR |
| Was the family member(s) present during CPR? | Yes/No | Yes = with the patient during all or parts of the CPR event |
| Was there a family support person assigned to the family in the room* during CPR? | Yes/No | Yes = there was an HCP on site who was assigned to take care of the family and explain the course of events during and after CPR |

*Family = the person(s) with whom the patient considers himself/herself to have a close relationship.
* HCP in this context means physicians, nurses, and assistant nurses but also physiotherapists, occupational therapists, counsellors and representatives from the hospital chapel as many of these individuals are knowledgeable in CPR and were present at the scene or were the ones who provided support to the family during CPR.
* Room - the place where the CA occurred; it can be, for example, the patient’s room, the operating room, the department's dining room, or corridor.

Narrative interviews
In Study III, narrative interview was used. First-person accounts can provide a description of the lifeworld of people in more detail than is usually possible using quantitative research methods. The interviews were based on a semi-structured interview guide, which means that a few open-ended questions of an exploratory nature are followed up with in-depth and reflective questions based on the interviewee’s account (Table 9).

The interview guide was pilot tested and developed together with a senior researcher familiar with the Interpretative Phenomenological Analysis (IPA) approach [183]. The interviews were conducted jointly with the patient and the family member(s) present and took place 4-10 months after the cardiac arrest event in the patient’s home or at the nearest hospital. All interviews were conducted by the PhD-student and were audio recorded.
Table 9. Interview guide.

| In-hospital cardiac arrest (acute phase in hospital) | 1. Can you tell me about the cardiac arrest? [To family members: Can you tell me what it was like for you to witness the cardiac arrest?] 2. Can you tell me about your experiences regarding your interaction with staff members during the cardiac arrest? |
| The period immediately following the cardiac arrest | 3. Can you tell me about your experiences in the hospital after the cardiac arrest? 4. Can you tell me about your experiences regarding contact with staff members in the hospital? |
| The period after wards (at home) | 5. Can you tell me what life has been like after the cardiac arrest? |
| The future | 6. Can you tell me about your outlook on life and death when you think about the future? |
| Concluding question | 7. Do you have any other thoughts about the cardiac arrest event that we have not talked about or that you would like to elaborate on? In-depth and reflective questions were asked based on the narratives, for example: Can you tell me more? What did you think then? What do you mean by...? |

Development, pilot testing, and evaluation of an educational video

Study IV consisted of three steps and involved the development, pilot testing, and evaluation of an educational video about FWR intended for HCPs (Figure 3).

Figure 3. An overview of the video development process

Step 1: The development phase of the educational video was initiated and driven by the research group with the PhD student as the project manager. Participatory research design that involves nurses, physicians, CPR instructors, an ICT (Information Communication Technology) educator, researchers and a video producer was used in all stages. The content of the video is based on previous research, including the results from studies I-III in this thesis, medical outcome measures, attitudes of HCPs, patient and family experiences and practical and ethical guidelines about FWR. The message is conveyed by an announcer's voice, authentic CPR scenarios,
Method

and quotes from family members and HCPs. Actors are HCPs who are experts in the field. In line with previous pedagogical research [184] the video is 10 minutes in length. The recording of the video took place in November 2021.

Step 2: A pilot study was conducted with physicians (n=11) and nurses (n=20) working in a cardiology department in a district hospital in the southeast of Sweden to test user friendliness, feasibility, experiences of the video, and perceptions of the video content and message, as well as to test the instruments in the web-based format (described previously). The pilot study was conducted with the same design as in the intervention study to evaluate the survey tool “Survey & Report” – a secure web application for building and managing online surveys for research studies. Interviews were conducted to determine the participants’ perceptions of the video (Table 10). Based on the participants’ answers and opinions, the video did not need to be revised further. The results from the pilot study are unpublished.

<table>
<thead>
<tr>
<th>Table 10. Interview guide – participants’ perceptions of the video.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Questions</td>
</tr>
<tr>
<td>1 How did you interpret the message?</td>
</tr>
<tr>
<td>2 How is your understanding affected about how it is to have a family member present in a cardiac arrest situation, after watching the video?</td>
</tr>
<tr>
<td>3 How was your self-confidence affected in terms of interacting with family members during a cardiac arrest situation after watching the video?</td>
</tr>
<tr>
<td>4 Do you think you will have more self-confidence after watching the video?</td>
</tr>
<tr>
<td>5 Is it possible to use the video to support the development of local guidelines regarding the presence of family member in the event of cardiac arrest?</td>
</tr>
<tr>
<td>6 What do you think about using the video in, for example, CPR training?</td>
</tr>
<tr>
<td>7 How could the video be improved?</td>
</tr>
<tr>
<td>8 How user-friendly was the video in terms of logging in?</td>
</tr>
<tr>
<td>9 What do you think about the length, language, images, sound, lighting, and quotes?</td>
</tr>
</tbody>
</table>

Step 3: The intervention study consisted of three parts: 1) completion of the pre-test online questionnaire, 2) intervention (i.e. access to the educational video) and 3) completion of the post-test online questionnaire (Figure 4). The questionnaires were accessed by a personal link and took approximately 20 minutes to complete.

In the pre-test, invited HCPs had one month to complete the questionnaires. After one month, those who answered the questionnaires were given access to the web-based educational video, which they could watch as many times as they wanted for the following month. After that, they were asked again to answer the same questionnaires. In the post-test survey, participants were also asked to answer how many times they had viewed
the video or if they have not seen the video, if they have seen parts of the video or have seen the video in its entirety.

There was also an opportunity to write free text responses to open-ended questions in order to gain a better understanding of the responses in both the first and second questionnaire. A general reminder was sent out two weeks after the questionnaires, as well as two weeks after the video had been distributed (Figure 4).

![Figure 4. Process of the pre-test, intervention and post-test](image)

### Data analyses

#### Quantitative methods

**Descriptive statistics**
In studies I-II and IV, data are presented as means and standard deviations (SD), or medians (Md) and quartiles (Q₁, Q₃) for continuous variables, frequencies and proportions (%) for categorical variables. Mann-Whitney U test (I) was used for comparisons of continuous variables on the ordinal scale level between different groups. The Kolmogorov-Smirnov test (IV) was used for test of normality.

**Bivariate analyses**
In Study II, group comparisons were determined by using the Student’s t-tests for continues variables and χ² tests for categorical variables. If the χ² test was significant and contained >2 variables, post-hoc tests with adjusted z-scores and exact p-values for the respective variable were performed.
Method

**Multivariate analyses**
In Study I, multiple linear regression (Enter method) was carried out to determine which of the variables were independently associated with positive attitudes towards FWR.

Linear and binary logistic regression models were used in study II to evaluate outcomes of resuscitation with and without family presence. Variables that were statistically significant in the bivariate analysis (p<0.05) were then included in the logistic regression to examine their associations with HCP invitations for family to be present during resuscitation.

All tests were two-sided. The statistical analysis was performed in IBM SPSS version 23.0, 25.0 and 29.0 for Windows.

**Sample size calculation**
Sample size calculation was only performed in Study IV and resulted in a minimum of 34 participants who completed the study (pre-test and post-test) and was based on a paired t-test with the following parameters: one group, two measurements (pre-test at baseline and post-test immediately after the intervention), a medium expected effect size (0.5), a significance level of 95% (p<0.05) and power of 80%.

**Qualitative method**

**Interpretive phenomenological analysis**
In Study III, interpretive phenomenological analysis (IPA) [183, 185] was used to explore what it is like to survive a cardiac arrest, how the family witnessing the resuscitation was affected and how life unfolds after going home with this shared experience. Since neither patients nor family members perceived FWR solely as “family presence during resuscitation”, but also the time before and after the cardiac arrest and the time after discharge, the FWR phenomenon was seen from this broader perspective in the analysis.

Most participants started their narrative in the days preceding the cardiac arrest. Those who had an out-hospital cardiac arrest before the in-hospital cardiac arrest, also described what happened during the out-of-hospital cardiac arrest. Participants then proceeded to tell their stories in a structured, temporal fashion, which included a clear beginning, i.e., what happened before they came to the hospital, as well as what had happened during the hospital stay and their experiences after discharge. None of the pa-
tients who were interviewed had any memory of the family’s presence during resuscitation, which means that the CPR situation as such cannot be described from the patients’ perspective.

IPA is based on three cornerstones: phenomenology, hermeneutics and ideography. IPA is an inductive phenomenological method that tries to interpret the personal experiences of the participants by investigating how people understand their lived experience and how they interpret the experience [183, 185]. In IPA, one speaks in terms of double hermeneutics. The participant tries to make sense of what happened and the researcher tries to make sense of the participant’s sense making [185].

Ideography means seeing the phenomenon as it is described, but it also explores how the phenomenon can be seen in contexts such as relationships, groups and events. Meanings change through the interpretation processes that take place in the interaction between individuals and their surroundings. People look at events based on the meaning that the event has for them [183, 185].

Each interview was transcribed verbatim by the PhD student and analysed separately. The analysis followed the six steps of the IPA [183, 185].

**Step 1 Reading and exploratory notes.** The PhD student listened to the interview several times and then read the text several times. Important parts were crystallized. Reflections and thoughts were written down.

**Step 2 Formulating experimental statements.** The text was read again, and 32 experimental statements were named according to content.

**Step 3 Finding connections and clustering experimental statements.** The 32 experimental statements were grouped into clusters and assigned a descriptive label (see examples in Table 11).

<table>
<thead>
<tr>
<th>Descriptive label</th>
<th>Clusters of themes</th>
<th>ORIGINAL TEXT</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The shortcomings of healthcare</strong></td>
<td>Lack of follow-up</td>
<td>Patient: <em>There is no advance notice whatsoever when you are discharged, so the follow-up is basically non-existent. so think for yourself, you have been connected to monitoring 24 hours a day.</em></td>
</tr>
<tr>
<td></td>
<td>Insecurity</td>
<td>Patient: <em>Yes, they said that now we have done our part, now you can go home, and you will have a return visit in 1.5 to 2 months. From having been under guard, it is so important to be guarded 24 hours a day, to now: “Two months will be fine” as it were. It’s a bit strange.</em></td>
</tr>
<tr>
<td></td>
<td>The mistakes of healthcare</td>
<td>Patient: <em>They made such a terrible mistake in the hospital, one day it was medicine... so... I kind of didn’t recognize the medicine. But I said to her: What is this thing, I do not recognize it? Yes, then she would have given me the neighbour’s [fellow patient] medicine. And then it happened one more time.</em></td>
</tr>
</tbody>
</table>
Step 4 Compiling the table of personal experimental themes. The text was re-read while attempting to avoid pre-conceptions formed by previous readings and groupings.

Step 5 Find patterns between the different interviews. Can a theme from one text illuminate another text? Which themes stand out as "strong"? Three main themes were created, which were accompanied by seven sub-themes.

Since IPA is based on ideography, i.e., the individual and personal, it is a fine balance to let the idiographic carry the meaning in each subtheme. This means that the voice of all patients and family members was not reflected in all subthemes (Table 12), however, everyone’s voice was reflected in the three main themes.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Preliminary sub-themes</th>
<th>Participants (15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare</td>
<td>Lack of information</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Lack of care and support after cardiac arrest</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Support during cardiac arrest to families</td>
<td>4</td>
</tr>
<tr>
<td>Death</td>
<td>Thoughts about what it is like to die</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Learning to live with death present</td>
<td>8</td>
</tr>
<tr>
<td>Living on</td>
<td>Valuing every day</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Impact on relationships within and outside the family</td>
<td>9</td>
</tr>
</tbody>
</table>

Step 6 Take interpretations to higher levels. In this part, the three themes were further condensed and given new names, and the eight sub-themes were given new names. Themes were strengthened with quotations followed by interpretations made by the PhD student.

Ethical considerations

Research involving humans can involve ethical problems. Respect for human worth means that humans cannot be used as a means to achieve certain goals and this applies regardless of the value of the goal. This means that individuals who contribute information must be protected both physically and psychologically. Confidentiality and integrity must be respected, and potential study participants may not be given inaccurate or misleading information. In this thesis, no participants were judged to be harmed by the current research project and all studies were conducted in agreement with the Declaration of Helsinki [186].
The data collection in Study I was conducted as part of the PhD student's master's thesis at Linköping University. According to guidelines of the Swedish healthcare authorities at the time of Study I, no ethical approval was needed for research studies conducted as part of an advanced educational programme. The study also did not fall under the criteria for ethical review as specified in the Ethical Review Act, since no health data was collected, no sensitive personal information was handled and the study was not otherwise subject to the provisions in the same act [187]. The Swedish Ethical Review Authority in Linköping issued ethical approval for Study II (2017/590-31) and Study III (2018/29-31) and an advisory statement for Study IV (2022-01974-01).

All data are stored in a safe manner so that unauthorized persons cannot access the data. The decoded databases in studies I, II and IV and the audio recordings in study III will be saved on a secure server for at least 10 years after completion of the study in accordance with applicable regulations. The server requires a login and will thus be inaccessible to outsiders.

In studies I and IV, written consent was obtained by the heads of the departments at each hospital. Participants received an e-mail with study information and an invitation to participate in the study. They were informed that participation in the studies was voluntary, the answers were treated confidentially and that they had the right to withdraw from further participation without giving any reasons. In studies I and IV, a completed questionnaire was equated with informed consent and in Study IV, participants had to actively tick a box for consent. In the pilot studies, participants were informed verbally and in writing about the aim of the pilot study and were asked to sign a written consent.

It was considered a risk that the completion of the online questionnaire (I, IV) could arouse strong emotions concerning previous experiences of FWR and/or CPR, both positive and negative, which could need to be processed. To account for emotions that could arise, each head of department was well informed about the study and that he or she was responsible for ensuring that personnel who needed support or help processing thoughts and feelings had the opportunity to talk, for example, to the manager or a counsellor at the clinic. In Study IV, participation was also considered to offer a potential benefit as the participants received educational training on FWR, something that had been requested by HCPs in Study I. There was also the option to provide free text responses to the open-ended questions in the questionnaires, which meant that the participants had the opportunity to express their point of view.
In Study II, consent from the register holder was required to access registry data. There is no requirement for patient consent for registration in a national quality register, but according to the Patient Data Act [188], the healthcare provider must inform the patient about the register. All survivors in the Swedish Register of Cardiopulmonary Resuscitation are informed by mail about their participation in the registry and can choose to withdraw their consent to participate at any time. All data were retrospectively collected in a pre-existing quality database and no obvious risks were seen for participants in Study II. The majority of patients who have survived a cardiac arrest have a telephone contact with the locally responsible registered nurse 3-6 months after the cardiac arrest event and may then be offered professional support.

In Study III, participants were informed verbally and in writing about the aim of the study and gave their written consent. The individuals who accessed the study results were nurses, who thus have a duty of confidentiality. Participation was voluntary and participants could withdraw their participation at any time. The interviews were decoded and processed so that unauthorized persons could not access them.

As a cardiac arrest is a life-changing and often chaotic experience, it can be difficult at an early stage to absorb information and make informed decisions about participation in a research study. Therefore, the patient and family member(s) in Study III were asked about participation 3-6 months after the cardiac arrest after being contacted by a registered nurse who was independent from the research group. The risk of harm was considered small but possible and discomfort caused by renewed memories and repressed feelings from the cardiac arrest event itself, both in the patient and family, was considered likely. The members of the research group have extensive experience in conducting qualitative research and are accustomed to caring for cardiac patients and patients and families who have experienced a crisis. This means that both knowledge and preparedness for action were available to deal with any questions, strong feelings and behaviours that may arise from the participants in Study III. There was also an opportunity for a follow-up meeting immediately after the interview. This meeting was conducted with the interviewer, the PhD student, who is a nurse by profession with extensive experience of conversing with patients and families.

In interviews with dyads, it is important to consider that both partners are given equal opportunities to speak. It is also important to be responsive and consider the conversation that takes place between the dyad, as the conversation can become deeper and highlight more aspects of the studied
phenomenon. As an interviewer, it is also important to consider and re-
spect what the participants think are acceptable topics for discussion. All 
of the above aspects were taken into consideration when performing Study 
III.

A potential benefit of participating in the interviews was that the dyads 
had an opportunity to share their thoughts and feelings with each other and 
address topics that they did not have the opportunity to talk about before. 
Despite the potential for discomfort related to data collection, it was con-
sidered important to acquire knowledge about patients’ and family mem-
bers’ experiences of the cardiac arrest event, the course of care and the time 
afterwards to be able to capture, elevate and respond to patients and family 
members in post cardiac arrest care.
RESULTS

Prevalence and outcome of family-witnessed resuscitation

Sociodemographic background and clinical data
A total of 3,257 patients were included in the registry Study (II), of which 1,988 were men (61%). The average age was 72.5 years (± 13.7). In the statistical analysis, the patients were divided into a FWR group (n=186) and a non-FWR group (n=3,071) based on whether the nurse who had been involved in the resuscitation had marked “yes” or “no” to the following question in the Swedish Register of Cardiopulmonary Resuscitation: Was there a family member present during resuscitation?

There were no significant differences between the FWR group and the non-FWR group in medical history before cardiac arrest when controlling for heart failure, diabetes, respiratory insufficiency, previous myocardial infarction, cancer and stroke. About 22% had a history of myocardial infarction and 35% suffered from heart failure.

The most common underlying cause of cardiac arrest was acute myocardial infarction in both groups, followed by respiratory insufficiency, circulatory collapse, hypotension/syncope, blood test abnormalities, interventional complications (e.g. during bypass surgery) and different forms of organ failure, primary arrhythmia, stroke and aortic dissection.

The initial documented heart rhythm was asystole or pulseless electrical activity in most patients (76%), with no significant differences between the FWR and non-FWR group.

In-hospital cardiac arrest and family presence
It was most common that patients suffered from cardiac arrest in a hospital ward (57%), followed by the cardiac intensive care unit (16%), emergency department (12%), and intensive care unit (9%). Six percent of cardiac arrests took place at outpatient clinics, Radiology departments, or laboratories.

A total of 395 patients (12%) had their family present when the cardiac arrest occurred. It was most common that the patient had a family member present in the emergency department (32%), followed by the cardiac intensive care unit (12%), and intensive care unit (10%). Eight percent had family visiting when the cardiac arrest occurred in a hospital ward.
Of the 395 family-witnessed cardiac arrests, 145 family members (37%) were offered the option to be present during the resuscitation, whereof 126 chose to be present. Sixty family members (15%) independently requested to remain during the resuscitation, while the remaining 190 family members (48%) were never given the option. Finally, a total of 186 (47%) family members chose to stay in the room during resuscitation, while the remaining 209 (53%) stayed outside of the resuscitation room.

It was more common for family’s to be offered the option to stay if the cardiac arrest occurred in the emergency department, cardiac intensive care unit, or intensive care unit, compared with cardiac arrest that occurred in a hospital ward (44% vs. 26%, p<0.001). It was also more common for the family to choose to be present during resuscitation if the cardiac arrest occurred in an emergency unit (emergency department, cardiac intensive care unit, or intensive care unit), compared with those that occurred in a hospital ward (52% vs. 47%, p=0.02).

In 62% of the family-witnessed cardiac arrests, a family support person was assigned to take care of family during resuscitation, either outside or inside the resuscitation room. A family support person was more common in the emergency department, cardiac intensive care unit and intensive care unit, compared to the hospital wards (68% vs. 56%, p=0.02). When a family support person was available, 86% of the family members were offered to stay during resuscitation, compared to 49% if a family support person was not available (p<0.001).

**Outcomes of cardiac arrest with and without family presence**

There were no differences in mean time from cardiac arrest to initiation of resuscitation between groups (non-FWR 0.53±1.20 vs. FWR 0.45±1.41, p=0.40) when controlling for patient and contextual covariates such as sex, age (>70 years vs. ≤70), initial rhythm (Ventricular Tachycardia (VT); Ventricular Fibrillation (VF); vs. asystole/ Pulseless electrical activity (PEA)), witnessed cardiac arrest (yes vs. no), FWR (yes vs. no) and alive after resuscitation (yes vs. no).

The mean time from cardiac arrest to completion of CPR was significantly longer if the family was present during the resuscitation than if the family was not present (20.67±23.16 vs. 17.49±15.90, p=0.02).

In total, 1,685 patients were alive immediately after resuscitation, with no significant differences between groups (53% vs. 57%, p=0.29). At 30 days, 943 patients were alive, 29% in the non-FWR vs. 35% in the FWR group (p=0.09).
Variables that were significantly associated with being alive immediately after resuscitation and being alive after 30 days were to be under 70 years of age (p<0.001); having a cardiac arrest in an acute setting such as the emergency department, cardiac intensive care unit, or the intensive care unit (p=0.04); Ventricular Tachycardia (VT) /Ventricular Fibrillation (VF) as initial heart rhythm (p<0.001); lower number of minutes from cardiac arrest to end of resuscitation (p<0.001); and witnessed cardiac arrest (p<0.001).

Patient and family member experiences of family-witnessed resuscitation

In Study III, 15 respondents (whereof 7 patients) from six different hospitals were interviewed about their experiences of FWR and its impact on life. There was a good spread of age (19-85 years), and participants had different relationships with each other (Table 6).

The analysis resulted in three themes, underpinned by eight subthemes (Figure 5).

Figure 5. Three themes and eight subthemes.
Theme: The intrusion of death – Powerless in the face of the fragility of life
None of the interviewees were prepared to face death and the experience of death was a disappointment for some. Several had heard stories about what it might be like to die and there was an expectation from an HCP that a patient would describe death as something more. The fact that dying did not turn out as they had imagined created anxiety and was frightening for some, while others had encounters with angels who they felt offered help and support.

For example, several patients received an implantable cardiac defibrillator (ICD), which should create a sense of security; however, sensations from the ICD were unpleasant and caused anxiety and a feeling that the body was screaming out “danger”. Every sensation in the body, such as a muscle twitch, triggered thoughts that something was about to happen. The feeling of powerlessness after the intrusion of death was something new patients had to deal with.

Theme: Being totally exposed – Feeling dissatisfaction and vulnerability in the care relationship
During CPR, family members were torn between hope and despair and were dependent on the support of HCPs to remain in control and find hope in an emotionally chaotic situation. The feeling of being seen while experiencing one of life’s most difficult moments was especially valuable. It made a major difference when HCPs showed that they were available. What the HCPs said about the medical treatment during resuscitation did not mean as much to family members as the sense of humanity they conveyed, a physical touch, or the acknowledgement of their presence through a simple look or smile.

The majority of the patients’ and family members’ lifeworlds revolved around the cardiac arrest – it was the most important event in their lives together and they perceived themselves as important people. However, they did not have this sense of importance reaffirmed by HCPs after the CPR event. Most of them did not receive any information after the cardiac arrest. They felt a need to talk through everything that had happened before discharge. Ideally, they wanted to talk to an HCP who had been involved in the resuscitation. However, prior to discharge, HCPs had not gone back and reviewed the cardiac arrest incident, creating an internal conflict where patients felt significant but were treated as insignificant, which was difficult to accept.
When patients returned home, they had follow-ups at several care facilities. Here, the patient and sometimes family members felt like messengers between HCPs. This created insecurity and the patients felt a burden of responsibility that they did not want to bear. The interviewees discovered that none of the HCPs at the various care facilities were interested in the cardiac arrest event and both patients and family members lacked a holistic view. The disappointment manifested itself as anger and a lack of trust in HCPs.

**Theme: Learning to live again – Making sense of an existential threat**

Returning home created anxiety and some patients had experienced their first cardiac arrest at home. In most cases, both patients and family members returned home without the information they needed, thus carrying the burden of unprocessed trauma with them. They felt uncertain about their new lives; life is never the same after a cardiac arrest and there are no guarantees.

They described varying approaches to dealing with the cardiac arrest in their relationship: some family members wanted to talk about everything, while other family members did not want to go into detail. Most patients wanted to talk about the cardiac arrest, but some were reluctant to talk about it because it was too difficult. Several family members also repressed the cardiac arrest event, which could be frustrating for patients who wanted to process the event.

The cardiac arrest incident and accompanying anxiety affected relationships. It could be challenging for the patient to be alone at home for even a short period of time. Everyday things became a matter of life and death and there was a lack of logic in the reasoning. The cardiac arrest event also affected the approach to the surrounding environment. The experience of the cardiac arrest made it a challenge to become involved in the problems of others. Surviving a cardiac arrest gives a different perspective on what really is a problem. Despite all of the difficulty, there was still a kind of gratitude for new insights. The individual’s focus shifted from seeing the problems in life to a focus on quality of life and what works. The cardiac arrest event can be seen as a process stretching from the event itself to surviving and living a "new life". Emotions come and go.

Being close to death reminded all interviewees of how powerless they were in the face of the fragility of life, but for some, the proximity to death also created a belief in life and a perceived sense of strength and it could also be a spiritual experience. Despite feeling exposed and vulnerable in the
caregiving relationship, with no sense of control or continuity and feelings of abandonment that sometimes led to a lack of trust, hope led some patients to seek reassurance in family, friends and HCPs when life became difficult. Learning to live with an existential threat constantly present did not only create negative experiences, on the contrary, some patients re-evaluated their lives and seized the day. The love and gratitude for life increased, along with the desire for freedom and independence.

During the analysis of the data based on the participants' stories, an analogy can be made visible with the three-leaf clover of faith, hope, and love. Despite the difficult circumstances that surrounded the cardiac arrest event, these values still characterized the patients and their families. Finding a four-leaf clover is generally recognized as a sign of luck. Surviving a cardiac arrest can sometimes feel like finding a four-leaf clover, as life takes on a new dimension and it is easier to find happiness in the small things, to not take anything for granted and to value life and family in a new way, (Figure 6).

![Figure 6. The Clover. The leaves of the three-leaf clover are connected and there are themes, but also concepts that the participants raised. The four-leaf clover symbolizes the new dimensions a cardiac arrest can give to life.](image)

**Local guidelines about family-witnessed resuscitation**

In Study I, 22.5% reported that they assumed that the hospital had local guidelines about FWR, while 77.5% replied that they did not know whether
their clinic had such guidelines. No one believed that they lacked guidelines. However, the heads of department reported that no hospital had local FWR guidelines.

In Study IV, 18.6% answered that they assumed that the hospital had local guidelines regarding FWR, 57.7% were unsure, and 23.7% replied that they lacked local guidelines (Table 13).

Table 13. Answers to the question: Does your unit/ward have a protocol or policy document on family presence during resuscitation?

<table>
<thead>
<tr>
<th></th>
<th>Study I</th>
<th>Study IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t know</td>
<td>77.5%</td>
<td>57.7%</td>
</tr>
<tr>
<td>Believe we have</td>
<td>22.5%</td>
<td>18.6%</td>
</tr>
<tr>
<td>Don’t have</td>
<td>0%(^1)</td>
<td>23.7%(^2)</td>
</tr>
</tbody>
</table>

\(^1\) Data from heads of department reported that they had no local guidelines about family presence during resuscitation.\(^2\) Data from study participants.

Healthcare professionals’ experiences of family-witnessed resuscitation

The same questionnaire about experiences and attitudes to FWR was used in studies I and IV, which makes it possible to describe and compare data over time in this thesis.

As described in Table 14, there was a wide range of experiences among nurses and physicians regarding in-hospital FWR in adult patients (I, IV).

In Study I, 67.6% reported that they had experiences of FWR, compared with 58% in Study IV. Likewise, more participants in Study I reported that they had been asked at some point by family members to be present during CPR compared with participants in Study IV (28.3% vs. 18.1%). There were more nurses than physicians in Study I who had invited family members to be present (35.8% vs. 24.6%) but these numbers were reversed in Study IV (25.2% vs. 45.2%). More nurses in Study I reported having previous positive experiences of FWR than in Study IV (70.4% vs. 32.8%), but at the same time, they also reported more negative experiences (37.8% vs. 21.4%).

When it comes to differences between the professions, more nurses (70.4%) than physicians (48.7%) reported positive experiences of FWR in Study I. In Study IV, these numbers were reversed, with 51.6% of physicians and 32.8% of nurses reporting positive experiences.
In Study I, it was found that HCPs with less work experience were more positive to FWR compared to those who had worked longer within their respective profession (p<0.01). No similar correlational statistics were performed in Study IV.

<table>
<thead>
<tr>
<th>Table 14. Comparison of nurses’ and physicians’ experiences of FWR (I, IV).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Years work experience mean</td>
</tr>
<tr>
<td>Working experience</td>
</tr>
<tr>
<td>Working experience</td>
</tr>
<tr>
<td>Years work experience median</td>
</tr>
<tr>
<td>Experiences of FWR</td>
</tr>
<tr>
<td>Previous professional experiences of FWR (yes)</td>
</tr>
<tr>
<td>Previous experiences of being asked by a family member to be present during CPR (yes)</td>
</tr>
<tr>
<td>Previous experiences of inviting a family member to be present during CPR (yes)</td>
</tr>
<tr>
<td>Previous positive experiences of FWR (yes)</td>
</tr>
<tr>
<td>Previous negative experiences of FWR (yes)</td>
</tr>
</tbody>
</table>

Legend: CPR=cardiopulmonary resuscitation; FWR=family-witnessed resuscitation in-hospital.

Some missing values, which explains the difference in %.

Percent that answered yes to each statement.

Healthcare professionals’ attitudes to family-witnessed resuscitation

Many participating nurses and physicians in study I and IV were indecisive and unable to express a position on if they had a positive respective negative attitude to FWR. See Table 15 for the most frequent statements that led to uncertainty among participants.

<table>
<thead>
<tr>
<th>Table 15. The top three statements in each study (I, IV) where participants were the most indecisive and answered, “do not know”.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Study</td>
</tr>
<tr>
<td>IV</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

CPR=Cardiopulmonary resuscitation
Among the topics where respondents were the least indecisive, only 5.7% in Study I and 2.6% in Study IV replied “do not know” to the following statement: If family members are present during CPR, there should be a member of the resuscitation team whose only role is to look after the family. As further described in Tables 16-18, it appears that the greatest attitude changes have occurred in physicians, where attitudes to FWR have gone from negative to positive.

In the Decision-making domain (Table 16), 13.8% of physicians in Study I and 14.8% of physicians in Study IV agreed that nurses should be responsible for deciding whether family members should be offered to be present during CPR. The comparable proportion of nurses was 33.9% in Study I and 26.0% in Study IV. Respondents still reported in study IV that physicians were the occupational category that should decide about FWR, but it is not as pronounced in Study IV (50.8%) as in Study I (63.1%). Similarly, more physicians in Study IV reported that deciding whether family should be present during resuscitation should be a shared decision within the team compared with Study I (58.1% vs. 48.8%).

Regarding the statements about the risk that a family member might argue with HCPs during resuscitation and whether confidentiality can be put at risk with FWR, nurses’ opinions have not changed significantly (I, IV). However, there is a difference among physicians regarding the belief that the family might argue with staff, where only 41.9% in Study IV agreed with this statement compared to 59.3% in Study I. Interestingly, in Study I, one in four physicians (23.8%) believed that confidentiality would be a problem with FWR, but in Study IV, as many as 56.5% consider this to be a problem.

The greatest difference in both nurses and physicians was the attitude towards offering family members the opportunity to be with the patient during CPR, where they believe that it should always be the decision of the family member. Positive attitudes to FWR among nurses increased from 58.7% to 77.1%, and among physicians from 29.2% to 58.1% (I, IV). Both groups were also more likely to agree with the statement that FWR makes family members more likely to accept decisions to withdraw treatment.
In the *Process* domain (Table 17), the participating physicians in Study IV had less concerns compared with the physicians in Study I that FWR would be too distressing for family members (18.0% vs. 31.7%). About one fifth of the nurses and 11-14% of the physicians in studies I and IV believed that a family member might interfere during the resuscitation process. Moreover, the majority believed that the resuscitation team may say things during resuscitation that are upsetting to the family members, with approximately 61% of the nurses in studies I and IV and 74.6% of the physicians in Study I and 62.9% in Study IV agreeing with this statement.

When asked if the resuscitation team would find it difficult to concentrate when family members are watching, negative attitudes among physicians decreased from 41.2% (I) to 21.3% (IV). There was also an increase

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**Table 16. Comparing proportion (%) in Decision-making within the attitude instrument, who disagree/agree to each item.**

<table>
<thead>
<tr>
<th>Statement a, b</th>
<th>Strongly disagree / disagree %</th>
<th>Don’t know %</th>
<th>Agree /strongly agree %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nurses</td>
<td>Physicians</td>
<td>Nurses</td>
</tr>
<tr>
<td><em>Decision-making</em> Study</td>
<td>I</td>
<td>IV</td>
<td>I</td>
</tr>
<tr>
<td>Nurses should have the responsibility for deciding if family members should be present during CPR</td>
<td>46.6</td>
<td>61.1</td>
<td>70.8</td>
</tr>
<tr>
<td>Physicians should have the responsibility for deciding if family members should be present during CPR</td>
<td>40.5</td>
<td>38.9</td>
<td>21.5</td>
</tr>
<tr>
<td>It should be the joint responsibility of all members of the resuscitation team to decide whether (or not) family members are allowed to be present during CPR</td>
<td>19.8</td>
<td>22.9</td>
<td>37.5</td>
</tr>
<tr>
<td>Family members should be present during CPR so that they can be involved in decisions</td>
<td>56.2</td>
<td>33.1</td>
<td>71.9</td>
</tr>
<tr>
<td>Because family members do not understand the need for specific intervention, they are more likely to argue with the resuscitation team</td>
<td>34.7</td>
<td>30.5</td>
<td>21.9</td>
</tr>
<tr>
<td>There may be a problem of confidentiality in discussing details about the patient if family members are present during CPR</td>
<td>38.0</td>
<td>33.3</td>
<td>40.0</td>
</tr>
<tr>
<td>Family members should always be offered the opportunity to be with the patient during CPR. It should always be their decision.</td>
<td>28.1</td>
<td>13.7</td>
<td>60.0</td>
</tr>
<tr>
<td>If present during CPR, family members are more likely to accept decisions to withdraw treatment</td>
<td>14.1</td>
<td>7.6</td>
<td>23.1</td>
</tr>
</tbody>
</table>

*a* I = Study I nurses (n=122) and physicians (n=66) working at cardiac care units at seven university hospitals  
*b* IV = Study IV nurses (n=131) and physicians (n=62) working at different departments at one university, one county, and four district hospitals.
in positive attitudes in the physician group from 11.1% (I) to 27.7% (IV) regarding whether FWR is beneficial to the patient. Both nurses and physicians (I, IV) were unanimously in agreement (90.5-96.1%) that someone should be designated to take care of the family during the resuscitation. However, a decrease was observed among nurses over the years, who report that there is not enough staffing to support the family, with 45.1% agreeing with this statement in Study I compared with 28.3% in Study IV.

In the Outcome domain (Table 18), nearly half of the nurses (47.7%) and physicians (45.2%) (IV) believed that FWR prolongs CPR, but also that FWR is important because it enables family members to share the last moments with the patient, nurses 49.6% and physicians 48.4% (IV). Less than

Table 17. Comparing proportion (%) in Process within the attitude instrument, who disagree/agree to each item.

<table>
<thead>
<tr>
<th>Statement *b</th>
<th>Strongly disagree / disagree %</th>
<th>Don't know %</th>
<th>Agree /strongly agree %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Process</td>
<td>Nurses I IV</td>
<td>Physicians I IV</td>
<td>Nurses I IV</td>
</tr>
<tr>
<td>Family members should not be present during CPR because it is too distressing for them</td>
<td>53.3 60.3</td>
<td>46.1 59.9</td>
<td>27.9 22.1</td>
</tr>
<tr>
<td>It should not be normal practice for family members to witness the resuscitation of a family member</td>
<td>43.7 47.3</td>
<td>28.6 54.9</td>
<td>21.8 29.0</td>
</tr>
<tr>
<td>Family members are very likely to interfere with the resuscitation process</td>
<td>56.5 49.6</td>
<td>65.1 77.4</td>
<td>23.8 24.4</td>
</tr>
<tr>
<td>During CPR the resuscitation team may say things that are upsetting to family members</td>
<td>18.9 17.6</td>
<td>12.7 17.7</td>
<td>19.7 20.6</td>
</tr>
<tr>
<td>Most bed areas are too small to have family members present during resuscitation</td>
<td>36.3 46.5</td>
<td>44.5 58.0</td>
<td>11.6 13.0</td>
</tr>
<tr>
<td>Resuscitation team members find it difficult to concentrate when family members are watching</td>
<td>69.7 54.9</td>
<td>44.5 60.7</td>
<td>9.8 21.4</td>
</tr>
<tr>
<td>The performance of the resuscitation team will be positively affected due to the presence of family members</td>
<td>46.8 39.7</td>
<td>58.8 38.7</td>
<td>40.1 48.1</td>
</tr>
<tr>
<td>Family presence during CPR is beneficial to the patient</td>
<td>23.9 18.3</td>
<td>57.1 40.3</td>
<td>43.4 46.6</td>
</tr>
<tr>
<td>There are enough staff to provide emotional support and remain with the family members during resuscitation</td>
<td>43.4 49.6</td>
<td>44.5 27.4</td>
<td>11.5 22.1</td>
</tr>
<tr>
<td>If family members are present during CPR, there should be a member of the resuscitation team whose only role is to look after the family</td>
<td>2.4 3.1</td>
<td>1.6 3.2</td>
<td>3.3 0.8</td>
</tr>
</tbody>
</table>

*To nurses: Nurses and resuscitation team members find it difficult to concentrate when family members are watching. To physicians: Physicians and resuscitation team members find it difficult to concentrate when family members are watching.

* I = Study I nurses (n=122) and physicians (n=66) working at cardiac care units at seven university hospitals

* IV = Study IV nurses (n=131) and physicians (n=62) working at different departments at one university, one county, and four district hospitals.
20% believed that family members will suffer from negative long-term emotional effects if they are present during CPR (I, IV).

Both physicians and nurses were more convinced in Study IV (67.2% vs. 64.1%) compared with Study I (42.8% vs. 43.8%) that FWR prevents family members from developing distorted images or wrong ideas of the resuscitation process if the patient dies.

In Study IV, positive attitudes among physicians increased from 54.7% (I) to 71.7%, to the same level as the nurses, where about 70% (I, IV) believed that FWR helps family members accept that everything possible is being done for the patient.

### Table 18. Comparing proportion (%) in Outcome within the attitude instrument, who disagree/agree to each item.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree/disagree%</th>
<th>Don’t know %</th>
<th>Agree /strongly agree %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rates of legal action against staff will increase because, when present, family members may misunderstand the actions of the resuscitation team</td>
<td>47.1 47.3 46.9 58.0</td>
<td>43.0 35.9 40.6 32.3</td>
<td>9.9 16.8 12.5 9.7</td>
</tr>
<tr>
<td>Family presence during CPR is not beneficial to the patient</td>
<td>37.2 34.6 14.3 36.7</td>
<td>31.4 46.9 30.1 33.3</td>
<td>31.4 18.5 55.6 30.0</td>
</tr>
<tr>
<td>The resuscitation team is more likely to prolong the resuscitation attempt if a family member is present</td>
<td>23.1 26.1 17.5 27.1</td>
<td>28.9 26.2 41.3 27.4</td>
<td>48.0 47.7 41.2 45.2</td>
</tr>
<tr>
<td>Family presence during CPR creates a stronger bond between family and healthcare professionals</td>
<td>19.9 13.0 29.1 17.7</td>
<td>49.2 47.3 38.7 40.3</td>
<td>30.9 39.9 32.2 42.0</td>
</tr>
<tr>
<td>Family presence during CPR prolongs emotional readjustment at the loss of the family member</td>
<td>28.9 27.7 23.4 37.1</td>
<td>55.4 52.7 64.1 45.2</td>
<td>15.7 20.2 12.5 17.7</td>
</tr>
<tr>
<td>Family members will suffer negative long-term emotional effects if they are present during CPR</td>
<td>43.8 40.4 39.1 39.3</td>
<td>43.8 40.5 46.9 49.2</td>
<td>12.4 19.1 14.0 11.5</td>
</tr>
<tr>
<td>Family presence during unsuccessful CPR is important because it enables family members to share the last moments with the patient</td>
<td>14.1 11.6 29.7 11.3</td>
<td>44.6 38.8 32.8 40.3</td>
<td>41.3 49.6 37.5 48.4</td>
</tr>
<tr>
<td>Family presence during CPR prevents family members developing distorted images or wrong ideas of the resuscitation process</td>
<td>18.2 9.9 15.9 13.1</td>
<td>38.0 26.0 41.3 19.7</td>
<td>43.8 64.1 42.8 67.2</td>
</tr>
<tr>
<td>Family presence during CPR helps the family members with the grieving process, if the patient does not survive</td>
<td>5.8 5.4 12.5 6.5</td>
<td>42.5 26.9 43.8 38.7</td>
<td>51.7 67.7 43.7 54.8</td>
</tr>
<tr>
<td>Family presence during CPR helps family members to know that everything is being done for the patient</td>
<td>10.7 5.4 17.2 5.0</td>
<td>18.2 24.8 28.8 23.3</td>
<td>71.1 69.8 54.7 71.7</td>
</tr>
</tbody>
</table>

* To nurses: Family presence during CPR creates a stronger bond between family and nurses. To physicians: Family presence during CPR creates a stronger bond between family and physicians.

1 Study I nurses (n=122) and physicians (n=66) working at cardiac care units at seven university hospitals

2 Study IV nurses (n=131) and physicians (n=62) working at different departments at one university, one county, and four district hospitals.
Healthcare professionals’ self-confidence in family-witnessed resuscitation situations

As described in Table 19, performing defibrillation therapies and delivering chest compressions during resuscitation efforts with family members present was not considered as a problem for either the physicians or the nurses in Study IV, although the physicians were even more self-confident (close to 100%). Both groups also felt confident in administering drug therapies and communicating about the CPR effort to family members.

In terms of enlisting the support of other team members when families are present and announcing the family member's presence to the other team members during CPR, physicians felt more confidence than nurses. Physicians were also more self-confident in communicating effectively with other team members and debriefing the family after resuscitation.

The ability to identify family members who show appropriate coping behaviours, thus making family presence during resuscitation suitable, appeared to be difficult, with 27% of nurses and 37% of physicians responding that they were not confident in this area.

Regarding encouraging family members to talk to the patient during CPR efforts, about half of nurses and nearly 70% of physicians felt uncomfortable. There were also more nurses than physicians who felt that they could delegate tasks to other team members in order to support the family during CPR (45.3% vs. 37.7%). Other areas where nurses seem to feel more self-confident than physicians were the coordination of bereavement follow-up with family members after resuscitation (50.0% vs. 39.3%) (Table 19).

Table 19. Proportion (%) of participants (n=193) within the self-confidence instrument, who agree with each item in Study IV.

<table>
<thead>
<tr>
<th>Item</th>
<th>Not at all / Not very Confident %</th>
<th>Somewhat Confident %</th>
<th>Quite / Very Confident %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nurses</td>
<td>Physicians</td>
<td>Nurses</td>
</tr>
<tr>
<td>I could encourage family members to talk to their family member during resuscitation efforts</td>
<td>52.7</td>
<td>69.4</td>
<td>21.7</td>
</tr>
<tr>
<td>I could coordinate bereavement follow-up with family members after resuscitation efforts of their family member, if required</td>
<td>32.3</td>
<td>32.8</td>
<td>17.7</td>
</tr>
<tr>
<td>I could delegate tasks to other team members in order for myself to support family members during resuscitation efforts of their family member</td>
<td>28.5</td>
<td>41.0</td>
<td>26.2</td>
</tr>
<tr>
<td>I could identify family members who display appropriate coping behaviours to be present during resuscitation efforts</td>
<td>27.5</td>
<td>37.1</td>
<td>25.2</td>
</tr>
<tr>
<td>I could identify spiritual and emotional needs of family members witnessing resuscitation efforts of their family member</td>
<td>20.8</td>
<td>25.8</td>
<td>26.9</td>
</tr>
</tbody>
</table>
In-hospital family-witnessed adult resuscitation

**Table 19. Proportion (%) of participants (n=193) within the self-confidence instrument, who agree with each item in Study IV.**

<table>
<thead>
<tr>
<th>Item</th>
<th>Not at all / Not very Confident %</th>
<th>Somewhat Confident %</th>
<th>Quite / Very Confident %</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could maintain dignity of the patient during resuscitation efforts with family members present</td>
<td>16.2</td>
<td>11.3</td>
<td>23.8</td>
</tr>
<tr>
<td>I could enlist support from the other team members for family presence during resuscitation efforts</td>
<td>13.8</td>
<td>14.5</td>
<td>21.5</td>
</tr>
<tr>
<td>I could announce family member’s presence to the other team members during resuscitation efforts of their family member</td>
<td>14.7</td>
<td>11.3</td>
<td>17.1</td>
</tr>
<tr>
<td>I could prepare family members to enter the area of resuscitation of their family member</td>
<td>12.4</td>
<td>14.5</td>
<td>17.8</td>
</tr>
<tr>
<td>I could provide comfort measures to family members witnessing resuscitation efforts of their family member</td>
<td>12.4</td>
<td>12.9</td>
<td>14.7</td>
</tr>
<tr>
<td>I could debrief family after resuscitation of their family member</td>
<td>14.5</td>
<td>5.0</td>
<td>16.8</td>
</tr>
<tr>
<td>I could escort family members into the room during resuscitation of their family member</td>
<td>9.2</td>
<td>9.8</td>
<td>9.2</td>
</tr>
<tr>
<td>I could administer drug therapies during resuscitation efforts with family members present</td>
<td>8.4</td>
<td>9.8</td>
<td>9.2</td>
</tr>
<tr>
<td>I could communicate effectively with other team members during resuscitation efforts with family members present</td>
<td>7.6</td>
<td>6.5</td>
<td>16.0</td>
</tr>
<tr>
<td>I could communicate about the resuscitation effort to family members who are present</td>
<td>9.2</td>
<td>1.6</td>
<td>6.9</td>
</tr>
<tr>
<td>I could perform defibrillating therapies during resuscitation efforts with family members present</td>
<td>4.6</td>
<td>1.6</td>
<td>10.7</td>
</tr>
<tr>
<td>I could deliver chest compressions during resuscitation efforts with family members present</td>
<td>3.1</td>
<td>0.0</td>
<td>9.2</td>
</tr>
</tbody>
</table>

The impact of an educational intervention on self-confidence and attitudes towards family-witnessed resuscitation

In Study IV, the aim was to evaluate if an educational intervention could influence self-confidence and attitudes towards FWR. Paired t-tests were conducted to compare the differences in composite scores for self-confidence and attitudes before and after attending the intervention (Table 20).

<table>
<thead>
<tr>
<th>Table 20. Comparisons of total mean scores in self-confidence and attitudes before and after attending the intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Endpoint</strong></td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>Self-confidence</td>
</tr>
<tr>
<td>Attitudes</td>
</tr>
</tbody>
</table>

*The analysis paired t-tests, included all participants with complete pre- and post-test data*
The educational intervention had a statistically significant positive impact on nurses’ and physicians’ self-confidence in facilitating FWR. The total mean self-confidence score increased from 3.83±0.70 to 4.02±0.70, p<0.001. Six of the 14 statements showed statistically significant positive changes in self-confidence after watching the video (Table 21).

HCPs reported increased confidence to communicate effectively with the others in the team in order to notify them of the presence of family members and to receive support from other HCPs at the FWR. Likewise, self-confidence was boosted by the ability to communicate about the resuscitation effort with the family, to identify spiritual and emotional needs of family members, and to debrief the family after the resuscitation of their family member.

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre-test</th>
<th>Post-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could identify spiritual and emotional needs of family members witnessing resuscitation efforts of their family member.</td>
<td>4.04 ± 0.99</td>
<td>4.23 ± 0.94</td>
<td>0.050</td>
</tr>
<tr>
<td>I could enlist support from the other team members for family presence during resuscitation efforts.</td>
<td>3.13 ± 1.06</td>
<td>3.56 ± 1.01</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>I could announce family member’s presence to the other team members during resuscitation efforts of their family member.</td>
<td>3.90 ± 1.06</td>
<td>4.10 ± 0.90</td>
<td>0.038</td>
</tr>
<tr>
<td>I could debrief family after resuscitation of their family member.</td>
<td>3.97 ± 0.99</td>
<td>4.18 ± 0.88</td>
<td>0.026</td>
</tr>
<tr>
<td>I could communicate effectively with other team members during resuscitation efforts with family members present.</td>
<td>2.49 ± 1.20</td>
<td>2.91 ± 1.36</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>I could communicate about the resuscitation effort to family members who are present.</td>
<td>3.20 ± 1.22</td>
<td>3.62 ± 1.15</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

The educational intervention also had a statistically significant influence on nurses’ and physicians’ attitudes towards FWR. The total mean score for attitudes showed a statistically significant increase from 3.38±0.49 to 3.62±0.48, (p<0.001). When the three sub-scores were analysed separately, there was a statistically significant increase in all three sub-scores: decision-making (3.22±0.46 to 3.44±0.45), process (3.38±0.63 to 3.58±0.54), and outcome (3.54±0.56 to 3.83±0.59), (p<0.001).
In-hospital family-witnessed adult resuscitation
DISCUSSION

In this thesis, different perspectives of in-hospital FWR have been studied. Prevalence, processes and outcomes of FWR have been presented. Overall, FWR was found to be rare, but the processes and outcomes for the patient do not seem to be negatively affected by family presence, suggesting that FWR practice can be introduced safely.

Furthermore, patients experiences of surviving and family members’ of witnessing a sudden cardiac arrest in-hospital have provided new knowledge about what can be improved in person-centred care, not only in the immediate care but also in follow-up of the patient and family.

This thesis has also shown that the experiences, attitudes and self-confidence of HCPs are of the utmost importance when it comes to inviting family members and managing FWR situations. A short educational video could be a way to strengthen the implementation process in line with national and local guidelines concerning FWR.

Discussion of the results

Prolonged cardiopulmonary resuscitation attempts

In this thesis, we found that FWR not significantly affects the time from cardiac arrest to the start of resuscitation (II). One possible explanation for this in Study II could be that Swedish nurses and physicians seem confident in performing defibrillation, administering drug therapies and providing chest compressions with family members present (IV).

However, the mean time from cardiac arrest to completion of CPR was longer if the family was present (II), which is in contrast to other studies that have found shorter, or comparable, mean time differences from cardiac arrest to completion of resuscitation [138, 139, 189]. Still, we found that the prolongation of resuscitation time when the family was present did not affect the immediate survival rate, which is in line with previous research [72, 119, 140], with one exception [138]; Krochmal et al. (2017) found that fewer patients achieved spontaneous circulation after FWR situations. A common concern among HCPs is that FWR will delay CPR attempts [190] or prolong resuscitation attempts that would otherwise have been deemed futile [56, 77, 191] and this was also found in Study IV where half of the participants believed that FWR will prolong resuscitation. This demonstrates the need for HCPs to receive education and knowledge about
how FWR affects the performance of CPR. Education has previously been shown to increase HCP engagement and comfort with FWR [61].

**Patient and family members’ experiences of cardiac arrest and post cardiac arrest care**

The cardiac arrest was an important shared event in the patient and family members’ lives, but it also affected them differently as individuals. There were mixed feelings of powerlessness, but also faith in the future and hope (III). The life of patients who survive a cardiac arrest can be affected in different ways [192, 193], but in many cases, the level of anxiety and stress among family members is higher than it is for the patient [144, 194]. Cardiac arrest shapes the life trajectory of both the patient and family members, as well as the relationship between them [144, 194, 195].

The results from this thesis (III) indicate that both patients and family members have a great need to be included in care, both in the acute phase and after the cardiac arrest, but also after discharge. Transitions occur when patients move between different care providers or between hospital departments, which is common in cardiac arrest care. The literature shows that when patients are moved around to different units, there is a risk for the patient’s safety and poor care [196]. This was confirmed in the interviews, where participants experienced that it was difficult to move between different units and meet new staff who did not know what the patient had been through. Furthermore, the patients and family members described that mistakes were common during the hospital stay and at discharge, which undermined trust in healthcare. There is no answer as to how this can be solved in practice, but if HCPs work with a more person-centred approach and document the patient’s preferences, the continuity of care can be facilitated [47] and the patient can feel more seen and involved.

Patients and family members had expected to receive answers to their questions and to be able to discuss the cardiac arrest event at discharge but unfortunately, care providers did not meet these expectations. The lack of discussion with physicians at discharge was reported in all study participants (III). Another study confirms that families of cardiac arrest patients report receiving inadequate information and that the discharge was forced, occurred too early and was an abrupt interruption from professional care [145]. It is evident that the discharge process is not tailored to meet the needs of the patient or family. No one in our study had had a conversation with a nurse before discharge (III), which may be due to the fact that nurses think that discharge is the physician’s responsibility [197]. But nurses can also provide support at discharge, listen to the patient’s and family's story,
explain what happened during the cardiac arrest and discuss the plan for continuing care after discharge with the patient and family [197, 198].

There is no justification for the fact that patients and their family members are not offered a proper discharge conversation after such a serious event. Support for families is often inadequate, especially in a highly patient-centred healthcare system that focuses more on the diagnosis than the person with the diagnosis and where there is a lack of systematic family involvement [145]. One way to make the discharge inclusive is to work with a person-centred care approach, which means that the patient and the family are not passive recipients, but part of a partnership between patient, family and healthcare professionals where short- and long-term follow-up is based on the patient’s story and all parties are involved [47].

The ERC guidelines also state that before the patient is discharged from hospital, the patient and family should be informed orally and in writing about how their follow-up care is planned [40]. Many of the participants (III) complained of a lack of continuity, where one caregiver did not know what the other was doing and the patient had to be the one to convey the information. Other research shows that for patients to experience continuity of care, they need to know what the next step is. They should not have to repeat information to new carers about previous care events and all care providers should follow the same treatment plan [199].

The patients in Study III looked forward to returning home after hospitalization, but it was also a time of anxiety. Being so close to death brings up a lot of thoughts and feelings. Patients and their family members had a significant need to meet with care providers during this difficult time, both together and individually. Our results are confirmed by other studies. Mion et al. (2021) report that physical limitations, low mood, loss of confidence, issues with memory/thinking and anxiety were common among cardiac arrest patients [200]. Among family members, fear of another cardiac arrest and death after returning home are common. Family often feel worse than the patient after a cardiac arrest, with a higher degree of anxiety, depression and PTSD, which may be explained by the fact that they witnessed the resuscitation [142]. Their need for security and support increases because of feelings of insecurity, vulnerability and fear of the recurrence of symptoms [201]. Family members usually want to feel included, to have their own questions answered and to receive information from HCPs to help them cope with feelings of anxiety and responsibility during hospital admission [145].

Established guidelines clearly indicate that cardiac arrest patients and their families need structured care. All cardiac arrest patients and close
family members should be offered follow-up within 1-3 months after discharge from hospital. After a cardiac arrest, the patient may need cardio-logical, neurological or psychological and psychosocial follow-up [40]. The results from Study III suggest that current follow-up often fails to address the issues that family and patients want to discuss and the majority of participants advocated for early follow-up following hospital discharge, as well as a holistic perspective from all caregivers involved.

We know from previous studies that cardiac arrest patients wish to receive follow-up at the cardiac outpatient clinic within one month from discharge [196]. However, support is not systematically offered after discharge [145] and many patients are not offered follow-up at all [202]. Patients and families do not want to receive follow-up through primary care (III), which is understandable given that primary care is not adequately prepared to meet their needs and provide the support that they need [156].

In today's highly specialized healthcare it is important to recognise that patients who survive a cardiac arrest do not only have cardiac problems, and healthcare providers needs to take a more holistic view of the overall consequences of surviving a cardiac arrest and work in a more person-centred way. In addition to this, healthcare is organized in different sectors, where some patients are followed up at the cardiac department and others are referred to primary care. This further underscores the need to follow existing guidelines for structured post-discharge care of cardiac arrest patients and their families.

Discharge from the hospital was often accompanied by inadequate information, little instruction and inadequate planning (III). If the patient does not feel ready to return home, it can be difficult to cope and lead to readmission [203]. Several patients in Study III felt chest sensations at home and went to the emergency department for what turned out to be symptoms of anxiety. In other cardiac patients, it has been seen that symptoms of uncertainty, fear, anxiety and depression are often associated with a lack of knowledge about their cardiac condition [204]. If patients are better informed before going home and know that they are included in a structured care plan, and that they will receive early follow-up, they may have an easier time dealing with anxiety and will not need to seek care at the emergency department.

A cardiac arrest changes the daily lives of the patient and family members, as well as their relationship [142, 195]. The patients in Study III talked about how difficult it was to go home. The roles changed. Patients placed higher demands on the constant presence of family because of their fear of death. Other patients described how they felt that the family was
overprotective. Another study found that it was common that family members who witnessed the cardiac arrest feared that it would happen again and became overprotective of the patient [142]. Dichman et al. (2021) describes the difficulties families face upon returning home. Suddenly being home alone with responsibility for the patient gave rise to feelings of insecurity, doubt, powerlessness and frustration when attempting to manage the daily life of the family [145].

Several of the participants (III) had changed their lives after the cardiac arrest. They took concrete actions like selling their house. They chose to spend more time with the people they felt were important to them. They gained a new perspective on life which increased both security and the quality of life. They tried to build a new life together. Whitehead (2020) describes how a cardiac arrest has an impact on both the patient and the family. Normality is disrupted and they need to establish a "new normal", rather than trying to return to the way life was before. Here, HCPs play an important role in helping individuals identify and incorporate important values into their "new normal" [205].

**Person-, patient- and family-centred care**

In this thesis, we found that positive attitudes towards offering FWR has increased from Study I to Study IV, which could be a result of the fact that person-centred care is being discussed more today than when Study I was carried out. We also found that the majority of family members who were offered the option to stay wanted to be present during resuscitation (II). This highlights the importance of asking what family members would prefer and if possible, asking about the patient's wishes for FWR at the time of admission in the event that he or she suffers a cardiac arrest during the hospital stay [53, 57].

Healthcare has moved away from the previous paternalistic approach to a more patient-focused approach, where family members expect to be involved in the care of other family members [15, 190].

Family- and patient-centred care has become a widespread concept throughout healthcare [206]. In Sweden, a paradigm shift is underway where the patient is seen as a person, an active partner, together with the family in a joint decision-making process [207]. Person-centred care emphasizes the importance of involving patients and their families in care decisions [208]. Person-centred care means that every patient encounter must be seen from a holistic perspective, where every person is treated as a human being with a family, social world and community. Nursing practice strongly supports a holistic approach where the role of the family is
important, and FWR can be a part of this practice [81, 119, 190]. Something that promotes person- and family-centred care is, for example, is open visiting hours [209, 210] that means the family can spend more time in hospital with the patient and this, in turn, means that more family members can be present if the patient suffers a cardiac arrest and can be offered FWR.

Families sometimes express a desire to be involved in decision-making during CPR. They often have background information about the patient’s values and preferences and can participate in decision-making about resuscitation [144]. Opinion leaders in Europe in resuscitation ethics argue that shared decision-making should underpin all patient-focused decision-making in healthcare, including resuscitation [24]. Shared decision-making has been associated with higher patient/family satisfaction [144]. Few of the HCPs in this thesis, especially in the physician group (I, IV), seem to embrace the idea that family members should be involved in decisions during FWR, which suggests that the idea of person- or family-centred care is not as well anchored when it comes to decision-making during FWR. As physicians bear the medical responsibility during CPR, they may be concerned that FWR could lead to discussions with family members about ending CPR or may lead to prolonged CPR that is not medically justifiable, which could explain their relative reluctance towards embracing FWR.

The results from this thesis show that there was increased concern among HCP, especially among physicians, about the patient’s confidentiality and integrity should be hampered if family members is present (I, IV) which is important to consider then patients’ confidentiality and integrity must be respected [186]. The notion among HCPs that it is difficult to maintain confidentiality or that there is a lack of staff can certainly influence whether HCPs choose to offer the family presence. The principle of justice requires that all families and patients are treated fairly and equally. This means that HCPs must not differentiate between family members who are quiet and are not perceived as disruptive and family members who become upset [17]. In study I and IV, about half of the HCPs believed that family members would not understand the situation and would argue with the resuscitation team, but only a few HCPs (IV) believed that family members would interfere with the resuscitation process.

Another ethical dilemma is that the majority of HCPs (I, IV) believed that there was a risk that the resuscitation team would say things that could upset family members. These results further underscore the importance of discussing who should provide family support in an FWR situation, explaining the medical jargon and what is said in the resuscitation room, and
developing guidelines for HCPs about how they should act in an FWR situation. The goal of HCPs is to achieve the maximum benefit and reduce harm for both the patient and their family. Introducing policies around FWR can contribute to equal care, regardless of how the family acts during resuscitation [17].

**Attitudes towards family-witnessed resuscitation**

In this thesis, there was an increase in positive attitudes towards FWR among HCPs between studies I and IV, and nurses seem to be more positive about involving family members in decisions than physicians (IV). Despite positive attitudes towards FWR among HCPs in studies I and IV, HCPs only invited family members to be present in 37% of cardiac arrest events in Study II, and it was more common to invite the family to be present in the emergency department, cardiac intensive care unit or intensive care unit, compared to hospital wards (II). There is no obvious answer as to why FWR was offered in such a low percentage of cases. However, the global staff workforce shortage is increasing the workload of nurses and physicians [211, 212], which could be one explanation for why family presence is not offered. Although HCPs are generally positive to FWR, the current shortage of HCPs — and the lack of a family support person — may explain why they do not offer FWR to a greater extent.

Only a few of the physicians (I, IV) agreed that nurses should be responsible for deciding whether family members should be invited to be present during CPR. It is worth noting that nurses are often the closest HCP to the patient and have a moral obligation to advocate for the patient and their family [129]. However, more physicians in Study IV believed that it should be a joint decision within the team compared to Study I. Hierarchies and gender differences in healthcare can negatively impact teamwork and the foundation for successful collaboration is the elimination of hierarchies [213]. CPR is a task with clear guidelines, which should mean that the relationship between the leader and the team is frictionless. Being a group leader is not about hierarchical roles [214]. Since the nurses are the HCPs who are with the patient most of the time, it is often their responsibility to create a functioning team and collaboration, as well as act as a leader [215]. This indicates that nurses could be responsible for FWR decisions.

In Study I, we found that those with less experience in their respective professions were more positive about FWR when it comes to decision-making, which is in contrast to what other studies have shown. One factor that increases the likelihood of FWR is the presence of senior HCPs [89, 157, 216-219]. Two large-scale studies with 9,620 and 8,112 nurses [220, 221]
show that professional experience and older age are contributing factors to positive attitudes towards the inclusion of family in care. In recent years, person-centred care has been incorporated into the Swedish healthcare system [222]. Healthcare education for HCPs in Sweden is based on the assumption that the care provided must be person-centred, where care is planned, if possible, together with the patient, family and HCP [223]. It is possible that person-centred care has been adopted to a greater extent by the younger generation, as it has been integrated into their education programmes in recent years, which could explain our divergent results.

**Self-confidence in managing family-witnessed resuscitation**

In Study IV, only about half of the participants reported that they had experience of in-hospital FWR. If the resuscitation team lacks experience, self-confidence will be affected, which tends to work against FWR. The self-confidence of HCPs plays a role in FWR [191]. Practical aspects of CPR, such as performing defibrillation therapies and providing chest compressions during resuscitation attempts with family members present were, however, something that HCPs felt confident performing (IV). These are also elements that are regularly practiced in healthcare [224].

Grimes (2020) addresses the necessity of debriefing after each FWR situation [19]. One area where debriefing could be used for education is to discuss how to identify family members who are displaying appropriate coping behaviours so that they can be invited in, or not invited in, during CPR. Role playing could also be a support for training, where one HCP plays the role of an upset and disruptive family member during CPR training, which increases the understanding of what it is like to have the family present during CPR [118, 131, 225].

Study IV demonstrates that HCPs need increased self-confidence in several areas. In general, high self-confidence among nurses provides safer nursing practices and increases patient safety [226]. Furthermore, nurses with higher self-confidence are more likely to have positive attitudes to FWR. Given the importance of the subject, this is something that should be considered by nursing managers and planners [227].

Swedish healthcare providers should encourage nurses to seek further education, since nurses trained at the master’s or doctoral level have been shown to be more positive towards family involvement in care compared to those with a basic nursing education [221, 228]. Sak-Dankosky et al. (2014) found that the self-confidence of highly educated nurses and physicians makes them more capable of performing innovative work [89]. HCPs with an advanced level of education and in-depth knowledge of person- and
family-centred care may be key people when it comes to speeding up the implementation of FWR in the Swedish healthcare system.

**Family support person - who should be given the role?**

Almost all HCPs (I, IV) believed that there should always be a team member whose only responsibility is to take care of the family during the resuscitation process. In Study III several family members expressed that they had not been cared for or had no staff by their side during the resuscitation to explain what was happening (III).

When a patient suffers a cardiac arrest, it is a difficult event for the family and they often need support from the staff. Families express the need to be prepared for what they will see during CPR. When family is not prepared, it is an even more unpleasant experience and family members can feel abandoned [144, 190]. Furthermore, family members who witness CPR without the support of staff may develop PTSD [13, 90]. But if the family is provided psychological support by a family support person, stress and anxiety may be reduced and it can prevent PTSD symptoms [94]. This knowledge serves as the basis for the current guidelines for FWR, which recommend the use of a family support person [40]. It has been shown that for the successful implementation and practice of FWR, it is crucial that a staff member take on the family support person role [166, 190].

It would appear that it is easier to invite the family in if a family support person is available. In Study II, the majority of family members were invited to stay during resuscitation when there was a designated family support person (II). Many family members want to be close to the patient, touch the patient, talk to the patient to show compassion, offer support and comfort the patient during CPR [144].

To support the growing global trend in favour of FWR, HCPs need to be trained to act in the role of family support person. The lack of education, combined with concerns about not being able to answer family members' questions, makes HCPs insecure in the role of family support person [95]. Nurses also report feeling unprepared to support family members and may be reluctant to step into this role [18]. However, we found that detailed explanations of the CPR procedure are not needed during FWR. Having a staff member nearby who shows compassion is enough (III), which has been confirmed in previous review studies [44, 72].

Powers et al. (2023) investigated how nurses experience the role of family support person. They discovered that nurses found the role to be challenging but rewarding. It was a challenge to make correct assessments of the situation while simultaneously supporting and informing family
In-hospital family-witnessed adult resuscitation

members, as there is a great variation in how families react [18]. Nurses reported that it could be difficult to get the right training to serve in the family support person role, but learning was facilitated by observing how colleagues treat the family and what techniques they use. Nurses with extensive experience were more confident in their ability to serve as a family support person [95].

Nurses have the skills and knowledge for the multifaceted role of family support person [123]. However, the question is whether it is possible to always have a nurse in the role of family support person in today's healthcare climate. Some of the nurses in this thesis did not think that there is enough staff available to support the family (I, IV). However, in an understaffed healthcare system, HCPs need to consider which other professions may be suitable for the family support person role, as it is important that the family support person can always remain with the family [190].

The literature suggest that the family support person role can also be filled by professionals from other disciplines, such as counsellors, anaesthesia technicians, respiratory therapists, healthcare chaplains, security guards, pharmacists and administrators [18, 110, 127, 229]. In Sweden, this role could be filled by individuals working as assistant nurses, a profession that is suitable for the task.

As a nurse, it could be difficult to envision security guards, pharmacists and administrators serving in the role of family support person. However, since many hospitals struggle with a shortage of HCPs, healthcare providers could broaden their view of who does what in a cardiac arrest situation. Maybe other professions could receive training to become part of the resuscitation team and perform CPR to free up a nurse who has the competence in nursing and care to take the role of the family support person.

In international nursing codes of ethics and nurse education guidelines, nurses are expected to provide spiritual care [230]. This is in accordance with the ERC ethical guidelines, where it is stated that HCPs should provide the option of spiritual support during and after resuscitation [49]. Spirituality is often important in the international healthcare context; however, a patient’s spirituality or faith is sometimes overlooked [231].

Access to spiritual support from HCPs can be difficult to accommodate in the Swedish healthcare system, but chaplains play a key role here by providing support during FWR and post resuscitation procedures [231]. It is not uncommon for family members to want to provide spiritual comfort to the patient during CPR [13, 44, 57, 60, 73]. FWR makes it easier for the family to practice their religion, which reassures patients and family mem-
bers [54, 76]. It can sometimes be important for family members to perform rites in connection with the approach of death [76, 77, 232] or feel that they establish a link beyond death with the family member by being a spiritual intermediary, maintaining a form of communication with the patient who has died or is in the process of dying [70]. Chaplains are trained to deal with trauma; spiritual, psychological and emotional needs; and are educated about cultural sensitivity, but they have limited medical knowledge. This suggests that CPR training for HCPs could also include chaplains, as chaplains can gain increased medical knowledge and can contribute their own knowledge of religious and cultural sensitivity [190].

Guidelines

It is clear from the literature that factors that facilitate FWR include the existence of local protocols regarding FWR [89, 157, 216-219]. In this thesis, HCPs expressed uncertainty about whether they had local guidelines about FWR in their unit (I, IV). Within the Swedish healthcare system, FWR polices have remained unchanged for last 15 years [28]. Internationally, the trend looks the same, where only about 8% of HCPs report that they have unit-level policies or protocols for FWR [13].

The first guidelines on FWR were published in 1993 [29], but there is still some resistance among some HCPs to implement FWR guidelines [233]. At the same time, a growing number of HCPs have been asking for local protocols for some time [19, 234]. Leading organizations recommend establishing an institutional policy for FWR [57, 120]. Written policies and protocols can assist HCPs in their decision-making, provide guidance in clinical practice, define roles for HCPs and contribute to a family-centred care strategy [13, 19]. Guidelines can also prevent conflicts between HCPs and families and prevent families from having to argue that they should be allowed to be present during CPR [144]. There are several things to consider when discussing FWR policy and this relates not only to whether the family will witness CPR, but managing the family when they see, for example, that the patient is occasionally conscious, groaning and opening their eyes [235].

An HCP’s approach to FWR may also be related to where at the hospital the cardiac arrest occurs; for example, emergency department trauma team members may consider patient disfigurement and the presence of blood during FWR to be inappropriate [236]. Research on families who have witnessed CPR performed on critically ill patients and trauma patients shows mixed results. Leske (2017) found that FWR had beneficial effects for fami-
ily members of trauma patients [81], but those who witness the resuscitation of critically ill patients may be at an increased risk for PTSD symptoms at one month [90]. This further demonstrates the need to have a local policy for FWR at each unit, based on the type of care provided at the unit and what the family may see. Care should, however, be person-centred, where an assessment is made in each unique situation about what is in the best interests of the person and/or family member.

A lack of organizational support and no local policy for FWR are two of the reasons why HCPs do not offer FWR [13, 19]. Without a clear policy on FWR accepted by resuscitation team members, there is a risk that guidelines will not be followed, depriving patients and their families of adequate support [190]. If a hospital-wide policy for FWR is developed, all of the hospital’s units and all staff categories must be able to be included. The policy must work in all departments around the clock, regardless of location and staffing [13, 19, 22, 110]. Organizations that support FWR often have written documents to support HCPs and provide recommendations regarding the implementation of FWR. Institutions are encouraged to create and publish protocols and interdisciplinary education modules to guide the implementation of FWR [120].

After compiling the studies in this thesis, it is clear that there is a need to implement local guidelines regarding FWR and to concretely discuss how FWR can be implemented in the workplace, as well as to ensure that employees are included in this process in a way that addresses their needs.

Methodological considerations

Design and research approaches
The studies included in this thesis combined both quantitative (I, II, IV) and qualitative (III) methods using cross-sectional, retrospective observational and quasi-experimental approaches for the quantitative studies and narrative family interviews for the qualitative study. The results are strengthened by the fact that data was collected from multiple sources and through a variety of methods when studying a phenomenon from different perspectives [169].

Participants
All participants were adults ≥18 years of age who either have a reported in-hospital cardiac arrest (II, III), are a family member (III) of a patient who suffered an in-hospital cardiac arrest or an HCP (I, IV) who cares for these
patients. The exclusion of non-Swedish speaking participants could be seen as a limitation. However, all HCPs in Sweden need to be able to communicate in Swedish; hence, this exclusion criteria should not have any impact on the selection. When it comes to the patients and their family members, an inclusion of non-Swedish speaking participants had likely enriched the data; there is a risk that valuable information about how families from other cultures and religions experience a FWR and what their expectations are of the Swedish healthcare system have been missed. Nevertheless, since those interviews in that case had to be performed together with a certified interpreter who also transcribed the interviews verbatim and later translated them into Swedish, this was not considered an option for the purpose of this study.

We planned to include about 200 participants in Study I, but no sample size calculation was made in beforehand. However, the final sample size of 189 respondents is comparable with other similar cross-sectional studies which have used the same instrument [83, 160-167]. Furthermore, it was only possible to calculate response rates for 5 out of 7 hospitals. In these 5 hospitals, the total response rate was 49% for nurses and 45% for physicians. Web-based surveys typically have a response rate below 50%, which indicates that our response rate is within the normal range [237].

When it comes to attitudes about FWR, a previous study similar to ours had an 18% response rate [55]. A possible way to increase the response rate could have been to make an in-person visit to all hospitals where both the nursing group and the physician group would be handed the questionnaire, which could be completed and collected by the researchers. It is likely that the response rate would have been higher with a personal visit. However, this was deemed ethically inappropriate because of the sensitivity of the topic and the fact that the participants’ anonymity could not then be guaranteed. In addition, the presence of the researchers on site could have been perceived as coercion to participate and thus would compromise voluntariness.

For Study II, we aimed to include all adult patients with an in-hospital cardiac arrest registered in the Swedish Register of Cardiopulmonary Resuscitation during the study period. However, the quality of the data in the registers is dependent on HCPs entering complete data. In this study, 527 out of 3,784 patients were excluded due to missing data on family presence.

In Study III, purposive sampling was applied and the nurses who recruited patients for the study were instructed to also use a logbook in which they were asked to record all patients that could be considered for participation in the study in terms of age and gender in order to enable a simple
external drop-out analysis. Unfortunately, the nurses did not have time to keep the logbook, so the number of patients that were approached is unknown. Furthermore, five planned interviews could not be conducted due to unexpected patient death or withdrawal of consent by the patient or family member. We planned to include 10-20 respondents, which is a common sample size given the three touchstones of the IPA [183]. We finally included 15 respondents, and during data collection, it was ensured that the included participants represented diverse demographic backgrounds and common experiences in order to answer the purpose of the study with data that is as rich as possible.

The result of the sample size calculation for Study IV showed that at least 34 participants were required to complete the study, but to compensate for internal dropout, which we calculated to be 40% for the post-intervention measurement, the sample size was set to a minimum of 48 participants. The sample size calculation did not consider possible subgroup analyses such as gender, age and occupation. Given the complexity of recruitment and the design of the study, considerably more HCPs were approached and finally, complete data were available for 78 and 61 participants for self-confidence and attitudes, respectively. The inclusion of more participants than is needed for statistical analyses could be questioned. However, we included significantly more participants since we initially also intended to do psychometric testing (i.e. factor analysis and Rasch analysis) of the included instruments and these require more participants than the intervention study itself [238].

Further, we had internal dropouts; 53% of participants gave their consent to participate in the study and answered the pre-test questionnaire, but later did not complete the post-test. No differences in age, gender, workplace or years in the profession were noted in the drop-out analysis between those who completed the study and those who did not, which implies that the results are representative for the whole sample. The completion of the intervention for Study IV is comparable with previous educational FWR studies. Dwyer and Friel (2016) invited 200 HCPs to an education about FWR, where 29 completed the pre-test and 18 completed the post-test [111]. Feagan and Fischer (2011) distributed a pre-test to 520 physicians and nurses, where 94 completed the pre-test and underwent the educational programme and 25 answered the post-test [157].
Data collection

The quantitative studies

Validity in quantitative research shows the degree to which an instrument measures what it is intended to measure, whereas reliability involves the degree of consistency or dependability with which an instrument measures the characteristics it is designed to measure [169].

The attitude instrument used in studies I and IV has shown a satisfactory internal consistency with a good test-retest reliability [27]. It was the only established instrument measuring HCPs’ experiences and attitudes of FWR available in Swedish at the time of planning studies I and IV. Other instruments [77, 104, 111, 113, 189, 239-242] were available in English but have not been used as extensively as the Fulbrook instrument [27], and it was not deemed reasonable to translate and validate another instrument within the time frame of the project. However, since the original English version of Fulbrook’s attitude instrument [27] had been translated into several languages and used in many international studies [83, 160-167], its comparison with others was seen as a strength.

No instruments measuring self-confidence in managing FWR situations in-hospital were available in Swedish at the time of planning Study IV. The FPS-CS [159] was chosen for translation and cultural adaptation and reviewed for content and face validity due to its high levels of internal consistency and the construct validity in the original instrument. The instrument has also been extensively used in international studies, making it possible for comparisons [14, 106, 110, 112, 116, 118, 121, 171-180]. The instruments used in studies I and IV could have benefited from additional psychometric testing with regard to validity and reliability. For example, exploratory factor analyses could have been performed. Furthermore, both instruments use Likert scales ranging from 1-5. The use of five or seven response alternatives has previously been criticised, and it has been suggested that the validity increases with six or more response alternatives, yet five-point options increase the response rate with less internal missing values [243]. However, this assumption was not tested within this project.

Both instruments were tested in a pilot study involving nurses and physicians in order to assure that the questions were also comprehensible to physicians and showed good relevance, understanding and legibility of the instruments.

In Study II, we used a large database from the Swedish Register of Cardiopulmonary Resuscitation to collect data. All emergency hospitals in
Sweden are currently included in the register [133]. Thus, this cohort represents data from all cardiac arrests and describes the clinical reality, which therefore provides high external validity. However, as with all registry studies, coding errors may exist thus resulting in the risk of misclassification bias. To increase credibility, we manually went through all 4,843 patients before performing the statistical analyses to exclude patients who, for various reasons, should not be included in the analysis. The new questions concerning FWR were developed in a collaboration between the research group and the register and later validated by nurses and physicians using a think-aloud technique [170]. Despite the thorough process used to develop these questions, additional testing could have been beneficial to establish the accuracy of the questions.

**The qualitative study**

Several considerations were made to increase the credibility of Study III. Tape recordings were used to obtain data, which is considered important when studying the active understanding among patients and family members [169]. In IPA, semi-structured interviewing is most often the method of choice for collecting data [183]. This method requires the interviewer to immediately interpret the participants’ answer to be able to make decisions about further questions [169]. Our interview guide was instead flexible with just a few open-ended questions, which enhanced the possibility of using probes. In addition, the interview guide was pilot tested without any further clarifications.

When interviewing multiple family members in the same interview, there is always a risk that one individual will dominate the interview. There is also a higher risk that the participants will go off topic for a substantial length of time, or that they will find it difficult to discuss sensitive areas [244]. Efforts were made to avoid such pitfalls; for example, the participants were thoroughly informed about the importance of letting the other person continue to speak and not be interrupted and that it was allowed to express feelings.

Meeting patients and their family members in the interviews created a special environment. They expressed that it was the first time they had the opportunity to talk to someone about the cardiac arrest and it evoked a variety of thoughts and strong feelings.

IPA researchers must always reflect on their own pre-understandings and setting aside their pre-understandings (i.e., ‘bracketing’) to the greatest extent possible in an attempt to minimise the impact on the research.
process [183]. Hence, interviewers made a deliberate choice to remain neutral and adhere to the interview guide and to avoid stepping into the nursing role during the interviews. However, topics raised that needed further processing after the interview were noted in writing so that follow-up conversations could be conducted when the interview ended.

Several participants showed signs of distress, including crying, breathing problems and palpitations during the interviews. They expressed anger and guilt. Some were so distressed that the interview had to be paused for a few minutes. When the patients had strong reactions, my background in nursing was an advantage as I did not feel worried or uncomfortable and could calmly continue the interview when the participants were ready. Participants were carefully informed that the interviews could be stopped at any time, but everyone was willing to continue the interviews despite the occasional expression of strong emotions. The strongest emotions were triggered when thinking about one’s own mortality or the prospect of being left alone.

During the interviews, a number of topics emerged that had not been discussed before, neither within the couple nor with an HCP, and the participants expressed that it was challenging to process what had happened. For some, the relationship had become complicated, as they had been trying to process a life-changing event together but in completely different ways. Nonetheless, all participants appreciated the opportunity to share what they had been through and to express their feelings, not only to the interviewer but also to each other.

**Data analyses**

**Quantitative data**

Likert scale instruments were used in studies I and IV. The most common criticism when interpreting Likert scale data is the reporting of mean values for responses [245, 246]. These measures are generally regarded as ordinal and non-normally distributed and should be analysed using non-parametric tests, as was done in Study I. However, several authors, including the creator of the FPS-CS, have used t-tests and have also tested pre-intervention homogeneity between groups with ANOVA. Furthermore, post-education changes between groups have been analysed with ANCOVA [112, 116, 121, 159, 247]. Hence, we decided to use a paired t-test in Study IV in order to be able to compare our results with others. However, to ensure that the results were not misleading, we also ran non-parametric tests without any differences in outcome.
When it came to deciding on suitable time points to measure the pre- and post-test in Study IV, a comprehensive review covering different educational interventions with a pre- and post-test design was performed, resulting in divergent results. The post-test was performed in a period ranging from immediately after the intervention to up to one year after the intervention. Three studies that used 2 [248], 6 [189] and 12 months [158] for their post-test showed no, or weak effects of education, while others who used the same time interval showed positive effects [110, 112, 113]. Studies that used a post-test immediately after the end of the educational programme also showed positive changes [115, 176]. Since no consensus on appropriate time point measurements could be found, we decided to measure our post-test after one month, as we considered this to be within a reasonable time frame while at the same time maintaining the participants’ interest in the study.

Another aspect may be the choice of instrument used as the primary endpoint, and not the time point. Four previous studies [110, 112, 116, 176], all with different types of educational interventions, have used the FPS-CS to evaluate self-reported changes in self-confidence in managing FWR situations. All studies demonstrated improved self-confidence after the intervention, despite the fact that the time point for measurement varied between immediately after the intervention to 1, 2 and 12 months after the intervention.

In Study II, we performed both bivariate and multivariate analyses to evaluate the outcomes of resuscitation with and without family presence. We adjusted for several patient and contextual covariates that could potentially confound the relationship between FWR and each outcome, based on evidence-based knowledge and variables available in the database. Even though this is one of the largest studies based on real-life data analysing the association between FWR and resuscitation outcomes, as in all observational studies, there is an inherent risk of unmeasured or unknown confounders, despite adjustments in multivariable models. Therefore, the results need to be interpreted with caution regarding causality.

**Qualitative data**

IPA, which was used for data analysis in Study III, has criteria that ensure good quality: sensitivity to context, credibility impact and confirmability [183].

*Credibility* is strengthened by the fact that the research process is carefully described regarding the selection process, design of the interview
Discussion

guide and the interview situation. The researchers have a good understanding of cardiac arrest patients and considered this during the analysis process. The construction of subthemes and themes was difficult, as the material was rich and extensive. The interpretation was a challenge because personal thoughts had to be put aside as much as possible in order to be open to new insights, but the pre-understanding may still have influenced the analysis and interpretation. The analysis was carried out by the PhD student, and the results were continuously reviewed by the research team. Verbatim quotes were plentiful, thus strengthening validity.

*Impact and importance* mean that the results shall add scientific value and be transferable to similar contexts. The themes are judged to be transferable to other cardiac arrest patients and their family members, with the important caveat that phenomena are in some sense inexhaustible. This means that similar studies are likely to find additional meanings and nuances of the phenomenon than are found in Study III.

*Confirmability-objectivity*, the focus was to examine the lived experience rather than the essence-level meaning of the phenomenon because IPA is more subject-oriented than phenomenon-oriented. This means that the feelings of one participant can reach the level of a theme or sub-theme, so making "saturation" is not non-compatible with IPA. After careful and systematic analysis of the results, credible sub-themes and themes have been created and transferability of the results is possible.

*Sensitivity to context*, there was an open dialogue during the interviews, with the aim of eliciting rich descriptions of the situation being studied. Interviews aimed to capture the feelings around the experience and how people understand it with a desire for new insights into what it is like to have such an experience. The research group had many ethical discussions about the question guide, how to handle empirical challenges and prepare for the interview situation and how the data is handled and interpreted during the analysis process.

The choice of IPA as a qualitative method in Study III was partly based on the idiographic part [183], where one sets out to determine how individuals experience situations in a specific context. Afterwards, the choice of method can be discussed. The goal of capturing the respondents’ shared experiences of the cardiac arrest event was hampered by the fact that no patient had any memory of the resuscitation itself and the presence of the family.
In-hospital family-witnessed adult resuscitation

The choice of pedagogical tool for the intervention

Previous research has shown that face-to-face education increases nurses' support for FWR but takes a lot of time and both the educator and the staff must be on site at the same time. Online education, on the other hand, can reach more participants [116, 118], and educational videos increase learning significantly more than face-to-face education [249, 250] because the video can be viewed multiple times and on different occasions [250].

When it comes to previous educational FWR studies aimed at HCPs, classroom and video FWR simulation with nursing students has been shown to significantly increase knowledge, perceptions and confidence related to FWR [176]. A prospective randomized controlled trial investigated whether knowledge of bystander CPR education in medical students differed between a traditional instructor-led classroom module and a group-led video instructional module and found no differences [251]. Powers and Candela (2016) were the first to demonstrate that online learning can improve perceptions and confidence in FWR among critical care nurses [116], and many nurses prefer computer-based/online education [118].

Considering the advantages of web-based online education, especially with the current staffing shortage in Sweden, we decided to develop and test an educational video to be used as the intervention in Study IV. Video can simplify what is perceived as complex and abstract and is often an effective way to capture attention [252]. Using video as an educational tool has its origin in cognitive theory and is based on three principles: we learn visually and auditorily, we can only take in a limited number of impressions and information and active processing is required for learning to occur [253]. Video can also offer realistic scenarios that promote awareness of patient experiences and attitudes while creating understanding and shaping change [254]. Furthermore, a topic that engages and arouses opinions is good to present as a video [255] and can be a good tool when approaching difficult subjects, such as:

- guidelines around situations that require professionalism, empathy, knowledge of interaction between people and ways of reacting to context and ethical reasoning;
- teamwork including patients and families;
- self-examination, reflection, thoughtful discussion [254].

It is important that knowledge can be put into a context in order to be able to apply it [256, 257]. Video involves the activation of both the visual and auditory senses [258] and is also considered an effective way to foster emotional engagement. Using patient stories in video is something that engages HCPs and helps them absorb knowledge. It links theory with practice.
Since FWR is a difficult and sensitive topic for many HCPs and often arouses strong emotions, the use of an educational video was deemed as appropriate in Study IV.

The research is unanimous regarding video length, with shorter videos being preferred as it increases learning [260]. Data from the Massive Open Online Course, comprising 6.9 million video clips, showed that viewers were almost 100% engaged for about 6 minutes, regardless of the total length of the video. After that, engagement drops and videos that are 9-12 minutes only have 50% engagement and engagement drops to 20% for videos that are between 12-40 minutes [184]. It is important to avoid factors that can impact cognition during the learning process [252], such as disruptive noises, excessive use of colours, cluttered images, etc. [261].

Another important aspect to consider is to avoid speaking too slowly in the video. It can be tempting for the video maker to want to speak slowly to ensure that the listener understands. The fact that the person speaking in the video does so in a committed way has also proven to be important in promoting the willingness to listen. Research has shown that increasing the rate of speech also increases the engagement of the listener [184, 261]. Based on the available evidence, we set 10 minutes as the maximum length of the video used in Study IV in order to ensure that viewers could maintain engagement. Narrators were asked not to speak too slowly and actors were asked to dress neutrally. To get good picture and sound quality, a professional film team was used.
In-hospital family-witnessed adult resuscitation
CONCLUSIONS

FWR in Swedish hospitals is quite rare. It mainly occurs in the emergency department and intensive care units and it is also more common for staff members to be assigned to care for the families in those facilities.

Patients do not seem to be negatively affected by FWR, which confirms that current national guidelines that recommend FWR should be followed and that local guidelines that consider the circumstances in the specific department or hospital need to be established, as these are seldom existing.

Many HCPs in Sweden have experience of FWR and have in general a positive attitude to FWR. Having a family support person to care for the family increases HCPs’ willingness to offer FWR. Still, there is uncertainty and a certain degree of resistance to FWR among HCPs, which is often related to a lack of education.

A short online educational video can be a way to foster positive attitudes towards FWR and increase the self-confidence of HCPs to act in a FWR situation. However, the message in the video is important. The HCP’s self-confidence did not strengthen in areas which were not addressed in the video, such as the ability to identify family members who are assumed to be present, encourage family members to talk to the patient during ongoing resuscitation and coordinate follow-up after death. These topics needs to be included in when revising to content in the educational video.

Surviving or witnessing a cardiac arrest in-hospital is a difficult experience for patients and family members. They are often vulnerable and feel insignificant and abandoned. They need to be seen and heard, both in the hospital and after discharge. HCPs need to show compassion and tend to the family’s needs, which means continuously evaluating how family members are coping during the cardiac arrest event, as well as providing support and information both during and after resuscitation.

Compliance with current national FWR guidelines should be increased. Improved care of cardiac arrest patients and their families can be achieved relatively easily with greater adherence to current national guidelines, which recommend FWR. The guidelines also recommend structured post-hospital care for cardiac arrest patients and their families. Adherence to guidelines can lead to reduced symptoms of depression and anxiety in both patients and families.
Clinical implications

In a broader perspective, this thesis will hopefully increase the awareness of how HCPs should relate to family members and patients during a cardiac arrest, as well as in the post-cardiac arrest care of both patients and their family members. Likewise, the knowledge gained from this thesis has the potential to be incorporated in the current resuscitation guidelines.

In order to introduce FWR in hospitals, trained HCPs, designated family support persons and local guidelines that consider the whole care chain from the cardiac arrest to the follow-up of the patient and family after hospitalisation are needed.

HCPs must be able to assess whether a family member can be offered FWR, considering various aspects such as psychological, social, cultural and religious influences. In an increasingly multicultural society, HCPs should also be educated about culture and spirituality to support family members who may have cultural or religious wishes, such as performing rites and ceremonies in the event of cardiac arrest and death.

Guidelines should be written at the local level to facilitate the introduction of FWR, designed to support staff in clinical decision-making around FWR. It is important to establish routines that ensure access to a designated family support person, including times of the day when staffing is limited. If we are to solve the challenge of providing family support persons in a healthcare system where there is a shortage of nurses, we may need to think outside the box, about other professions who can be helpful in a cardiac arrest situation. One approach could be that before each working shift, staff members decide who will take responsibility for various tasks in the event of a cardiac arrest, including roles when family members are present.

When it comes to decisions about FWR, nurses appear to be the profession best suited to take this responsibility. The nurse often has a holistic view of the patient and an established relationship with the family and can ensure that someone is assigned the family support role. If there is not enough staff to assign an individual to the family support role, someone in the team can take on the role of informing the family of what is happening. The most important thing is that the family is not denied the option to be present during CPR. Debriefing for staff should also be a requirement after every FWR situation, so that HCPs can process emotions and learn from each other how to best care for family members. Debriefing for the family is also important, where the staff can get feedback from the family about
their experiences of the cardiac arrest situation and the support they received.

**Future perspectives**

There is a need for trials to evaluate whether FWR can reduce costs related to sick leave, medical visits and medications that may be needed in complex grief work for family members who want to be present during resuscitation but are denied the opportunity, compared to those who are present when the patient dies.

Improved strategies are needed in order to implement local guidelines for FWR and in order to understand why the occurrence of local guidelines are sparse, there is a need for more qualitative studies involving participants at a management level.

Survey studies investigating which educational needs HCPs’ have is warranted, especially among HCPs working outside emergency departments and intensive care units.

Future research should also investigate whether a short educational video intervention has an impact on the number of times the family is invited to be present during CPR, not just an impact on self-confidence and attitudes as demonstrated in this thesis. This could be done using the new variables measuring family presence in the Svenska Hjärtläkarinnorregistret.

Qualitative studies also need to include fellow patients who witness resuscitation and see and hear the reactions of family members during FWR. As a fellow patient, witnessing another patient’s resuscitation can arouse strong emotions and existential thoughts. Fellow patients need to be interviewed about their own needs in order to determine how well they cope with the situation after the fact.

Finally, attitudes towards death and to resuscitation are highly influenced by culture and the acceptance of FWR can vary according to the cultural and religious traditions of different countries. There is a need to consider cultural and religious influences when discussing FWR in Sweden and there is a need for education for HCPs that includes the cultural and religious perspective.
SVENSK SAMMANFATTNING

Avhandlingen handlar om närståendes närvaro vid hjärtstopp på sjukhus. Årligen inträffar drygt 2,500 oväntade hjärtstopp på svenska sjukhus varav knappt var tredje person överlever och blir utskriven från sjukhuset. Närståendes närvaro vid hjärtstopp på sjukhus har varit en omdiskuterad fråga i över 40 år.


Den närstående upplever inte alltid att de erbjuds att närvara under hjärt-lungräddningen (HLR) eller att de blir omhändertagna av vårdpersonalen. Att få information om den närståendes tillstånd är viktigt och det underlättar den närståendes acceptans av utgången efter HLR. I det svenska HLR-rådets riktlinjer påtalas att närstående bör erbjudas närvara under HLR om de så önskar. Närstående som inte tillåts närvara upplever ofta brist på information, de drabbas oftare av posttraumatisk stress och genomgår ett försvårat sorgearbete.

Vårdpersonal uttrycker tveksamhet till närståendebevittnad hjärt-lungräddning (NBHLR); de tror att närstående ska ta skada psykiskt av att närvara och att situationen kan vara skrämmande och traumatisk, samt att personalen anser att de själva inte fått utbildning i att kunna hantera NBHLR. Dock ser personalen från de få sjukhus som systematiskt praktiserar NBHLR att det är positivt för de närstående att närvara. Närstående ser att allt gjordes för den sjuke, de får möjlighet att säga farväl och sorgeprocessen underlättas. Utbildning för vårdpersonal behövs kring riktlinjer och evidens.

Syftet med projektet var att studera närståendebevittnad hjärt-lungräddning på sjukhus;

-Vilka erfarenheter och attityder har vårdpersonal till NBHLR?
-Vilka är patienters och närståendes erfarenheter av att vara med under ett hjärtstopp?
-Hur ofta förekommer NBHLR, hur går det för patienterna när närstående närvarar, påverkas överlevnaden?
- Kan en 10-minuter lång utbildningsfilm riktad till vårdpersonal påverka attityder till NBHLR samt tilltron till den egna förmågan att agera under ett hjärtstopp när familjen är med?

Avhandlingen bygger på fyra delstudier med olika datainsamlingsmetoder:

**I:** En webenkät skickades ut till 189 sjuksköterskor och läkare från hjärtavdelningar vid alla universitetssjukhusen med frågor om deras erfarenheter och attityder till NBHLR.

**II:** Registerdata på 3257 patienter från Svenska Hjärtläkarregistret användes för att ta reda på hur ofta närstående var med vid hjärtsstopp, och om bl.a. överlevnad påverkades av NBHLR.

**III:** Patienter och närstående intervjuades tillsammans om hur det var att vara med om en hjärtstoppshändelse och hur det påverkade tiden efteråt.

**IV:** En webenkät skickades ut till läkar- och sjuksköterskor med frågor om deras erfarenheter och attityder till NBHLR samt tilltron till deras egen förmåga att agera under ett hjärtstopp när familjen var med. Därefter fick de se en utbildningsfilm och NBHLR för att sedan återigen besvara enkäterna.

Kunskap som att avhandlingen bidragit med:

**Studie I:** Universitetssjukhusen saknade lokala riktlinjer kring NBHLR och personalen hade svårt att ta ställning till NBHLR. Sjuksköterskor var något mer positiva än läkargruppen.

**Studie II:** Totalt 6% av återupplivningsförsöken bevittnades av en närstående. Det var vanligare att närstående var på plats om hjärtsstoppet inträffade på akut/intensivvårdsavdelning och det var också vanligare att någon personal var avsatt för att ta hand om närstående där. Överlevnaden påverkades inte av närståendes närvaro.

**Studie III:** Patienter och familjemedlemmar kände sig obetydliga och övergivna efter hjärtstoppet på sjukhuset. Att överleva och bevitta ett hjärtsstopp på sjukhus är en kritisk händelse för alla inblandade. Patienter och familjemedlemmar är sårbara och behöver synas och höras, både på sjukhus och efter utskrivning. Följaktligen måste vårdpersonal visa medkänsla och ta hand om familjens behov, vilket innebär att kontinuerligt utvärdera hur familjemedlemmar klarar sig under processen och ge stöd och information under och efter återupplivning.

**Studie IV:** Sjuksköterskor och läkare på olika avdelningar på sex sjukhus fick se en kort utbildningsfilm online. Filmen förbättrade vårdpersonals självförtroende att kunna agera i en hjärtstoppssituation och attityderna till inkludering av familjemedlemmar under återupplivning blev mer positiva.
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Papers

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