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Relatives' experiences of unsuccessful out-of-hospital cardiopulmonary resuscitation attempts: a qualitative analysis

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Abstract

Aim Relatives of patients who have experienced an out of hospital cardiac arrest (OHCA) experience confusion and distress during resuscitation. Clear information from ambulance clinicians and the opportunity to witness the resuscitation helps them navigate the chaotic scene. However, UK-based evidence concerning relatives' experiences of unsuccessful resuscitation attempts and interactions with ambulance clinicians is lacking. This qualitative study explores those experiences to inform ambulance clinician practice.

Methods Two ambulance services in the UK identified OHCA events attended by their clinicians within the previous two weeks. After a minimum of three months relatives of non-survivors of these events were invited to participate in either a remote or face-to-face interview. Interviews focussed on their experiences of the resuscitation attempt and interactions with ambulance clinicians, their feelings at the time, and their reflections on the event afterwards. Data were analysed using reflexive thematic analysis.

Results Semi-structured interviews were conducted with 14 relatives of OHCA non-survivors. Thematic analysis identified four themes. Cardiac arrest is a traumatic event for relatives, with chaotic noisy scenes increasing their distress. Many described feelings symptomatic of Post-Traumatic Stress Disorder since the event. During resuscitation, participants needed information from clinicians about what was happening, and provided information about their relatives' wishes. Participants needed reassurance from clinicians that everything possible was done to save their relative and were reassured when they could witness some of the resuscitation. Participants were surprised how long resuscitation seemed to last; some were distressed that it lasted so long.

Conclusion Relatives' experiences highlight two key challenges for ambulance clinicians: (1) being aware of the tension relatives feel between needing reassurance that the crew is doing everything to save the patient and wanting to avoid prolonged and ultimately futile resuscitation attempts; and (2) having ongoing conversations with those present to inform clinical decision-making whilst managing the resuscitation attempt.

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Keywords Out of hospital cardiac arrest (OHCA), Resuscitation, Ambulance clinicians, Relatives

Background

According to NHS England, ambulance services attempt resuscitation in approximately 30,000 out-of-hospital cardiac arrests (OHCA) each year [1, 2]. In the UK, the Verification of Death in Adults guideline, previously called the Recognition of Life Extinct (ROLE) guideline, informs ambulance clinician decision making when attending OHCA [3]. The guideline indicates when cardiopulmonary resuscitation (CPR) should be started (or continued if bystanders have already begun), and whether clinicians should treat the patient on scene, transport them to hospital, or terminate resuscitation. Over half of all patients who have an OHCA in the UK are declared deceased at the scene [2]. Among patients where resuscitation is attempted up to 9% survive 30 or more days post-arrest [1, 2, 4, 5].

It is estimated that over 75% of OHCA occur in the home [6], meaning that relatives of the patient are often first on scene and may be required to perform CPR, liaise with emergency services, and witness the resuscitation attempt. Two recent reviews have explored relatives' experiences of emergency care and cardiac arrests. Satchell et al. synthesized 35 quantitative and qualitative studies of family and bystander experiences of emergency ambulance care, 17 of which (from North America, Scandinavia, France and Australia) focussed on OHCA [7]. They found that family members experienced confusion during the event, and were critical of poor communication from ambulance clinicians. Relatives accepted resuscitation being terminated at the scene when it was clear there was no chance it would be successful. A similar mixed-method review focussing on the experiences of relatives of survivors and non-survivors of both in- and out-of-hospital cardiac arrests also noted that clear information from clinicians and the opportunity to witness the resuscitation helped reassure relatives [8]. A synthesis of qualitative evidence on the presence of family members during invasive procedures and CPR found that relatives often acted as 'key informants', providing details about the patient to inform their care [9].

Qualitative studies focussing on relatives' experiences of OHCA events have predominantly been conducted in North America and Scandinavia and there is a lack of UK-based evidence in this area. This study is part of a wider mixed-method research project focussed on ambulance clinicians' decisions about when to continue and when to stop resuscitation of patients who have experienced an OHCA [10]. This qualitative study aims to explore the experiences of relatives of OHCA non-survivors, focussing on their experience of the unsuccessful resuscitation attempt and their interactions with the

attending emergency clinicians, to inform UK ambulance service practice.

Methods

Design

We conducted this qualitative study using semi-structured interviews. We worked within the critical realist paradigm underpinned by the assumption that participants' language reflects reality, but this reality is mediated by the interpretations of our participants and ourselves [11]. We focussed in depth on participants' lived experience of the resuscitation attempt, how they made sense of their experience and the meaning it holds for them [12].

Participants and recruitment

Two ambulance services in England identified patients who had an OHCA, over 18 years old, attended by their clinicians over an eight-month period. In our initial study design both OHCA survivors and relatives of non-survivors were eligible to participate, and we report efforts to recruit both groups. However, as no survivors volunteered, the study shifted in focus to relatives of non-survivors and unsuccessful resuscitation attempts. Survivors of cardiac arrest and their relatives suffer significant psychological issues with many having persistent symptoms three months after the event [13–15], therefore we waited at least three months before approaching potential participants. After the three-month period, the ambulance services accessed the patient's clinical record or their NHS Summary Care Record to obtain their contact information, or the name and address of their relatives, and wrote to survivors and relatives of non-survivors inviting them to participate. Information provided included the study aim, what would be involved, how they could withdraw, that they could have someone with them for support, and that they would receive a 'thank you' gift voucher for their time. A Patient and Public Involvement (PPI) group, who supported the wider research study, commented on the study design and patient-facing materials. Given the possible high drop-out rate, invitation letters were sent to 108 eligible people. We did not set a limit to the number of interviewees so that anyone who wanted to participate was given the opportunity to talk. A sample size of between 10 and 15 interviews with this specific target population, which are focussed in aim and quality of dialogue, should hold sufficient information power for in-depth analysis, and meet sample size parameters for data saturation [16, 17].

Procedure

As part of the sensitive interviewing process [18], participants were given the choice of a remote (telephone or online) or face-to-face interview. Prior to the start of each interview, the research aims and interview topics were discussed, reassurance was provided about the participants' right to stop the interview or withdraw from the research, and informed consent was recorded. Interviews were conducted by ER (a Research Nurse), JK (a Research Paramedic), or CH (a Research Psychologist) and lasted between 28 and 72 min (median=43 min). Interview topic guides were developed for this study (see [Supplementary Material](#)) by the study team, including a senior paramedic (MS). Participants were asked to describe what happened during the cardiac arrest, the actions of the ambulance clinicians, their feelings at the time, their reflections on the event afterwards, and what they would want others to learn from it. After the interview, participants were given contact details for organisations that provide support for people who have experienced cardiac arrest and bereavement. Interviews were recorded and transcribed verbatim.

Analysis

Data were analysed using reflexive thematic analysis [19, 20]. For each interview CH listened to the recording and closely read the transcript. Each transcript was inductively coded, using semantic and latent codes. Higher order codes were then assigned and these were organised into thematic clusters across the dataset. ER and JK reviewed the thematic clusters with CH to add interpretations based on their experience of conducting the interviews. The analysis was then shared with the rest of the study team, who provided critical feedback and additional interpretations, and the analysis was further refined.

Ethics

This study was reviewed and approved by the East Midlands - Derby Research Ethics Committee (REC reference: 19/EM/0358).

Results

Participant demographics

A total of 29 people (3 survivors and 26 relatives of non-survivors) expressed an interest in taking part. Fifteen potential participants, including all survivors, dropped out prior to interview by failing to respond after their initial contact. We conducted 14 interviews with relatives of non-survivors; 13 people were interviewed alone, while one couple was interviewed together. Most ($n=13$) interviews were conducted via telephone, while one was face-to-face. Participants lost their spouse/partner ($n=9$), parent ($n=2$), grandparent ($n=1$), cousin ($n=1$),

and child ($n=1$). We do not know the ages of two of the deceased, but of the remaining 12, four were over 80 years old, two between 70 and 80, five between 50 and 69, and one under 40. All cardiac arrests occurred at home; 10 resuscitation attempts were terminated at the scene while four patients were transported to hospital where they later died.

Thematic findings

We identified four themes. First, we report the participants' experiences of the trauma of the event as this influenced their descriptions of their interactions with ambulance clinicians. We then report the other themes: relatives need information and understanding but can also provide critical information to ambulance clinicians; relatives need reassurance that everything was done to save the patient; resuscitation went on longer than many participants expected or wanted.

Cardiac arrest is a psychologically traumatic event for relatives of the patient

All our participants described their relative's cardiac arrest as unexpected. Some occurred without warning, however it also felt unexpected for those whose relatives were in palliative care. Those who had time to plan for the death or accepted that their relative had the death that they would have wanted (e.g. in bed at home, or suddenly without pain) were able to rationalise the event afterwards. However, all participants described the psychological trauma they experienced because of their relatives' cardiac arrest: *"it's the worst possible thing that I think anybody could go through"* (Interview 14).

Many participants had to perform CPR while waiting for the ambulance, and described the horror of this, knowing that their relatives' life depended on them: *"it's a horrifying experience to think that you've got to keep this man going with CPR"* (Interview 13). Once ambulance clinicians arrived, participants described the scene of the resuscitation attempt as being crowded and noisy, with instructions shouted between different personnel, telephones left off the hook (after emergency dispatchers had ended the call), and the noise of resuscitation equipment: *"there was the, the awful noise of the machine that was doing the chest compressions"* (Interview 12). This noise added to participants' distress, and some wanted to stay away from the scene as a result.

Since the event, participants described experiences and feelings that are typically symptomatic of post-traumatic stress disorder. These included avoiding the place where the cardiac arrest happened, constant negative thoughts and questions, depression, anxiety, and re-experiencing the event: [21]

“you just relive it all the time, right? You relive, you know, how frail they were, hearing, you know, the cracks potentially of their ribs. [...] You relive the tiredness that, and the fatigue that you feel as you’re, you know, doing the chest compressions. You relive the hopelessness that you have [...] And you relive the, the pain of a body turning cold in front of you” (Interview 2).

While ambulance clinicians tidied the scene afterwards, occasionally pieces of packaging were left behind. As one participant explained, finding these triggered feelings of panic and distress:

“after they’d gone I did find a package some days later that the defibrillator pads had been in and things like that, which is (panicked noise) ‘ooh’ you know, an ‘ooh’ moment and I think perhaps [ambulance clinicians] just have to be mindful of the fact ‘have, have we moved everything?’ [...] it was just a, you know, it was only a pack, but it was still there, you know...” (Interview 7).

Due to the stress, shock and trauma of the event and aftermath, participants’ memory of it tended to be hazy. Participants were often aware of gaps in their memory or confusion when they described what happened: *“I honestly don’t know. I don’t remember. There is a lot of things that might be a bit of a blank” (Interview 1).*

Relatives need information and understanding, but provide critical information to ambulance clinicians

Participants told us that families need to have some understanding of what is happening to the patient, and what is likely to happen. They described needing information from ambulance clinicians about actions they had already taken and what else they could do. Information about the likely trajectory was important for participants to prepare for a possible negative outcome. Some described how clinicians implied this by asking them to summon relatives which suggested to them that they should expect bad news:

“they didn’t give any false hope, and I think that was wise. They just played it straight. The lady said ‘Get your family to the hospital’ and that told me everything about what was, what was potentially coming. And I think that was, that was it, just that one sentence was enough” (Interview 14).

However, others recalled how ambulance clinicians did not give them the information they wanted. One participant described being *“pushed”* away from her husband and into another room. She accepted this need for her

to be removed from the scene as the four attending clinicians needed space to treat her husband, and she felt that they were all working hard. However, she would have appreciated one of them talking her through their actions, so she had a sense of what was happening to her husband: *“when they pushed, told me to go out of the room, I wish one had come and said ‘Well, we, we’re doing this and we’re doing that.’ You know what I mean? Just for, for me to know what they’re doing” (Interview 13).*

Information and communication remained important after the event. Participants reported feelings of anxiety, regret, or guilt about different aspects of the event that they did not understand. For example, one participant did not understand why, after her husband died, the ambulance crew waited for five hours outside her house until the police arrived, while she lay inside on her own next to her husband’s body. Another participant described how no-one told her where her cousin’s body had been taken, which increased her distress: *“afterwards, we didn’t know where the body went [...] we were ringing round to find out what hospital. Surely it wouldn’t be a big thing to let the relative know what hospital” (Interview 4).* These participants indicated that clear explanations at the time would have helped ease their anxiety after the event.

Participants also described having information about the patient’s wishes and preferences, which was used (or could have been used) to inform clinical decision making. Some participants had had discussions with their relatives about resuscitation. One participant, whose husband was receiving palliative care, discussed the benefit of having had time to talk about his wishes in advance. She told the ambulance clinicians that he did not want to go to hospital, and that he had a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form. Ambulance clinicians terminated resuscitation efforts when this was produced, which enabled her husband to have a *“calm sort of end”* (Interview 11). Where the patients were younger or apparently in good health these explicit conversations had not taken place. However, participants talked about having some sense of what their relatives would or would not have wanted, which could have informed decision-making during the resuscitation:

“he was only 55 [...] So, I suppose we hadn’t necessarily had an explicit conversation, but I knew, I knew his, his views on, on those things like that. [...] I don’t think there’d be any consideration of not resuscitating at, at the age that he was. [...] he certainly very much wanted to live...” (Interview 12).

Relatives need reassurance that everything possible was done to save the patient

Participants described how they needed to feel that everything possible was being done to save the patient. While they were not always able to understand what was happening (either due to their distress or the lack of information given to them) they were reassured when they could see the ambulance clinicians doing things or when they were told that everything possible had been done:

"I wasn't in the room for long with them. With the paramedics. But, as I said, I could see the [defibrillator] machine was on him, so I knew they were doing their best." (Interview 13).

"he said, 'Don't worry, everything that he would've had in a hospital, we've got here.' So that was very reassuring, I really appreciated that." (Interview 12).

Most participants felt that the ambulance clinicians did do everything they could; they took charge of the situation, worked hard to save the patient, and treated the family kindly and professionally: *"I would give the ambulance service people absolutely top marks because they were very, very kind, very professional and tried their hardest to get my husband... to get his heart working." (Interview 10).* This was reassuring to participants as they dealt with the aftermath of the OHCA.

In contrast, one participant was critical of the ambulance clinicians. This participant described how the ambulance clinicians had exchanged "looks" early in the resuscitation which suggested to him that they were not expecting a positive outcome. He felt they had not communicated this to him, and thought they were 'going through the motions' of resuscitation when there was little hope of recovery for his grandmother: *"can I say they were unprofessional? No, absolutely not, they were thoroughly professional, but it also felt very perfunctory. [...] I didn't feel a sense of urgency" (Interview 2).*

Resuscitation went on longer than many participants expected or wanted

Most participants did not know how long the resuscitation actually lasted, however, many described how it felt like a 'long time' and was longer than they had expected: *"they were working on him for a long time, much longer than I expected" (Interview 1).*

Several participants said they 'knew' their relative had died before it was officially confirmed by clinicians: *"I really felt, in my heart, that she'd gone" (Interview 9).* In some of these cases participants felt that continued resuscitation prolonged their trauma and distress: *"when I come home I was saying to my husband 'They*

kept trying to save him, and I knew he was gone' so it was like, prolonging my agony" (Interview 5). One couple were unhappy that resuscitation was continued when they felt their relative had already died. While they accepted that clinicians had to follow their protocol, they were upset that their relative had endured treatment they felt was unnecessary. During the resuscitation, ambulance clinicians informed them that they had to continue resuscitation because the participants had already started bystander CPR, which created feelings of guilt, deepening their emotional trauma:

"I got very hysterical because they were saying, because we had started doing it [CPR], they had to carry on. So I was then blaming myself. [...] If we hadn't have done that, and she'd just died, she wouldn't have gone through the trauma of that 20 minutes, and neither would we..." (Interview 6).

Participants accepted that while they wanted every effort made to save their relative, resuscitation attempts could not last indefinitely. They discussed how the length of attempted resuscitation should be weighed up against a person's age and health:

"I think the context is important. Would I want resuscitation to be performed on one of my healthy family members? Absolutely. Would I want it to be performed on someone who is elderly? To an extent I would want to know that every effort was taken to recover someone, but I think it's a coin toss in my mind right now [...] as to whether or not I would want it to go on for as long as it did" (Interview 2).

The patient's dignity and expected quality of life if they did survive were also referenced in these discussions. Participants were certain that their relatives would not have wanted to survive if it meant living in a vegetative state or with prolonged suffering: *"I don't think he would have wanted to have come out of it and find himself having to suffer even more" (Interview 3).*

Discussion

Participants experienced the resuscitation attempt, interactions with ambulance clinicians, and the aftermath as traumatic. Our findings align with previous studies, which found that the relatives of patients who had an OHCA experienced clinically significant mental health consequences after the event [7, 14, 22–25]. Situational stressors (such as noise and leftover equipment packaging) compounded the distress participants experienced both during and after the resuscitation. This suggests the importance of ambulance clinicians addressing relatives'

distress by attending to their needs during the resuscitation attempt and in its immediate aftermath.

Mirroring previous research into both in- and out-of-hospital cardiac arrests, our participants noted that witnessing some of the resuscitation attempt and receiving clear information from ambulance clinicians helped them understand what was happening, feel reassured that clinicians were doing their best, and prepare themselves for their relative's death [8]. However, while participants needed to feel that everything possible had been done to save their relative, they also felt that prolonged resuscitation attempts were distressing if it seemed their relative had already died. This highlights the delicate balance clinicians need to achieve when negotiating and explaining the uncertainties and dilemmas presented in OHCA events. Family members' care needs have been previously identified, including clear communication and extended emotional support [8, 26, 27]. Paramedics consider communication with relatives during resuscitation to be extremely important [28]. However, when faced with a stressful and fast-moving scene, cognitive overload and the affective challenges presented by distressed relatives can negatively impact the quality of this communication [28–32]. Future research should explore ambulance clinicians' confidence in their communication skills in such situations to establish whether they may benefit from more training in this area, to support effective communication with relatives on scene.

Ambulance services could both attend to relatives' distress and improve communication by adopting a family-centred care approach. Family-centred care (which originated in paediatric services) views the whole family as care-recipients, not just the patient [33]. In terms of prehospital care this could involve: naming a dedicated ambulance clinician whose role is to communicate with the family, or (if this is not possible because of a lack of resources) clinicians narrating their actions and decisions using lay language; providing emotional support by remaining calm and asking empathetic questions; allowing relatives to be close to the patient if they wish; and debriefing the family after the event [8, 34].

Strengths and limitations

This is the first study of the experiences of relatives of OHCA non-survivors in the UK. A strength is the focus on the unsuccessful resuscitation attempt and interactions with the attending emergency clinicians, and how these impact the trauma and distress relatives experience after the event. Our research is limited by the fact that only a select group of people will volunteer for interviews on this topic; many people may not wish to talk about the death of a family member. Therefore, our participants may not be representative of relatives of patients who had an OHCA. We could not collect data on people who

expressed an interest in participating but did not complete an interview, so we cannot explore whether there were any differences between this group and the participants. Furthermore, no cardiac arrest survivors or their relatives volunteered to participate in the study. Research has shown that after a cardiac arrest survivors experience confusion and anxiety caused by a changed body, memory loss, and the disconnect between the past and the present [22]. Future research would benefit from including survivors and relatives of OHCA survivors.

Conclusion

Relatives of non-survivors of an OHCA needed to feel that ambulance clinicians had done everything possible to save the patient. However, prolonged resuscitation attempts were distressing, particularly when they believed that the patient had died. Relatives needed dialogue with the ambulance clinicians about what was happening, what was likely to happen, and what the patient's wishes were. This highlights two key challenges for ambulance clinicians during OHCA when relatives or someone close to the patient is in attendance: being aware of the tension relatives feel, between needing reassurance that the crew is doing everything to save the patient and the distress caused by prolonged and ultimately futile resuscitation attempts; and having ongoing conversations with those present to inform clinical decision-making.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12873-024-01117-4>.

Supplementary Material 1

Acknowledgements

Not applicable.

Author contributions

CH developed the interview topic guide, conducted interviews, analysed the data and wrote first draft of manuscript. ER conducted interviews, contributed to analysis and interpretation, and has edited the paper for critical academic content. JK conducted interviews, contributed to analysis and interpretation, and has edited the paper for critical academic content. KE developed the interview topic guide, contributed to analysis and interpretation, and has edited the paper for critical academic content. GG contributed to analysis and interpretation, and has edited the paper for critical academic content. GDP is the co-chief investigator for the study. He designed the study and has edited the paper for critical academic content. MS is the co-chief investigator for the study. He designed the study and has edited the paper for critical academic content. RF was a co-applicant for grant funding. She designed the study, and has edited the paper for critical academic content. AMS was a co-applicant for grant funding. She designed the study, developed the interview topic guide, contributed to analysis and interpretation, and has edited the paper for critical academic content. FG was a co-applicant for grant funding. She designed the study, developed the interview topic guide, contributed to analysis and interpretation, and has edited the paper for critical academic content.

Funding

This article presents independent research funded by the National Institute for Health Research (NIHR) under the Health Services and Delivery Research Programme (project number 17/99/34). The views expressed in this

publication are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

Data availability

Although data in this qualitative study were pseudonymised, it is possible that with access to raw data individuals might be identifiable from participants' descriptions of events. The data are highly sensitive and not suitable for sharing beyond what is contained within the manuscript. Further information regarding this can be obtained from the corresponding author.

Declarations

Ethics approval and consent to participate

This study was reviewed and approved by the East Midlands - Derby Research Ethics Committee (REC reference: 19/EM/0358). Participants provided informed verbal consent for remote interviews and informed written consent for the face-to-face interview.

Consent for publication

No identifiable individual information is included in this manuscript.

Competing interests

RF, MS, A-MS and FG have been awarded research funding from the National Institute for Health and Social Care Research. KE has been awarded funding from the Medical Research Council. GDP has been awarded research funding from the National Institute for Health and Social Care Research, Resuscitation Council UK, Laerdal Foundation and British Heart Foundation. GDP is a trustee for the Resuscitation Council UK, holds other volunteer roles with the European Resuscitation Council and International Liaison Committee on Resuscitation, and is an editor for the journals *Resuscitation* and *Resuscitation Plus*. GDP is supported by the National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) West Midlands. A-MS is a member of Resuscitation Council UK's ReSPECT wider stakeholder group. The remaining authors have no competing interests.

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Received: 7 August 2024 / Accepted: 17 October 2024

Published online: 05 November 2024

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