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"To Be or Not to Be"—Cardiopulmonary Resuscitation for Hospitalized People Who Have a Low Probability of Benefit: Qualitative Analysis of Semi-structured Interviews

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Abstract

Purpose. Our aim was to understand the decision making of patients in hospital who wanted cardiopulmonary resuscitation despite low probability of benefit. **Methods.** We included patients admitted to general medical wards who had a low chance of surviving in-hospital cardiopulmonary resuscitation (CPR) and had an order in the chart to administer CPR. We developed an interview guide to explore participants' decision-making process, sources of information, and emotions associated with this decision. **Results.** We developed 3 themes from the data. 1) "Life is worth living . . . for now": Participants describe their enjoyment of life and desire to carry on in their current state. 2) "Making sense of CPR outcomes": Participants saw CPR outcomes as binary, either they live, or they die; deciding not to receive CPR means choosing death. Participants were optimistic they would survive CPR and cited personal experience and TV as information sources. 3) "Decision process": Participants did not engage in shared decision making. Instead, they were asked a binary yes/no question with no reflection on their values or discussion about harms or benefits. **Limitations.** The probability of successful CPR in our sample is unknown. Findings may be different in a population who is imminently dying but still requesting CPR. **Conclusions.** Participants chose CPR because they perceived life as worth living and CPR as a chance worth taking. Participants did not want to be left in a severely debilitated state but did not have accurate information about this risk. **Implications.** Decision making about CPR in-hospital can be improved if it is grounded in accurate risk understanding and the patient's values and wishes.

Keywords

CPR, shared decision making, risk understanding, patient values

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During cardiac arrest, cardiopulmonary resuscitation (CPR) can restart spontaneous circulation and prolong a person's life, but it is rarely successful for seriously ill patients in hospital. For example, an 85-year-old person admitted for pneumonia who has dementia and other comorbidities has less than a 1% chance of surviving to discharge with intact neurologic function after in-hospital CPR.[1,2] During serious illness when death is inevitable and time is short, most people express a wish for a peaceful end that does not include attempted CPR.[3] In contrast, others want all treatments administered to prolong

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life even if the probability of success is low.[4] For the medical team, being asked to administer CPR when it is unlikely to work can cause moral distress because they feel responsible for needlessly depriving their patient of a peaceful death.[5,6] Often, there is uncertainty if the request for CPR is grounded in an accurate understanding of prognosis and a desire to prolong life or denial of mortality and misunderstanding of CPR outcomes.[7] To our knowledge, no research has explored the decision-making process of people in hospital who request CPR in the event of cardiac arrest despite very low probability of benefit. Our team previously completed a randomized control trial of a decision support intervention that presented hospitalized patients who had already decided they wanted CPR but had low probability of success with probabilities of harm and benefit and a values clarification exercise.[8] We found no difference between groups in the proportion who chose CPR. The present study was motivated by a desire to understand our negative result and to understand more broadly why some people choose CPR despite a low probability of benefit. Furthermore, understanding requests for treatments that offer little benefit could help clinicians engaging in shared decision-making conversations and improve design of standardized communication tools.

Our objective was to explore the decision-making process of people in hospital who request CPR despite a low probability of benefit. We performed semi-structured interviews with hospitalized patients with a high risk of death who had requested CPR in the event of cardiac arrest after they viewed a CPR video decision aid.

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Methods

Approach and Researcher Characteristics

We used a qualitative descriptive approach with thematic analysis.[9] The team consisted of a qualitative methods expert (Y.L.), an internal medicine physician (D.K.), a decision scientist (P.W.), a psychologist (V.S.), and 2 trainees in nursing (T.A.) and internal medicine (K.L.). Our study was approved by the Ottawa Health Science Network Research Ethics Board.

Setting and Participants

Our study took place on the internal medicine wards of The Ottawa Hospital, a multisite tertiary care teaching hospital. We used the same inclusion criteria we used in our randomized controlled trial (RCT). Patients were approached if they had an order in their medical record placed during the current admission stating they would want CPR in the event of a cardiac arrest and had an elevated risk of death defined as 1) 55 y or older with 1 or more of a) severe chronic obstructive lung disease, b) congestive heart failure New York Heart Association class IV symptoms and left ventricular ejection fraction $<25\%$, c) cirrhosis Child-Pugh class C liver disease, d) metastatic cancer or stage IV lymphoma, e) end-stage renal disease requiring dialysis or 2) any patient 80 y of age or older admitted to hospital from the community because of an acute medical or surgical condition. Others have used these criteria to define patients who are high risk of death.[10] We continued sampling until we had reached thematic saturation, with no new code or theme identified in 3 consecutive interviews.[11]

Study Procedures

To replicate what happened in the intervention arm of our RCT and to ensure that patients had engaged in a decision-making process and understood the choice options, they were shown a 7-min CPR video decision aid that included the harms, benefits, and probabilities of surviving CPR.[8] Participants interviewed in hospital viewed the video immediately prior to being interviewed. Those who were already discharged were sent a link to the video to view prior to the interview. All interviews were audio recorded. The interview guide was developed to inquire about the decision process, sources of information used in the decision process, and emotions associated with this decision (Appendix 1). Prior to the COVID-19 pandemic, interviews were conducted in patients' rooms. Once the pandemic began, research staff

were not allowed in the hospital; therefore, patients were called after discharge and interviewed by phone.

Analysis

Interviews were transcribed in an orthographic format. We conducted a recursive, inductive thematic analysis using Braun and Clarke's[12] 6 steps to guide our process. A thematic analysis approach was selected, as the process foregrounds the understandings of experiences, thoughts, and behaviors of participants.[13]

First, data familiarization was performed by Y.L. and K.L. Transcripts were read closely, with jot notes taken in margins about insights and theoretical hunches regarding potential themes and codes. Data familiarization also included listening to the audio files. This step was essential to understand how participants expressed themselves—tone of voice, pauses, or emotions not captured in transcripts were noted. Second, Y.L. and K.L. independently generated initial codes for 2 transcripts and held regular meetings to discuss topics in the data that could comprise a theme or a code. Next, K.L. and Y.L. developed a codebook based on coding 2 interviews independently and resolving meanings of codes through discussion with the full team. Once the codebook was generated, K.L. and Y.L. coded all interviews; meanings were discussed and finalized throughout 10 analysis meetings. During the theme-development phase, Y.L. created a list of candidate themes and illustrative quotes for team discussion. Y.L. incorporated feedback from the team about code meanings and which codes could be collapsed into themes and continued the process by reviewing and refining the themes and subthemes by further engagement with the data. Consensus on the finalized themes and subthemes was high, and discrepancies were resolved through discussion.

Results

We performed 13 interviews between December 2019 and October 2020. The mean age of participants was 78 y, and 10 (77%) were male (Table 1). Interviews lasted between 12 and 61 min. Three themes and 8 subthemes were developed from the data. The themes developed were 1) life is worth living, 2) CPR outcomes, and 3) decision process.

Table 1 Participant Characteristics

Characteristic	*n* (%)
Age, mean (SD)	78 (8.69)
Sex (male)	10 (76.92)
Inclusion comorbidity	
• Lung disease	0 (0.00)
• Congestive heart failure	2 (15.38)
• Cirrhosis	2 (15.38)
• Metastatic cancer or lymphoma	2 (15.38)
• End-stage renal disease	1 (7.69)
• Age >80 y	6 (46.15)

Theme 1: Life Is Worth Living . . . for Now

This theme describes how participants' choice for CPR is directly associated with their desire to continue living. Participants justify their choice by citing their good health and other facets of their lives that they wish to keep enjoying. However, some participants also expressed limits to these desires to keep living, stating that if CPR kept them alive but only as "a vegetable," then they would not want it. Three subthemes were developed: 1) certainty of wanting CPR to prolong life, 2) patients' current state of health and, 3) the "vegetable clause."

Subtheme: Certainty of wanting CPR to prolong life. "Certainty of wanting CPR to prolong life" captures participants' first response when asked if they want CPR. Most participants responded to this question without hesitation in their voices; their responses conveyed their conviction that they would want CPR to prolong their lives. They used declarative vocabulary such as "absolutely," "definitely," "of course," and "it was a natural reaction." One participant stated,

> . . . in the event before, they put me on the helicopter, they said, "you want resuscitating?" and I said, "of course I do!" It just came out like that. (P2)

Another participant, when asked about any thoughts that come to mind about their decision to opt for CPR, stated,

> . . . yeah, I have no thoughts. I just want them to do and do it [CPR]. (P5)

After having watched the 7-min video outlining the risks of CPR and being asked whether he would want CPR to keep him alive at all costs, another participant was steadfast in his decision, even knowing that CPR is unlikely to work:

> Oh, I'll definitely want to have the intervention . . . absolutely, yeah. (P8)

The above quotes highlight that our participants have certainty in their decision and visceral reactions about CPR. They did not need any time to deliberate about what they want and were able to immediately give their answer. As P8 aptly stated, "It's essentially life." Similarly, P11 shared this sentiment, adding a quote from Shakespeare for emphasis:

> The prolongation of life, potentially or not at all. That's assuming that the cardiac arrest was such that the heart would not revive itself within a short period of time. "To be or not to be," if I were to paraphrase Hamlet. "To be or not to be." (P11)

The participants were readily able to discuss their strong beliefs in CPR being an essential intervention for them despite being shown evidence that it may not be beneficial for them.

Subtheme: Patients' current state of health. The second subtheme, "patients' current state of health," refers to their current state of health and activities they wish to keep doing. For instance, the following participant showcases what he can do:

> I still ride an ATV 4-wheeler. I hunt and fish. I do lots of walking when I can. I've already walked over to the heart institute this morning and get the whole, all the hallways back and forth. And I just climbed the stairs this week. Twice. (P6)

Here, the participant told the interviewer about the physical activities that he "still" engages in, implying that despite his current diagnosis, he can do many things, serving as his justification for opting for CPR. Similarly, another participant substantiated his decision to opt for CPR, saying,

> Well the decision that I am today, right now that I am telling you is based off the fact that I have been given a new life. I have already faced the adversity of death and I am most prepared for death. It's not something that I [inaudible] over anymore. Living a new life is something that I know that if the opportunity is there, the fact that I have a new liver, I have a new strength and energy, if I went into cardiac arrest, I'll certainly want CPR administered to me because I am living a new life and I am getting stronger every day, I'm rehabbing. It's not like I'm critically ill and I'm not going to live. Those choices are all based on my health and well-being moving forward. (P8)

This participant had already experienced a severe medical setback in an earlier hospitalization, and at the time of the interview, he stated he had been "given a new life." He therefore shared that because he is "rehabbing," there is no reason not to choose CPR; his life is now "new" again. His experience with medical interventions is that they will improve his quality of life and even prolong it. Having undergone a medical intervention that had a successful outcome might have influenced his strong beliefs in the ability of medical interventions to improve his "health and well-being," despite being shown outcomes that might contradict this belief. In a similar vein, another participant declared that even her physician was impressed with her heart health:

> And my doctor, the cardiologist, was quite astonished. He said, "You have a very healthy heart. Good as if you were 50." And he said, "You've got no heart trouble at all." So I mentioned it must be all those stairs I had to climb up—3 flights of stairs in my apartment. (P13)

This participant as well used their current health state as a justification for the appropriateness of CPR as an intervention. Due to their "very healthy heart," CPR would of course be an intervention they would choose despite being shown contradictory evidence.

Subtheme: The vegetable clause. When probed further about the potential complications of CPR, some participants cited an exception to their decision for CPR: the "vegetable clause." The "vegetable clause," as coined in an opinion piece by Breu,[14] is a statement that means that the patient would not want CPR if it would leave them in a vegetative state indefinitely. Participants cite the "vegetable clause" as an undesired outcome of CPR.

> I don't want to be a vegetable living off machines. (P1)

> Because the chances of survival are less than 10%. They are not good. And then of course the outcome over that 10%, you could be a vegetable or something. Nobody wants to live their lives that way. You are trying to improve your life. You are not trying to take a step backwards. (P8)

> Like if I knew what the result was, that I was going to be a vegetable, okay, then I think . . . I would say no . . . if I'm told there's a 100% probability of being a vegetable then that would scare me away from CPR. After that there's degrees of disabilities maybe physical or mental and as those probabilities go up then the more scared I get of having CPR. (P9)

Furthermore, P10 shared that "surviving and being in a vegetative state" was the one thing that would scare him

enough to decide against CPR. Participants were certain about two things: they want to prolong their lives, which they describe as currently fulfilling, and they do not want to be left in a vegetative state.

Theme 2: Making Sense of CPR Outcomes

This theme focuses on participants' knowledge of the harms and benefits of CPR. The 3 subthemes are a) a binary outcome, b) personal knowledge and past experiences, and c) long-term outcomes.

Subtheme: A binary outcome. At a surface level, some participants understood CPR as having a binary outcome: live or die, as illustrated in the quotes below:

> If you don't have it, you are going to die. I mean, I love life, I love all aspects of life. . . . my feeling is that I should take every chance at life and if CPR is one of the things they offer and if they crack my chest it will heal, don't you think? (P3)

> Well, the benefit is life. The risk is death. (P8)

> What would happen if it wasn't successful? I simply wouldn't recover. (P11)

> The alternative is death, basically, and unless you're really ready to go. (P13)

As these quotes from participants demonstrate there was a belief that CPR led to either prolonging their life, or it was unsuccessful, and they would certainly die as a result of not choosing the intervention. There was the impression that saying no to CPR was choosing to die, and the alternative was that you would get to live longer with the administration of CPR. When answering questions about deciding to have the intervention, it was continually given as a stark binary choice between life and death. There was no discussion about the end of life what a good death would look like for that person.

Subtheme: Personal knowledge and past experience. While binary understandings are present in the data, participant knowledge of CPR does not end here. The second subtheme, personal knowledge and past experiences, is about personal experiences that inform decision making. For instance, one participant remembered his father, who endured CPR on several occasions:

> He had 2 quadruple bypasses. He was a miracle man on 2 legs. I mean they did CPR on dad more times than you can count on hands I think, over the course of 5 or 6 y. I remember going to the hospital and saying to mom, he's never coming home. Sure enough, either a week or a month or however long later, there we were wheeling him out to the car. It was just unbelievable. That's a first-hand experience of someone that was in the family that had CPR and CPR saved his life on many occasions. (P8)

We can infer from this participant that his father's experience with CPR informed his knowledge of CPR outcomes—that CPR "worked" several times on his father, defying his expectations that his father would not be returning home.

Participants' knowledge came from sources outside their personal experiences, including media portrayals of CPR, as claimed by the following participant who declared,

> Oh, I know a lot [about CPR] because I always watch [inaudible] hospital on TV and they do everything. (P4)

Media portrayals, specifically medicalized drama television shows, were used as a knowledge base by participants when they were asked about their personal understanding of CPR and its implementation.

Subtheme: Long-term outcomes. The third subtheme, "long-term outcomes of CPR," offers a more nuanced picture of participants' understandings that extend beyond the binary perceptions they expressed initially. One participant explained,

> Well there are the medical complications that may exist because of the condition you are living with at the time. People like myself, kidney issues or liver issues or whatever. There is a lot of potential areas of concern than having CPR done and how CPR will affect the outcomes. But I don't know. (P8)

It is evident that the participant is aware there are complications from CPR based on the person's comorbidities; the participant appears to be aware that CPR is a more complex intervention than just being "brought back to life" and carrying on. This is supported by another participant who mused about CPR outcomes:

> Well, the heart starts beating hopefully it gets its own oxygen naturally, and the brain has been preserved so that you haven't lost your, you know crucial parts of the brain. Hopefully you have a normal life again. That's what I hope happens. It may or may not happen in all cases. There are a lot of different conditions and complications. (P13)

The participant spoke about what she "hopes" will happen during and after CPR in an ideal situation to

preserve cognitive function and resume life as usual. However, she admitted that this may not happen. Participants considered their current health status and what their health status may be in a future state, as shown here:

> Well, my attitude on that is CPR, it depends on a whole bunch of other things, including the status of my health at the time. Whether I was completely disabled or near being disabled. And so on, in which case what is the point of the CPR? (P11)

Theme 3: Decision Process

Participants described brief and rushed decision making in the hospital. Consent for CPR was treated casually by physicians. The 2 subthemes are a) critique of the decision-making process b) and CPR is worth a try.

Subtheme: Critique of the decision-making process. Participants criticized the decision-making process. Many thought it was too fast for meaningful consideration or discussion:

> They [healthcare providers] are standing in front of you with a consent form, although that time I didn't sign anything because of COVID but you only have about 20 s to figure it out . . . so it's all based on the first thing that comes to your mind that is most important to you. (P8)

This participant went on to describe the process:

> They didn't really tell me much about it other than the fact that in the event they had to administer CPR, what will my position be in terms of acknowledging do I want it or . . . at the time you are lying in the bed, you are sick, you are not necessarily as I was, with it because your kidney, your brain, your liver function is just about finished. And you are having to make a decision. . . . I wasn't in the position to start weighing all my medical elements because I didn't understand them. (P8)

The participant's recollection of his experience being asked about CPR illustrates that he would have appreciated engaging in a decision-making process, but given the time pressure and his illness, his answer resembled a "reflex." It is also crucial to note that the participant recognized that there needed to be time to "weigh" different factors before deciding but that he did not understand what these factors might be, given the rushed process and lack of information.

Another participant echoed this reaction, stating that he did not know if he was asked:

> So, in the whole thing maybe I was asked, and it was like an automatic response. I don't recall. (P9)

Similar to P8, this participant indicated that his response to the CPR question was "automatic"; he also stated that there was "no discussion" about options, harms, or benefits but that he would have liked to have had "a discussion with the doctor about the pros and cons or something like that" (P9).

Other patients commented on the rapid decision making, or lack of decision making, with little opportunity to consider the harms and benefits:

> Oh, I didn't go through any steps. It was a direct thing . . . it was a pretty direct line. Heart stops, you want to get it going again, CPR can help. (P13)

> They didn't talk about CPR. . . . I don't remember talking about that. (P4)

> Well again I don't want the negative outcome, I don't know. There was not much thinking at this stage. (P9)

The questions in the interview guide assumed that participants had gone through "steps" to decide about CPR; however, the above quotes suggest there were no steps and, in turn, no thoughts held or remembered by participants in those moments. We can only surmise that the process was in fact not "a process" but rather a simple "yes or no" question, to which participants summoned their natural instinct to keep living and responded "yes," emphasized by this participant:

> Yeah, it was a pretty short task you know I mean it's kinda, the decision is sort of hope versus no hope, or possible positive outcome versus never thought of the other side. (P9)

Subtheme: Worth a try. Since participants perceived the decision-making process as a binary question rather than an opportunity to discuss harm and benefits, the second subtheme, "worth a try," is not surprisingly the only rationale they could give for their decision. Being hemmed in by a "yes" or "no" question with no space to consider what opting for CPR would mean beyond the intervention led to a trite form of reasoning. Some participants conceded that, despite the low odds, it would still be worthwhile to have the intervention:

> There's a better than a 5% odd of surviving. I mean surviving in a reasonably good condition. . . . I figure it is worth

> trying. . . . Oh, and I don't have any reason not to say yes. I'm going to say it seems to be a fair-ish moderately fair odds of surviving. . . . I suppose any odds are better than none. (P12)

Similarly, the following participant believed that regardless of her age and the odds, CPR is worth a try:

> I wish I knew that it had a greater degree of success, but even though I know it's only 18% for people probably in my category, or it might be a little lower 'cause I'm 81, it's a chance of getting back to a normal life and you know, why wouldn't anybody want to have it done? . . . there were always a few that didn't come through it well, but that's not a reason not to try it as far as I'm concerned. (P13)

The subtheme "worth a try" illustrates the type of reasoning that patients are confined to due to the paucity of good information on the risks and benefits of CPR and discussions with their care providers. Thus, the binary answers from patients mirror the binary question and rushed process.

Discussion

We performed semi-structured interviews with seriously ill patients in hospital who requested CPR in the event of cardiac arrest to understand their decision process. We developed 3 themes. "Life is worth living . . . for now" describes what people enjoy about their lives and their desire to continue living. "Making sense of CPR outcomes" describes what people think happens after CPR. The question of CPR is not only a question about the intervention but also, according to participants, a question about whether they want to live or die. Participants equate CPR with life and no CPR with death. Many think that the outcome of CPR is binary, live or die; personal experience and television are powerful sources of information about CPR outcomes; and some people understand that surviving CPR does not necessarily mean full recovery. Lastly, the "decision process" theme describes an absence of a process for most patients. Patients received little guidance in decisions about CPR leading many to rationalize their choice for CPR, saying it is "worth a try."

Patients in our study chose CPR because they had a good quality of life and wanted to keep living. CPR was understood as an intervention to prolong life with few risks aside from dying, which is guaranteed if CPR is not attempted. This is not true. Between 5% and 52% of people who survive in-hospital CPR have severe cognitive impairment at discharge, a state that some would describe as "being a vegetable" and consider worse than death.[15–17] Participants in our study expressed that they would not want to be a "vegetable," but there was little exploration of what this meant to them, presumably they would not want to have severe neurologic impairment that left them unable to interact with the world. No participants discussed how likely they thought this outcome was or mentioned lesser states of disability after CPR.

Participants watched a CPR video decision aid with icon arrays to visualize the harms and benefits of CPR prior to the interview but cited personal experiences and media portrayals of CPR as their information sources. This could be because the interview guide asked about personal experiences with CPR, but the interviews contained almost no reference to information in the video. CPR success rates in TV shows and movies are higher than reality and rarely do justice to how traumatic true CPR often is.[18,19] The importance placed on personal experience and media portrayals is not easily overcome with an icon array depicting the probability of surviving with intact neurologic function.

It is concerning that patients did not describe shared decision making or any discussion of the harms and benefits of CPR with their health care provider.[20] Decisions about in-hospital CPR are unique because they are about a future event that may never occur, and if it does, the patient will not have the capacity to engage in shared decision making at the time. Most medical decisions involve choosing between options that can be immediately acted on. Because CPR is not needed for most patients in hospital, it is often reasonable to defer a thorough discussion of the harms and benefits until there is a diagnosis that is likely to end their life. Furthermore, patients may think discussions are not necessary if they have already completed an advance directive that lays out their wishes.[21] Moreover, discussions about CPR can be scary for patients and can damage patient-physician trust, especially when meeting for the first time. Conversely, for patients like those in our study who have a high risk of death, complete lack of shared decision making about CPR poses a risk of catastrophic discordance between the patient's wishes and the treatment administered.[22] Even though most patients will not require CPR while in hospital, the risks of administering CPR or allowing death against a patient's wishes are grave. The solution is honest communication of the harms and benefits of CPR during the consent discussion with every patient, guided by an understanding of goals, values, and fears.[23,24]

We selected patients who had an elevated risk of death with the expectation that some would describe being "tired of life"[25] or have severe symptoms that make the prolongation of life undesirable, but this is not what we heard. Being "tired of life" is a well-described phenomenon in which people feel that life is complete and no longer worth living, but participants told us that their lives were full and rich, which explains why choosing CPR was an obvious choice.[26] CPR was seen as a choice between a full life and certain death. The only way to know if a patient sees their life as full of meaning or are ready for its end is to ask them, but this did not appear to happen for participants during their hospital stay.[27] Notably, there was no mention of natural or peaceful death as a benefit of deciding against CPR. No patients reflected on how they would want life to end when the time comes. The responsibility for this glaring omission falls on physicians who discuss wishes for CPR in isolation instead of engaging in the broader discussion about serious illness, death, and dying. The serious illness conversation guide is an evidence-based method to engage patients in these discussions by asking them about their illness understanding, goals, values, and fears.[24] Understanding each patient's values, goals, and fears can allow a health care provider to make a patient-centered recommendation about CPR.

Limitations

Our inclusion criteria were designed to select patients who wanted CPR despite limited probability of benefit, but the probability of successful CPR for our sample is unknown, and participants did not think the probability was near 0. Explicit calculation of CPR success probability using a validated risk algorithm such as the GO-FAR score[1] would have allowed us to explore the accuracy of participants' risk estimates and discordance between calculated risk and risk perception. Patients who request CPR despite a near 0% probability of success are likely rare and may express different motivations for choosing CPR than the participants in our study. Our sample was relatively small with only 13 patients, although we did reach thematic saturation. Lastly, our study took place at a single center entirely in English. Lack of cultural and linguistic diversity may influence results and limit generalizability.

Conclusions

Patients with a high risk of death choose CPR as part of their care plans because they want to continue living and see CPR as a chance worth taking. Participants were well enough to want to keep living. Participants did not describe any elements of shared decision making. CPR decisions can be more patient centered if we standardize sharing accurate information about CPR and listen to patients' values, fears, and goals to make patient centered treatment recommendations.

Appendix 1

Semi-structured interview Guide to understand Decisions about CPR in Hospital – Patient Version

As you know, people have the choice as to whether or not they would want to receive CPR while in hospital should they go into cardiac arrest. Today, we are interested in understanding your decision to receive CPR in hospital should this happen to you. These questions are not being asked to place judgement on your decision, our team is truly interested in understanding what your decision means to you. Specifically, we would like to better understand your attitudes, beliefs and values about your decision. Please remember that your participation is voluntary, and you can skip any questions that you do not feel comfortable answering and you can stop at any time without needing to provide a reason.

Before we start I would like to show you a video that can help people make a decision about whether CPR is a treatment that they would want if their heart stopped. Can I show you this video? It is 7 minutes long.

<Show the CPR video decision aid> https://vimeo.com/48147363

Whether you choose to have CPR or not, treatment is still focused on helping you live as well as you can for as long as you can. You will always receive treatment to help you with symptoms such as pain and shortness of breath and care for your needs.

Now that you have seen the video, given your current health condition, at this point in time, what would you want **if your heart were to stop beating?**

a) **Use machines and all possible measures including Cardiopulmonary Resuscitation (CPR) with a focus on keeping me alive at all costs**
b) **Allow a natural death with no artificial prolongation of life and no resuscitation (CPR).**
c) **I am unsure**

Knowledge:

1) Can you tell me why someone would need CPR?

2) What happens during CPR?
3) What are the possible outcomes after CPR?
4) Before your recent hospital admission what did you know about CPR?

Process:

5) Why do you think your doctors ask you about CPR?
6) You were selected for this interview because your medical record states that you would want CPR if your heart stopped in hospital. What were the steps you went through?
7) What were some of your thoughts when you were making your decision?
8) Who else is involved with this decision? Is there anyone else's opinion that you need to consider when making this choice?

a) Do you feel pressure from this (these) person(s) to decide one way or the other?

9) Do you feel like your doctor in hospital has an opinion about whether you should or should not receive CPR in hospital if your heart stopped?

Prompts

a) What is their opinion? Do you feel pressure from them to decide one way or the other?

10) Can you tell me why you have decided to receive CPR (not to receive CPR or are unsure if you want to receive CPR) if your heart were to stop while in hospital.
11) Did you know enough about risks and benefits of CPR to make a decision?
12) What information about CPR would have helped you make a decision?

Beliefs: I am also interested in understanding your beliefs about CPR.

13) Have you had any personal experiences, or heard stories about CPR in hospital? If so can you tell me about them?
14) What would it mean to say "No I would not want CPR if my heart were to stop"
15) What would it mean to say "Yes I want CPR if my heart were to stop"
16) If your heart stopped and you received CPR what do you think would happen?

(*Continue to prompt patient to understand what they think the process and outcome of CPR would be for them*)

a) Do you think you will survive CPR?

17) What are some of the reasons that you want CPR?
18) When you think about CPR in hospital what would be good about choosing CPR?

Prompts:

a) Why would you prefer to have CPR as opposed to not having CPR?
b) What matters most to you about having CPR?
c) How could CPR help if your heart were to stop?
d) What are the benefits of CPR?

19) Thinking about CPR in hospital what are the reasons to choose against receiving CPR in hospital?

Prompts

a) What would be bad about choosing CPR? What are the downsides? What bad things could happen?
b) What complication/side effect would scare you away from choosing CPR?
c) What are the disadvantages of choosing CPR?
d) Which of these matter most to you? Which of these is most frightening?
e) What are the risks of CPR?

Feelings/Emotions: Lastly I would like to know what you feel about CPR in hospital.

20) What emotions did you feel when making a decision about CPR?
    a) Is this scary to talk about?
21) Are you worried about what your loved ones will think?

Thank you. Is there anything else you would like to add that you feel was an important factor during your decision-making process?

Semi-structured interview Guide to understand Decisions about CPR in Hospital – SDM Version

As you know, people have the choice as to whether or not they would want to receive CPR while in hospital should they go into cardiac arrest. As a substitute decision maker, it is your job to represent what your loved one would want if they could talk to us about their wishes. Today, we are interested in understanding your decision to choose CPR in hospital should this happen

to your loved one. These questions are not being asked to place judgement on your decision, our team is truly interested in understanding what your decision means to you. Specifically, we would like to better understand your loved one's attitudes, beliefs and values about your decision. Please remember that your participation is voluntary, and you can skip any questions that you do not feel comfortable answering and you can stop at any time without needing to provide a reason.

Before we start I would like to show you a video that can help people make a decision about whether CPR is a treatment that they would want if their heart stopped. Can I show you this video? It is 7 minutes long.

<Show the CPR video decision aid> https://vimeo.com/48147363

Whether you choose CPR for your loved one or not, treatment is still focused on helping them live as well as they can for as long as they can. Your loved one will always receive treatment to help them with symptoms such as pain and shortness of breath and care for their needs.

Now that you have seen the video, given your loved one's current health condition, at this point in time, what do you think your loved one would want **if their heart were to stop beating**?

☐ Use machines and all possible measures including cardio pulmonary resuscitation (CPR) with a focus on keeping your loved one alive at all costs
☐ Allow a natural death with no artificial prolongation of life and no resuscitation (CPR).
☐ I am unsure

Process:

1) Your loved one was selected for this interview because their medical record states that s/he would want CPR if their heart stopped in hospital. Prior to now, who made the decision for your loved one to receive CPR?

   If the SDM made the decision ask: Before you came to the hospital and went through this process, what did you know about CPR?
   If the participant made the decision ask: Before your loved one came to the hospital and went through this process, what did you think s/he knew about CPR?

2) Can you provide me with a step by step process on how this decision was made? OR Do you know how your loved one made this decision?
3) What were some of your thoughts when you were making your decision for your loved one?
4) What was the biggest factor in deciding that your loved one would want CPR if their hearts stopped? OR What do you think was your loved one's biggest factor/influence?
5) Who else is involved with this decision? Is there anyone else's opinion that you need to consider when making this choice? OR Did your loved one consider someone else's opinion when making their choice?
   a. Do you feel pressure from this (these) person(s) to decide one way or the other?
   b. Did your loved one feel pressure from this (these) person (s)?
6) Do you feel like your loved one's doctor in hospital has an opinion about whether your loved one should or should not receive CPR in hospital if their heart stopped?

   Prompts
   What is their opinion? Do you or your loved one feel pressure from them to decide one way or the other?

7) What do you or does your loved one think about CPR as an option for in-hospital cardiac arrest?
8) How do you feel about CPR as a response to cardiac arrest (when a heart stops)?
9) May you please tell me about why you have decided your loved one would receive CPR (not to receive CPR or are unsure if your loved one would want to receive CPR) if their heart were to stop while in hospital.

   Prompts:

   a. What would it mean to you to have CPR if you were to go into cardiac arrest (if your heart were to stop?)
10) What additional information would you have liked to receive when you made your decision for your loved one to receive CPR in hospital?

Beliefs: I am also interested in understanding your beliefs about CPR in the event of in-hospital cardiac arrest.

11) If your loved one's heart stopped and s/he received CPR what do you think would happen?

   (*Continue to prompt patient to understand what they think the process and outcome of CPR would be for them)*

Prompts:

a. On a scale of 1 to 10, what do you think her/his chances are of surviving CPR? 10 is definitely and 1 is no, I won't survive
b. What complications do you think are associated with CPR?

12) Have you had any personal experiences, received any education, or heard stories about CPR as an option during in-hospital cardiac arrest? If so, please describe how these experiences have shaped what you believe about your loved one receiving CPR during an in-hospital cardiac arrest.

Feelings/Emotions: Lastly I would like to know what you think and feel about receiving CPR in the event that you heart were to stop while in hospital.

13) For some people they choose CPR because they want to live as long as possible or get the best treatment possible and they feel this includes CPR, what are some of the reasons that you want CPR?
14) When you think about CPR in hospital what would be good about choosing CPR?

Prompts:

a. Why would you prefer to have CPR as opposed to not having CPR?
b. What matters most to you about having CPR?

15) Thinking about CPR in hospital what are the reasons to choose against receiving CPR in hospital?

Prompts

a. What would be bad about choosing CPR? What are the downsides?
b. What are the disadvantages of choosing CPR?
c. What complication/side effect would scare you away from choosing CPR for your loved one?
d. Which of these matter most to you? Which of these is most frightening?
e. What would it mean to you if you chose against receiving CPR?

Thank you. Is there anything else you would like to add that you feel was an important factor during your decision-making process?

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Author Contributions

D.K. and P.W. contributed to the conception, design, analysis, and drafting of the manuscript. V.S. contributed to the design of the work. T.A. contributed to data acquisition, analysis, and interpretation. D.L. and Y.L. contributed to the analysis. Y.L. drafted the manuscript. All authors critically revised the manuscript, approved the final version, and agree to be accountable for all aspects of the work.

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Supplemental Material

Supplementary material for this article is available on the *MDM Policy & Practice* Web site at https://journals.sagepub.com/home/mpp.

Data Availability

The full coding scheme is available upon request from the authors.

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