

PERSONAL NARRATIVE

How Can We Make Out-of-Hospital CPR More Family Centered?

Caroline Mawer, MRCP, MBBS, MSc, MFPH

Abstract

This personal narrative examines what physicians owe patients in ways that might be just as novel as any new technology for cardiopulmonary resuscitation (CPR). The narrative uses the actual words of Linda (not her real name), a woman who had to lead CPR on her mother. Rather than concentrating only on CPR, the narrative also discusses what happens—and does not happen—before and after an out-of-hospital cardiac arrest. Linda's story suggests possible ways to take better care of terminally and chronically ill patients at home: by listening in different ways to patients and families.

Unsuccessful Cardiopulmonary Resuscitation at Home

Contrary to public expectations, cardiopulmonary resuscitation (CPR) after out-of-hospital cardiac arrest leads to long-term survival in only a small minority of people.¹ Sicker and frailer patients have even worse survival rates.² Research suggests that even doctors don't always accurately estimate cardiac arrest survival.³ Perhaps this is why Americans talk about do-not-resuscitate (DNR) orders: these orders reinforce the "rescue fantasy"⁴ that resuscitation will always be a possibility.

I'm a family physician in the United Kingdom (UK). Here we have perhaps more realistic do-not-attempt-cardiopulmonary-resuscitation (DNACPR) orders.⁵ I think this shift in language can help patients, families, and doctors understand what's at stake. Even so, when I surveyed my colleagues, they also had limited knowledge of true survival rates after out-of-hospital CPR.⁶

I mainly work out of hours, and I most commonly encounter sequelae of CPR when I am asked to declare death after an unsuccessful resuscitation. I am typically invited into homes where I see frail, elderly, palliative care patients lying dead on the floor with their clothing in disarray and an intubation tube still protruding from their mouth. Some of these CPR attempts could have been predicted to be futile.⁷ To me, it often feels that many are worse than futile. Family members are understandably distressed not only by what happened during the death itself but also afterwards, when it's difficult to say goodbye to a medicalized corpse. I am frequently told: "At least everything was done." I nod respectfully, but privately I sometimes think, "What about sitting with your relative,

holding hands, and telling her you love her?” That’s surely another sort of “everything” that might have been done.⁸

With all this in mind, I wanted to expand on my clinician survey by exploring the views of patients and the public on out-of-hospital CPR. Therefore, when I was volunteering with a UK end-of-life charity,⁹ the charity’s supporters were emailed a modified version of my previous questionnaire. Of course, this convenience survey cannot produce quantitative results. However, it has suggested some key issues. Mirroring findings in a literature review,¹⁰ my respondents’ most common concern was that they might be subjected to CPR against their wishes. Several respondents also wanted to tell me what had happened to members of their family and how upsetting these deaths had been. I focus here on one response, from Linda (not her real name). Her story illuminates fundamental ethical principles at stake in out-of-hospital CPR. Specifically, it suggests that improving patient-clinician communication about end-of-life care and better respecting patient dignity at the end of life could support alternatives to futile CPR.

Linda’s Story

I’m a trained first aider. My mum [mother] had lived alone since Dad died. She had always been independent, but she had 4 chest infections in a row last winter, so I was staying with her. The problems with her chest were getting her down. She told me she was fed up with life, so I asked for a nurse to come round to assess her. Anyway, she went to the toilet, and I felt she was gone too long. When I went to check, I found her collapsed.

Faced with that situation, instinct and training kicked in. I got her onto the floor, rang for the EMS [emergency medical services], and started CPR. I know I broke her ribs—I felt a horrible, sickening crunching as they snapped under my hands. It was nothing like the dummy we’d practiced on.

The doctors in the emergency room told me it was common in elderly people, but they never teach you that in first aid courses. And it was all so undignified, squashed in her hallway, and me knowing all the time that if I revived her she would probably never forgive me.

I don’t know how long the EMS took to arrive, but it felt like forever. I was glad to hand Mum over to the professionals and did my best to pull her pants back up and try to restore at least a little dignity to her. They applied the paddles and got her heart beating. But I couldn’t tell the EMS [staff] that I wanted to let her go. That I knew my mum. That I knew there was no way she would want to live the remainder of her life no longer capable of being independent.

She was unconscious, but they got her stable enough to transport her to hospital. I left in my car at the same time but arrived at the hospital before them. When they rushed her into the emergency room, the EMS staff told me that I’d given her the best possible chance of survival, but her heart had stopped again on the journey and they’d had to resuscitate her again.

The EMS staff were brilliant. But on the way there I'd had time to think. Mum had managed to plan her funeral—she'd even written down what she wanted to wear, what to place in her coffin, and the exact service she wanted because she'd been so impressed with Dad's funeral.

But we hadn't thought about the actual dying. And nobody teaches you the words to say when you want the doctors to let somebody go. Not to resuscitate them if their heart stops again. It was not an easy decision but I knew it was right. Your head is saying "let her go" but your gut is churning and you desperately don't want her to die. You also do worry about what the doctors will think of you—will they think you don't care? Will they try to persuade you to change your mind when it's already the most difficult decision you've ever had to make?

I could bear that the professionals might think badly of me. But I couldn't bear that my mum would hate me for keeping her alive without being fully restored to health and fitness, and I just knew no doctor could do that. They agreed to make her comfortable—to not try resuscitating her again—and see how she fared through the night.

I was called back to the hospital at 4:30 the next morning, as they thought the end was near. The doctors told me her body was shutting down. The decision to turn off the life support machines was easy, as was the decision to donate her corneas. If something good was going to come out of tragedy, that was a comfort. I held her hand as she passed away. But by the time I said the words I'd always wanted to say, my mum was unconscious. I've been told that hearing is the last sense to go so I like to think she did hear.

No one wants their mum to die. But who wants their mum to suffer? I loved my mum enough to try to save her. But I also loved her enough to let her go.

Learning From Linda

As a physician, I've been privileged to have heard many personal stories. Linda's narrative is exceptional. I felt that she was writing primarily as her mother's protective and loving daughter as well as implicitly reflecting on the almost-inevitable power imbalance in patient-physician relationships.

Linda wrote that this was the first time she had ever shared her story with anyone. Two years after the events she described, she was still worried that the ribs she had broken had contributed to, or even caused, her mother's death. I wrote back to her how sorry I was, not only about what happened to her mother but also that she had to do all this by herself. I reassured her about her mother's ribs. I told her that I admired her bravery both in trying to save her mother and—even more difficult—in letting her mother go.

We emailed back and forth several times, and Linda told me how keen she is on clinicians being able to learn from what happened to her and her mother. I have removed the most undignified parts of her story and made some small changes so that Linda and her mother cannot be identified. Otherwise, you have read Linda's own words.

Before, During, and After CPR

Much of the literature ignores the harsh reality of many out-of-hospital cardiac arrests. Guidelines,¹¹⁻¹³ ethical analyses,¹⁴⁻¹⁸ and the rest of the significant literature¹⁸⁻²² primarily discuss autonomy issues concerning family involvement during CPR. Inevitably, though, family members are likely first responders.²³ Theoretical musings are pushed aside when, as Linda describes, “instinct ... kick[s] in.” This is almost inevitably the case when emergency situations have not previously been contemplated.

What happens after any return of spontaneous circulation (ROSC) is another unpleasant and rarely discussed reality.²⁴ There are few investigations of ROSC that do not focus simply on survival or the adverse effects of CPR. A rare Midwestern study of those whose death terminated a post-CPR admission found that roughly 84% of patients died either after life support was withdrawn or while it was ongoing. Median survival time after a heart was restarted was only 1.5 days.²⁵ Linda’s mother fits this pattern.

The time before the CPR, the years and months when chronic diseases or cancer become more burdensome and treatments become less curative, is an obvious opportunity for intervention.²⁶ Over the course of one winter with 4 chest infections, Linda’s mother was given a range of medical treatments. Sadly, however, there was no effective consideration of advance care planning. Linda’s mother actually told Linda that she was “fed up with life,” implying that she might well have chosen a DNACPR if this option had been discussed.

Berry’s “imaginary inquiry” into an unsuccessful CPR attempt underlines how many physicians apparently think it is **not the right time** or that they are not the right person to start important conversations touching on death.²⁷⁻²⁹ Although some physicians worry that these conversations are difficult,^{30,31} consider how even more difficult it was for Linda, standing in an emergency room with her unconscious mother. Linda had to lead—in a situation that was extraordinarily challenging.

Applying Lessons Learned From Linda to Your Own Practice

Linda’s story provides clues to some potential ways forward for clinicians when working with individual patients and their families on advance care planning.

Linda’s narrative of what it can be like for families during and after CPR underlines the importance of all clinicians using **guidelines for advance care planning** and decision making (including for DNR or DNACPR orders) and physician orders for life-sustaining treatments.³²⁻³⁵ When we listen and respond to people who don’t want CPR, we can make out-of-hospital deaths more family centered. Linda’s worries about what happened when she attempted to resuscitate her mother should also prompt clinicians to actively listen for family members’ expressions of feeling traumatized and regretful after a CPR attempt.

Linda and many of my other respondents didn't even try to answer most of my questions. They were not interested in numbers, even though quantitative analyses are often a focal point for clinicians. Instead, my respondents focused on what was important to them. I think this practical focus underlines the limitations of some decision aids, even when supported by detailed data.³⁶ Using a scenario analysis to consider the best, worst, and most likely cases may offer a useful alternative approach to emergency care planning for individuals and families.³⁷

Returning specifically to Linda, her biggest regret was not her mother's medical care but that she hadn't said what she'd "always wanted to say." This sort of thing can't be assured even with the best guideline or advance directive, and it would not have been identified in any routine audit of the CPR attempt. What Linda's story suggests is that we need to listen differently. For example, we could explore the times things go well, from a family point of view, in as much detail as we investigate problems from clinical or systems points of view. Thinking hard about what went as well as possible could help clinicians learn how to make things as good as possible (rather than merely reducing errors) in their end-of-life cases. One junior hospice physician, Nishma Manek, is already doing something similar by diminishing focus on "fixing what is in my control."³⁸ For example, instead of looking only at blood pressure, pulse, and lab results, Manek focused instead on understanding what was important to her patient when she worked out that the most valuable thing she could do was to get this patient a bucket of fried chicken. An emergency room physician, Andre Kumar, broke the algorithm rules when he asked a patient with recurrent chest pain what he wanted, then set up a system that avoided the revolving door of repeated admissions.³⁹

As we acquire new and more technical skills, some of us might begin to devalue understanding, empathy, and imagination.⁴⁰ But we don't have to do this if we step back and listen in different ways to patients and families. We can listen and hear when people like Linda's mother are "fed up with life" and recognize that, however uncomfortable we might think talking is, we *are* the right person, and it *is* the right time to consider advance care planning. We can remember how Linda sat and held her mother's hand as she died. And we ourselves can sit with those who have no loved ones to do this for and with them.⁴¹ More fundamentally, we can look beyond Linda's regret and distress and help families and communities develop ambitions beyond Kellehear's "healthy dying."⁴²

Death is an inevitable part of the cycle of life. Clinicians have a duty to at least not make death worse and preferably to make it better for patients and families. If we personalize our listening and really hear patients and families, we can help make deaths as personal and even good as lives can be.

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Caroline Mawer, MRCGP, MBBS, MSc, MFPH is a physician and multimedia artist who has been interested in patients’ last years of life since her first job working with AIDS patients in the years before effective treatments were discovered. She has cared for patients in Siberian tuberculosis prisons, on the island of Montserrat, and in the United Kingdom. Time with her with her terminally ill father helped shape her orientation to practice.

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