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Clinical paper

A qualitative exploratory case series of patient and family experiences with ECPR for out-of-hospital cardiac arrest



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Abstract

Objective: There is currently no existing data examining the opinions of patients and families after treatment with extracorporeal cardiopulmonary resuscitation (ECPR) for out-of-hospital cardiac arrest (OHCA). We sought to interview family members and patients to learn from their experiences and satisfaction with treatment.

Methods: We contacted family members and survivors for all cases treated with ECPR for refractory OHCA at St. Paul's Hospital between January 2014 and July 2018. We performed semi-structured interviews with participants, specifically within the topics of: information sharing (including impressions of an ECPR informational pamphlet), prognostication, organ donation, and perceived value of ECPR. Due to low participant enrolment, we described all interviews in a narrative approach.

Results: Within the study period, there were 23 OHCA treated with ECPR; two survivors and three family members agreed to participate. Participants were satisfied with the treatment provided, including information sharing and prognostication. There were mixed opinions about the best method of information-sharing (verbal vs written), as well as the timing of organ donation conversations. All participants believed ECPR for OHCA to be of high value.

Conclusion: Patient's conveyed satisfaction with ECPR treatment, with mixed views on the best information sharing strategy. Further study is needed to define the optimal methods and timing for discussions of organ donation, especially for treatments of with a relatively low likelihood success.

Keywords: Extracorporeal membrane oxygenation, Extracorporeal cardiopulmonary resuscitation, Heart arrest, Out-of-hospital cardiac arrest, Cardiopulmonary resuscitation

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<http://dx.doi.org/10.1016/j.resplu.2021.100129>

Received 30 December 2020; Received in revised form 14 April 2021; Accepted 15 April 2021

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Introduction

Extracorporeal membrane oxygenation (ECMO) provides hemodynamic support to cardiac arrest patients (called extracorporeal cardiopulmonary resuscitation, “ECPR”).^{1–3} The initiation of ECPR for out-of-hospital cardiac arrest (OHCA) requires emergent candidacy assessment and transport to hospital for rapid ECMO implantation, with intensive critical care management over the subsequent hours and days; despite these efforts, mortality is high.^{3–6} Post-ECPR recovery also includes physical and psychological challenges requiring rehabilitation.^{7,8} While there are data describing experiences of those affected by cardiac arrest,⁹ none specifically examine those affected by ECPR, a complex therapy which may pose unique challenges for communication with patients and families. We sought to learn from the experiences of those impacted by ECPR, especially pertaining to: information sharing, prognostication, organ donation, perceived value of ECPR.

Methods

Study design and setting

This qualitative study retrospectively identified cases treated with ECPR for OHCA at St. Paul’s Hospital (January 2014–July 2018), and invited survivors and family members to be interviewed. The St. Paul’s hospital ECPR protocol involves prehospital identification of select OHCA, with transport to hospital for ECPR initiation in the emergency department (ED), and ongoing cardiac surgery intensive care management.¹⁰ This study was approved by the University of British Columbia research ethics board.

Recruitment and consent to participate

A St. Paul’s Hospital administrator contacted each potential participant (by mail and/or telephone) to request permission to provide contact information to the study team. A research team member contacted consenting individuals to provide study information and obtain consent. Interviews were offered in an individual or group format.

Clinical case data collection

We collected clinical data describing basic cardiac arrest case details, and outcomes (classified by cerebral performance category [CPC] scale at hospital discharge)¹¹ through a chart review of the participant’s medical record.

Qualitative data collection

We conducted in-depth semi-structured interviews using an interview guide (Appendix A), employing a qualitative descriptive approach, allowing the interviewee to guide the conversation while providing direction around certain topics.¹² This approach has been used for understanding intimate perspectives on the delivery of emergency health care.¹³ Interviews were audio recorded (and transcribed verbatim) and supplemented with field notes to collect data such as social dynamics and emotional aspects.¹⁴ Interviews were conducted by A.S., a clinical counselor and clinical psychology

PhD student. For survivors, discussions focused on their experiences with information sharing and impressions of ECPR value (including quality of life for the patient). For family members, discussions focused on information sharing (and the value of an ECPR informational pamphlet [Appendix B] created for this study [was not utilized during clinical care of these patients]), prognostication, organ donation discussions and timing, and perceived value of ECPR (the interviewer shared details of the cost-per-patient and typical success rates). For relatives of non-surviving cases, we sought opinions regarding whether the chances of success were worth the attempt, and whether there may have been other benefits such as time to deal with the situation or the possibility of organ donation. The selection of follow-up questions, question order, and phrasing varied according to each participant’s narrative. An ECPR survivor assisted in the development of the project. Data was managed using NVivo12 qualitative software.

Data analysis

Data analysis occurred in conjunction with data collection in order to continuously monitor emerging patterns and areas for further exploration.¹⁵ We had planned, *a priori*, to use the emerging coding framework to guide a de-novo analysis of the entire data corpus for overarching themes,¹⁶ however, due to low participant enrolment we elected to instead use a narrative style case study approach to present the clinical cases and highlight important insight shared by each interviewee. The dataset was analyzed inductively and coded by one author (KND). Results were discussed iteratively with the team which acted similarly to having additional coders, as team members were equally familiar with the transcripts (given only three cases).

Results

There were 23 ECPR-treated OHCA during the study period, of whom 12 did not respond to phone/mail communications. Potential participants from eight cases agreed to be contacted by the research team, of whom three declined to participate (for one case the next-of-kin was not involved in the hospital course, for one case the individual was not local and did not want a telephone interview, and the third did not provide a reason) and five did not respond to communications. Individuals connected to three cases (two survivors and three next-of-kin) agreed to participate. There was a minimum of 12 months between the cardiac arrest and interviews.

Case A

Paramedics treated a previously healthy male (Mr. A) in his 30’s with decreased level of consciousness after exposure in a cold environment (temperature 27°). Cardiac arrest occurred during scene extrication; initial rhythm was non-shockable. ECMO was initiated in the ED after 2.6 h of CPR. He was treated with ECMO for 2.4 h, successfully weaned, and discharged from hospital after nine days with no neurological deficits (CPC 1).

Interview with the patient (37 min; hospital conference room)

Mr. A had no recollection of his event until he woke up after five days in hospital. He did recount a nurse being readily available who provided him with all needed information. He was candid to say the information was a lot to take in after just waking up.

"I mean I'm not saying that this is not nice to know or maybe like when you leave the hospital, it's like okay hey, this is what they did to you to kind of save you, but . . . I mean like you're pretty weak after that . . . you kind of like you have more immediate concerns"

He thought the information pamphlet about ECMO would have been really good for his family to know what was going on. However, he was bothered by the organ donation information.

"I don't think that when, you know, like your loved one's life is sort of hanging in the balance and you don't know what's going to happen, like I don't think organ donation talk is like the best thing." [Mr. A]

He stated his family was very stressed about the possibility of him needing long-term care and that bringing up organ donation would have put them "over the edge". He thought that hearing statistics could be traumatizing. To this day, whenever his family and friends talk about his arrest, it is the chance that he might have died or had severe brain damage that really shakes people up. He is thankful for his ECPR treatment and views it as a valuable treatment option, even in view of the costs.

Interview with the patient's mother (59 min; phone interview)

Mr. A's mother expressed that the care her son received and the information provided was excellent and appropriate. She was grateful that he had been chosen for ECPR treatment, felt that it was responsible for his survival, and has since become a very strong advocate for the technology. She felt the costs and outcomes were appropriate. However, she did not feel the informational pamphlet was ideal, as was overly complicated and it was inappropriate to ask families to focus on something as complicated as ECMO at such a stressful time.

"The word of a human being to emotional disturbed loved family member is hundred thousand times more important than giving him piece of paper, and saying "Go and read"." [Mr. A's mother]

She had discussed organ donation with her son's care team as he had thankfully regained neurological function. However, she felt that it would have been very upsetting and "unethical" if anyone had approached her about organ donation.

"Because my son was still alive and a mother has a hope that he will get out of it and it wasn't time to talk about organ donations because if doctor opened his mouth or her mouth asking me about the organ donations, to me it signs of two things. First, they've given up. Second, they're more interested in that patient organs than bringing him to life. I knew his condition and as horrible and awful to say but there are people who prefer to keep their loved ones by years on these machines. I'm not the one. But I did believe that it was not his time." [Mr. A's mother]

Case B

Mr. B, a long-distance runner in his 60's with a history of coronary artery disease and ulcerative colitis, had a witnessed arrest at work soon after exercising. Bystander CPR was performed. Upon paramedic arrival the cardiac rhythm was ventricular fibrillation however defibrillation was unsuccessful. The patient was transported

to hospital and initiated on ECMO (9-1-1 call-to-ECMO 59 min; ED arrival-to-ECMO 16 min). He received a stent to the LAD, was weaned from ECMO after 2.8 days, and discharged from medical care after 120 days (CPC 2).

Interview with the patient & his sister together (46 min; hospital conference room)

Mr. B and his sister were interviewed together. Mr. B had a longer recovery after his cardiac arrest, with three months prior to discharge home. He has little memory of his time in the critical care ward. His sister stated that they received a lot of information during ECMO treatment, although it was difficult to process at the time. She repeatedly mentioned that the nurses were incredible sources of information.

"I think they were doing the best they could as far as relaying information, but again, like just emotionally it was hard to suck up a lot of what they were – you know, you'd listen and then if you asked me to repeat what they were saying it's like, "Huh?"." [Mr. B's sister]

When shown the information pamphlet Mr. B's sister said "I would have loved to have this!" because it would have been something to refer to when things were less stressful. She mentioned that she got most of her information about cardiac arrest and ECMO at a St. Paul's information function subsequent to her brother's event. She clearly remembered having the conversation about prognostication and possible organ donation while Mr. B was still undergoing treatment. When asked about the timing of the conversation she said it was absolutely fine, and necessary to talk about (despite that she and Mr. B had not talked about it previously). They both felt it was a very important conversation but that the message delivery had to be very careful to be well accepted at that stressful time.

Regarding costs and outcomes, Mr. B and his sister were asked if they felt ECMO was worth doing, they both agreed emphatically.

". . . I think anything I mean to save a loved one, absolutely it's . . . and you know what, as far as the medical team goes, every time they use this, if it fails or if it succeeds, like it's a learning curve for them too and if you don't try you don't know." [Mr. B]

Case C

Mr. C was a previously healthy man in his 60's who had a witnessed OHCA with bystander CPR. Initial rhythm was pulseless electrical activity. The patient was transported to the ED with ongoing resuscitative efforts. ECPR was initiated (9-1-1 call-to-ECMO 55 min; door-to-ECMO 16 min). Adequate ECMO flows were unable to be achieved and thus ECMO support care was withdrawn. An autopsy showed aortic dissection.

Interview with family member (47 min; phone interview)

The partner of Mr. C explained the story of her husband's collapse at home. At the hospital there were a lot of people in the room and she remembered someone mentioning her husband was on ECMO. She knew what ECMO was because of her medical training (not because they explained it to her). "It was a blur," she said, and that all of the information she received was verbal. She commented that consent for

ECPR should be assumed and that most people in her position would just want whatever could be done to save their loved one's life.

"Do whatever you can to save my loved one's life. Just do it . . . I think we cover our asses too much with all this medical/legal crap, and I think that if you're trying to save somebody's life, go ahead and save their life. Your explanation probably wouldn't be understood by the person at that time anyway because they're in such a state of mind that they are not in – like they can't absorb everything you're saying." [Mr. C's partner]

Regarding prognostication and she appreciated being kept well informed by the physician in charge. When the decision was made to transition the focus of care to comfort measures, she felt prepared to make the decision, but was aware that her medical training likely came into play. She had voiced her support for donating her husband's organs, and that having her husband on ECMO prolonging his life made her think about it proactively. She did not feel that there would have been a conflict of interest created by the physicians bringing up organ donation during the initial treatment phase—it was clear they were trying to save his life. Regarding raising the issue of organ donation at the beginning of ECMO she said "I think that would be a little harsh" but did say that once she saw her husband on ECMO she realized the seriousness of the situation and that he might not survive.

Within a discussion of ECPR value, the interviewer described that only 2 out of 10 patients placed on ECMO survive and that each time the treatment is used the cost is approximately \$50,000. Her response was clear

"My husband was worth \$50,000, and 2 out of 10; at least there's 2 that survive and live. And every time they do ECMO I'm sure they're learning from it and improving, and I expect over time those numbers would go up. So absolutely it's worth it." [Mr. C's partner]

Discussion

The objective of this study was to better understand the experiences with information sharing, end-of-life care, organ donation, and perceived value of ECPR of patients and families treated by ECPR for OHCA. We used a unique case series approach to provide a description of the patient and family experience and insight on types of information provided within an ECPR program for cardiac arrest.

Although our results are limited by sample size, family members interviewed were satisfied with access to information. There was variability in desired information-sharing medium (verbal vs. paper-based) and timing (upfront detailed information vs. delayed). Overall, participants felt that the ECPR information pamphlet would have been helpful for family members, although one did raise concerns about language complexity. Tramm et al. interviewed 10 family members of ECMO-treated patients, some with cardiac arrest, and reported the most important theme was communication from the medical team.¹⁷ Similar to our results, the desired type of information provided varied, with some individuals wanting detailed information such as how ECMO worked and long-term consequences, and others feeling that these details were too complex and overwhelming, preferring basic information with estimates of short-term (i.e. daily) outcomes. Family members of ICU-treated patients have indicated similar results.^{18–20} Offering several options for

information sharing, including differing mediums and depth of information, may be the optimal solution.

Similarly, there was variation in participant perspectives on the best timing and method of providing information on organ donation. This is complex, with medical teams often preferring to wait until a declaration of futility to avoid perceptions of conflicts of interest.²¹ This is important for high-mortality ECPR cases, many of whom may be potential donors however who may rapidly decompensate with little time for organ donation assessment. Organ donation information in the ECPR informational pamphlet potentially "decouples" discussions of patient treatment and organ donation—such that next-of-kin can obtain early information about organ donation, but that treating providers can avoid becoming involved in this discussion until actual prognosis is known.²² From 228 cases classified as brain dead, de Groot et al. investigated the timing of organ donation discussions over a 20-year period.²³ While initially organ donation was only raised in 13% of cases prior to brain death determination, in the second decade organ donation was discussed prior to declaration in 82%. One study of 420 potential organ donors found no association between consent rates and the timing of the first donation request.²⁴ The topic of timing of organ donation conversations, especially in cases undergoing active dynamic treatment but with a low likelihood of success, requires further research to ensure appropriate messaging to safeguard against misinterpreted intent.

Participants in our study felt that ECPR was worth providing, despite a high upfront cost and relatively low success rate, and that the processes that they and their loved ones went through were worthwhile, given the potential for survival regardless of the actual eventual outcome. One investigation evaluated the benefit and cost-effectiveness of ECPR for OHCA, reporting that ECPR was associated with improved neurological outcomes with a cost per life-year gained of \$28 792, which is typically considered cost-effective.²⁵

Haydon et al. published a systematic review of the qualitative literature exploring the experiences and quality-of-life of survivors of a cardiac arrest.²⁶ Their synthesis highlights the complexity of survivorship after cardiac arrest and underscored both the psychological and physical changes influencing survivors' perceptions of quality-of-life post-arrest. Surviving a cardiac arrest is a major event for all involved and the experience of the first few days and weeks can be the most traumatizing and overwhelming time, especially when extensive and invasive treatments are required. It is our hope that by presenting these patient and family perspectives, we can highlight benefits and challenges of ECPR and the impact it has on the patient and family experience.

Limitations

This study is limited by small sample size and thus were unable to make robust conclusions with qualitative analytics, especially for non-surviving family members. The predominant reasons for refusing participation were unclear as the majority did not respond to communication attempts.

Conclusions

Individuals affected by ECPR may have different information-sharing preferences; several media options may be valuable. The timing of organ donation discussions is complex and with varying opinions.

ECPR was viewed as worthwhile among surviving and non-surviving cases, despite the high mortality. Incorporating qualitative analyses into ECPR research may enhance our understanding the impact of on loved ones, especially pertaining to communication and organ donation.

Authors contribution

BG, RM, JG conceived the study idea. BG applied for ethics. BG, RM, KM, SS, AC, JG designed the protocol with input from all authors. BG and AC contributed to participant recruitment. AS performed interviews. KD and AS performed qualitative analysis. BG collected clinical data. BG drafted the manuscript. All authors contributed to interpretation of data, manuscript revision and final approval.

Funding

Canadian Institutes of Health Research, MOP-133509.

Conflicts of interest

BG has received speaking honoraria from Stryker Corp.

Acknowledgements

We would like to thank Chelsie Thurlow for her input in our study design, the contributions of Helen So, as well as the efforts of all individuals from St. Paul's Hospital and BC Emergency Health Services in the ECPR program, especially Drs. Bashir, Boone, and Abel, Luke Harris, Brian Twaites, Sarah Carriere, Tanya Campbell, and Ron Straight.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.resplu.2021.100129>.

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