

Spouses' experiences of a cardiac arrest at home: An interview study

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Abstract

Introduction: In case of out-of-hospital cardiac arrest (OHCA) influence of a bystander spouse is decisive for the chance of survival.

Aim: To describe spouses' experiences of witnessing their partners' cardiac arrest at home, focusing on the time before the event and when it happened.

Methods: Interviews with fifteen spouses were recorded and transcribed verbatim. Qualitative content analysis was conducted.

Results: In the domain entitled "Time before cardiac arrest", four themes emerged in the analysis process: "Lack of early warning signs", "Difficulty interpreting early warning signs", "Interpreting signs in the light of previous illness" and "Denial of serious illness". In the domain entitled "The cardiac arrest event", three themes emerged: "Perceiving the seriousness", "Being unable to influence" and "Doing what is in one's power". The emergency call services' (ECS) ability to instruct and help the spouses to do what they can becomes evident in these themes.

Conclusion: Spouses who experienced OHCA demonstrated a lack of confidence in or ability to interpret early warning signs and symptoms. This lack of confidence also extended to the process of cardiopulmonary resuscitation (CPR). The support from the ECS and CPR training was acknowledged as helpful and important. Further research is required to determine which interventions can improve people's ability to intervene as early as possible.

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1. Introduction

Out-of-hospital cardiac arrest (OHCA) accounts for a large percentage of the mortality in cardiovascular diseases [1]. Among those who die due to an acute myocardial infarction, the majority die of a cardiac arrest (CA) prior to hospital arrival [2].

The value of bystander-initiated cardiopulmonary resuscitation (CPR) is well documented [3–7]. As most of the OHCA's occur in the patients' homes [5,7], the persons most

likely to witness these events are family members and most often the spouse.

Studies have shown that, even if family members are trained in CPR, there is no guarantee that they will start CPR [8–10]. In a study in the USA, only 35% of the bystanders who were trained in CPR said that they had performed CPR when the CA occurred at home [10]. The most common reason stated for not starting CPR was panic, while doubts about being unable to perform CPR correctly and fear of hurting the patient or perceiving that the patient was dead were also expressed. In nearly half the cases the reason for not starting CPR was unknown [10].

Only one study, using a qualitative method, was found in which the experiences of family members as witnesses of

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OHCA were studied. Weslien et al. [11] interviewed family members about their experiences of the CA event, focusing on the relationship between the family members and the staff that were involved. Information on how spouses perceive the time immediately before a CA at home and how they react and act is lacking, as no further studies have been found on this topic.

The aim of this study was to describe spouses' experiences of witnessing their partners' CA at home, including the time before the event and when it happened.

2. Method

2.1. Participants

Fifteen spouses or co-habitants (hereafter called spouses), twelve women and three men, were interviewed about their experiences when their partner suffered a CA at home. Their age ranged from 48 to 87 years (median = 69 years).

2.2. Sample and data collection

All spouses identified as being present when the CA took place, from January 2004 until March 2006, were considered for participation. They were found through the registration of their partners' OHCA in the Swedish Cardiac Arrest Register.

All patients who had suffered a witnessed CA at home due to probable cardiac cause and who had been brought to the Sahlgrenska University Hospital during the study period were identified. Using these criteria, 85 patients below the age of 80 were identified. The medical records for these patients were examined. During this period of time, two patients had survived after one month. The spouses of these two patients were not contacted. In 36 of the cases, it was possible to find the name, address and telephone number of the spouse who had been the witness.

A letter containing brief information about the background and purpose of the study and a request for participation was sent to these 36 spouses. It was emphasized that their participation was voluntary and could be withdrawn at any moment without further explanation. Furthermore the consequences of participating were described, confidentiality was guaranteed and information to enable contact with the researchers to answer any queries was included.

Approximately one week after receiving the letter, the spouses were contacted by telephone by the first author and asked if they were interested in participating in the study. Three spouses could not be reached by telephone and 18 declined participation. Finally, 15 spouses, all Swedish speaking, participated.

2.3. Interview

The interviews took place 10–27 months (median 22 months) after the CA event. Five of the spouses were

interviewed in a designated room at the hospital, while the rest were interviewed in their homes, according to their choice. All the interviews were conducted by the first author and lasted between 27 and 97 min (median 56 min).

The spouses' narrative of their experiences was initiated by the question, "Could you please tell me in as much detail as possible what happened?" Follow-up questions were used to focus the spouses' perceptions, thoughts and feelings, reactions and actions during the CA event. During the interviews, tact and empathy with a sensitive ear was paramount, even if it was at the same time essential to ensure that the true meaning of what they said was correctly understood [12]. After the interviews, time was spent to ensure that the spouses could cope with their situation. If needed, one of the welfare officers at the hospital was available for support. A digital recorder was used and the interviews were transcribed verbatim.

2.4. Data analysis

The authors agree with Krippendorff [13] in there being no single meaning waiting to be "found" and "described" in a text and that every text can be read in different ways. Our intention was to capture the spouses' experiences.

The qualitative content analysis process, performed in the study, started by reading the transcribed interviews repeatedly until a grasp of the whole was obtained. The whole text was then brought together in one document and the text was read meticulously, with the aim of the study in mind. Text referring to the spouses' experiences was divided into meaning units, which were condensed. The condensed meaning units were then labelled with codes.

The text was then divided into three different time domains of experience; 1) the time prior to the CA and 2) the CA event. The third domain, the time after the CA, will be presented elsewhere. The analysis was then performed for each of the two domains separately to simplify handling the vast amount of text [13]. The text for each domain was read in detail, during which the whole interview text for each spouse was used as a context. The codes were compared, based on similarities and variations, throughout the analysis.

A number of preliminary themes were formulated to cover the codes. These themes were then reduced in number in the analysis process by the absorption of those that were covered by another theme. Finally, four themes in the first domain and three themes in the second domain emerged from this process. The analyses were checked and discussed by all the authors until agreement on interpretations was obtained.

2.5. Ethics

The study was approved by the Committee for Ethics in Medical Investigations, Gothenburg University (No: S 299-02), and conforms with the principles outlined in the Declaration of Helsinki [14].

Table 1
Characteristics of the bystander spouse, measures taken and outcome.

	<i>n</i>
Age (years)	
<65	5
65–74	6
>74	4
Gender	
Male	3
Female	12
Previous CPR training	6 ^a
Offered CPR guidance	8 ^b
Started CPR prior to the arrival of the ambulance	8
Advised on recovery position by the emergency call services	3
Patient admitted to hospital	4 ^c

^a Five of these spouses started CPR prior to the arrival of the ambulance.

^b Six of these spouses accepted guidance and started CPR.

^c Three of these patients received CPR prior to the arrival of the ambulance.

3. Results

Characteristics of the bystander spouses, measures taken and outcome are presented in Table 1.

The results are presented in the two domains with respective themes in Table 2.

3.1. The time before cardiac arrest

When narrating the event, all the spouses began by describing the time before it occurred and that it was unexpected. However the patients' condition prior to the event varied from being completely healthy, to having various cardiovascular or pulmonary diseases, or even being terminally ill with cancer. One patient had a severe cold and another was help dependent due to Parkinson's disease. In all cases, the spouses looked for signs that may have been missed. In some cases, these were eventually found. In other cases, they found nothing that could have led them to the decision to call for an ambulance at an earlier stage.

3.1.1. Lack of early warning signs

There were often no signs that could have guided the patient and the spouse to consider seeking care. The event was completely unexpected and everything had appeared to be completely normal. Both the spouse and the patient had

been carrying out their lives as usual, talking about ordinary things or the patient could have been joking just before it happened:

“He leapt into bed and pulled the sheet over himself” (IP 12).

3.1.2. Difficulty interpreting early warning signs

In some cases, signs which were either diffuse or more specific were present; absent-mindedness in connection with a stab of pain the day before the event, leaving the patient withdrawn; patient saying that he/she felt unwell, being uncertain and irritated hours before the CA. Unpleasant feelings and dizziness were also described. The signs that were noted were sometimes interpreted as normal. One spouse whose husband had a myocardial infarction one week before said that her husband seemed to be restless and irritated:

“I asked how he was. ‘I don't know,’ he said. So he began to feel... he didn't say it was anything, but he was a bit irritated and curt in some way. It was just as if his body didn't fit him but he couldn't... so I know I said, I think we have to eat, I think we are hungry. We have been going since lunch” (interview person (IP) 15).

Without prior knowledge of what could be considered to be normal so soon after a myocardial infarction, even the patient's complaint of severe pain in the arm when putting food on a shelf in the refrigerator after the meal did not cause any alarm.

3.1.3. Interpreting signs in the light of previous illness

In some cases the patients had a previous illness and this could lead to a misinterpretation of the symptoms and signs and to the use of old treatment strategies, even if they were ineffective. Abdominal pain in connection with the first appearance of a myocardial infarction several hours before the CA was interpreted as originating from a previous pancreatitis:

“The terrible thing is that, if he hadn't previously had pain in his belly, I might have realised that it was something else. I was completely... yes all of me believed it was what he had suffered from before. He never had any problems with his heart. He was operated on and checked and never had any problems with his heart” (IP6).

Some spouses recalled seeing signs of tiredness prior to the event. When the patient was already ill or needed help, tiredness or feelings of discomfort were interpreted as being due to this illness.

3.1.4. Denial of serious illness

Some patients withheld information concerning their health or well-being from their spouse; possibly indicating denial of a serious illness by the patient. In one case, when

Table 2
Domains and included themes.

Domain	Theme
Time before the cardiac arrest	Lack of early warning signs
	Difficulty interpreting early warning signs
	Interpreting signs in the light of previous illness
	Denial of serious illness
The cardiac arrest event	Perceiving the seriousness
	Being unable to influence
	Doing what is in one's power

afterwards realising that the patient had taken a small amount of alcohol during the night, one spouse came to the conclusion that her husband must have had some kind of pain or trouble during the night but wanted to wait until the morning.

There was also a component of consideration for the other person's independence. The explicit expression of suspicion of a myocardial infarction by one patient led to a "wait-and-see" policy, as the spouse wanted to be considerate towards her husband:

"But if you have had (infarction), we have to go to the hospital. Yes, we'll wait a little. Interviewer He wanted to wait. IP I understood it was because it was his birthday the next day, so he probably thought he would be lying in hospital and I didn't want to nag any more" (IP4).

While denying serious illness, the patients try to cure themselves by trying to rest and by taking different medication or alcohol, as described above.

3.2. The cardiac arrest event

When a CA developed, all the spouses rapidly perceived it as serious. In two cases, the spouses called for an ambulance shortly before the CA took place. In one case, the spouse called because of a sudden onset of severe abdominal pain and in the other because of a presumed difficulty breathing. Other signs noted a few minutes or seconds before the patient collapsed were feebleness, breathing difficulties, hyperventilation and the sudden onset of pain in the arm/arms.

All the patients were taken to the hospital by ambulance following the event. Four of them were admitted (Table 1) to the intensive care unit and all died soon after or within a few days.

3.2.1. Perceiving the seriousness

The signs spouses perceived as serious were seeing changes in the patient's posture together with a change of colour in the patient's face or hearing him/her wheezing. Seeing the patient fall or sit in a strange position prompted the spouses to immediately attempt to make contact with the patient and to wake him or her up by shouting, shaking or slapping the cheeks. Realising that the patient was completely without muscular tone and observing his/her lifeless eyes helped the spouses to understand that the situation was really serious. A few spouses described checking for a pulse and when asked if the patient was breathing, other spouses reported occasional gasping for breath. This was not interpreted as a sign of life by any of these spouses.

Thoughts about the situation were described as the patient dying or already being dead. Comments on the person having "gone" were common.

..."I saw that he had gone. I saw that his eyes had gone. The only thing I heard was some kind of... I can't describe it better than a kind of snoring" (IP13).

Even though many of the spouses said that they did not know what to do, they all quickly called for an ambulance. The feelings that were expressed were insecurity, fear and panic, which show an awareness of the seriousness of the situation. A sense of unreality was common.

3.2.2. Being unable to influence

Not understanding the importance of immediate help or lacking the ability to intervene, some spouses desperately put their faith in the emergency services and believed they would come and rescue the patient. When they had called for an ambulance, they tried to help by facilitating the ambulance staff's access to the patient.

Some spouses, due to a lack of physical strength and fear of hurting the patient, were unable to intervene when asked by the operator on the ECS to pull the patient from the bed or chair onto the floor. Feelings of panic also inhibited intervention, which sometimes led to the inability to carry out instructions. When the perceived signs were interpreted as signs of death or dying, some spouses saw no real reason for intervening. Wanting to help but not knowing how or what to do was expressed by some of the spouses.

"It felt as if I couldn't do much more than talk, a little hysterically" (IP13).

3.2.3. Doing what is in one's power

This theme goes from wanting to make the best of the situation and do what one can to fighting for the other person's life with every possible means. The spouses try to influence things to the best of their ability. As this ability varies due to the spouses' physical strength and knowledge, the interventions differ. The spouses accepted guidance from the ECS:

"During the time I received instructions from the ECS on what I should do, lay her down and what to do... try to do massage and blow in the mouth and something like that, which I have no knowledge of and have never done before. So I felt very insecure... but I tried my best" (IP7).

The guidance from the ECS appears to be important, as several spouses said that they were encouraged to continue their efforts by the operator and that they felt supported. Even in one case where the spouse was a trained CPR instructor who reacted by instinct and started CPR immediately, doing everything as described in the CPR instruction book, when her husband collapsed, the guidance felt important:

"... but I pulled him to the floor and went on (with CPR) and he was with me on the phone all the time, the guy at the ECS. Count out loud! And I counted out loud, one, two, three, and he said 'You have to do it faster', so he helped to count out loud so I did it faster" (IP 12).

All the spouses who had previous CPR training tried to influence the course of events and did everything in their power.

4. Discussion

4.1. Methodological considerations

The aetiology of all the CAs for the patients in this study is not known, as in most cases an autopsy was not performed. They were all, however, judged by the ambulance nurses to have a probable cardiac cause. Only the spouses of patients who had not survived were interviewed. This decision was made, as the situation was deemed to be different for a spouse whose partner survived.

One limitation in this study is that only Swedish-speaking spouses were interviewed. We do not know how people from other cultures experience an OHCA in Sweden. The strength of this study is that the spouses were willing to share their experiences, feelings, fears and shortcomings in this situation. However, less than half of those who were invited agreed to participate in the study. Some of those who declined participation said that they did not want to talk about the event and stir up emotions, leaving us with no knowledge of their experience. The spouses who agreed to be interviewed were positive about talking about the event. One of them admitted, when asked afterwards, that it was distressing to talk about the event, however, no one regretted his/her participation.

Recall bias could be a concern, as the interviews were conducted 10 to 27 months after the event. However, the spouses' descriptions were detailed and strong emotions were expressed, as though the situation had occurred recently. It has been shown that events of critical importance and negative emotional events are easier to recall [15]. Wisten et al. [16] interviewed parents of young adults who died suddenly in CA and even though these interviews were made 5–12 years after the event memories concerning it were quite vivid. This indicates that our findings could be transferable to similar settings or other groups of participants.

4.2. Findings

When narrating the event, the spouses spontaneously started by talking about the time before it happened. While talking about and noticing the signs or the lack of signs that could have warned them, they tried to understand the unexpected event. As described by others [17,18], narration is the principal way in which we make sense of our experiences. The spouses tried to make sense of their experience and understand why the person suddenly died in front of them, without any symptoms or signs preceding the event. Even in those cases in which signs were present, it was difficult to grasp the mystery of life; at one moment he was there and the next second he was not.

The majority of unexpected CAs are due to ischemic heart disease and occur in the early phase of the development of a myocardial infarction [2]. The difficulty involved in interpreting early warning signs, as shown in this study, is easy to understand, as the signs that were noted were not what people generally associate with myocardial infarction. Previous

studies [19,20] have shown that people expect central chest pain in the event of a myocardial infarction and, when symptoms do not match these expectations, the seeking of care is delayed. Additionally, as many as one third of patients diagnosed with a myocardial infarction do not experience any chest pain [20,21] and the symptoms often differ from those expected by the patients [19,20,22]. Even the spouse whose husband had a myocardial infarction one week earlier did not classify the signs as cardiac, as the symptoms were different from the previous infarction. This was also described by Pattenden et al. [23] in a qualitative study of the decision-making processes among patients who had at least one previous myocardial infarction. They found that symptoms were often different from those experienced during the onset of the previous myocardial infarction and that the patients waited until a symptom in common with the previous myocardial infarction occurred before they sought care [23]. Spouses are important in the decision-making process [24] and as the decision to call for an ambulance is often difficult for the patients themselves, the spouse can take over responsibility from the patient and call for an ambulance [23,25]. The variety of symptoms and signs which may occur must therefore be explained to both parties following the first admission based on suspicion of a myocardial infarction.

Having experience of a previous illness sometimes led to the misinterpretation of symptoms and the use of old treatment strategies instead of seeking care. As pointed out by Pattenden et al. [23], patients attempt first to recognise and understand the signs and cope with the situation when experiencing symptoms. Uncertainty regarding the cause of symptoms was a common reason for delay in seeking care in a study conducted by Carney et al. [26]. They showed that those who did attribute their symptoms to their heart were four times more likely to seek care within 1 h compared with those who did not recognise their symptoms as heart pain. Delay in seeking care is a major problem not only for the risk of OHCA but also because treatment with thrombolysis must be given at an early stage for reducing the heart muscle damage and mortality [27].

In cases where the patient withheld information, the spouse had no chance of influencing the situation. We found these signs of denial in a few cases. Denial is a common coping strategy, which has been described by other authors [24,28,29]. The more threatening the situation is perceived to be, the greater the risk of the unconscious use of defence mechanisms aimed at neutralising the threat [28].

Being a witness when someone near and dear suffers a CA is a traumatic experience. A sense of unreality was described by many of the spouses. This is a normal reaction in severe crises designed to protect the individual [30,31]. The sense of unreality underpins the fact that the spouse experienced the situation as traumatic. They all perceived the seriousness and quickly called for an ambulance when they were unable to make contact with the patient. It is noteworthy that the detection of an absent pulse was not an issue in any of the cases in our study, even if a few spouses had tried to check for a pulse. These findings support those of Weslien et al. [11], who

found that family members understand the need for assistance when interpreting outer signs as serious. However, in their study, some of the family members rushed for help or started CPR even before they called ECS when they realised the seriousness of the situation.

The actions then varied. Some of the spouses saw no possibility for intervention when the patient appeared to be dead. This is in agreement with Swor et al. [10], who found that perceiving the patient as dead was one reason for not starting CPR. The possibility to influence the course of events when a person looks dead is not common sense but is conveyed in CPR courses. However, Swor et al. [10] found that many of those who were trained in CPR did not start CPR, especially if the training was outdated. Being in a state of shock easily leads to an inability to react correctly, but, according to the present study, this can be overcome by guidance from the ECS. We were surprised by the crucial role played by the ECS when helping a number of spouses to perform the appropriate actions. The spouses who were offered guidance felt encouraged and supported and no one was offended by being asked to start CPR.

4.3. Implications and further studies

The lack of and the difficulties in interpreting early warning signs clearly shows that the ongoing work of increasing the number of people trained in CPR has to continue. Nevertheless, as the greatest chance of survival exists when the CA never actually develops, people need to understand the signs that could signal an imminent myocardial infarction and seek care at an early stage when signs are present. CPR courses and cardiac rehabilitation programmes should therefore focus on knowledge of the variety of signs and symptoms that may precede an acute myocardial infarction, together with individual psychological factors and defence mechanisms.

Increasing the number of witnesses who can act and accept guidance from the ECS when a CA occurs is a challenge. Further studies are needed to find ways to support those people who do not see any possibility to influence the situation, as they perceive that the patient is dead.

5. Conclusions

Spouses who experienced OHCA demonstrated a lack of confidence in or ability to interpret early warning signs and symptoms. This lack of confidence also extended to the process of CPR. The support from the ECS and previous CPR training was acknowledged as helpful and important. Further research is required to determine which interventions can improve people's ability to intervene as early as possible.

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