

Article

"If I Become a Vegetable, Then no": A Thematic Analysis of How Patients and Physicians Refer to Prognosis When Discussing Cardiopulmonary Resuscitation

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Abstract

Background: Documenting decisions about the relevance cardiopulmonary resuscitation (CPR) is a standard practice at hospital admission yet a complex task. Objective: Our aim was to explore how physicians approach and discuss CPR prognosis with older patients recently admitted to a post-acute care unit. Method: We recorded 43 conversations between physicians and patients about the relevancy of CPR that took place at admission at the geriatric rehabilitation service of a Swiss university hospital. Thematic analysis determined (i) who initiated the talk about CPR prognosis, (ii) at what point in the conversation, and (iii) how prognosis was referred to. Results: Prognosis was mentioned in 65% of the conversations. We categorized the content of references to CPR prognosis in five themes: factors determining the prognosis (general health, age, duration of maneuvers); life (association of CPR with life, survival); proximal adverse outcomes (broken ribs, intensive care); long-term adverse outcomes (loss of autonomy, suffering a stroke, pain, generic, uncertainty); and being a burden. Discussion and conclusion: Discussing CPR is important to all patients, including those for whom it is not recommended. Information about CPR prognosis is essential to empower and support patients in expressing their expectations from life-prolonging interventions and attain shared decision-making.

Keywords

cardiopulmonary resuscitation, CPR, geriatric patients, shared decision-making, patient-physician communication,

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Introduction

Documenting decisions about the use of cardiopulmonary resuscitation (CPR) is standard practice at hospital admission, at least under the tradition of "modern medicine" (Dignam et al., 2021). In the absence of a documented decision, the default response to cardiac arrest during a hospital stay is usually to attempt CPR. This, however, can be problematic for patients suffering from severe comorbidities for whom CPR may not be in their best interests (Stapleton et al., 2014). The established standard for determining whether CPR is relevant or not relies on the model of shared decision-making, in which the physician and the patient participate in information sharing in the spirit of a therapeutic partnership (Elwyn et al., 2012). The shared decision-making model calls on physicians to engage in tasks that confer agency to patients, essentially by providing them with quality

information and by supporting their deliberation (Elwyn et al., 2012). Nevertheless, in practice, patients who are able to provide informed consent are still often excluded from the decisional process; reasons include previous discussions with their relatives or among health professionals, communication barriers experienced by physicians, judgment that inclusion is superfluous (either because their clinical situation is evaluated as being good, thus automatically warranting for CPR, or too bad, thus automatically excluding the intervention)

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(Hurst et al., 2013). Two dimensions often disregarded in research and education are incremental to the achievement of good communication: physicians should possess the "quality information" that they are supposed to share with patients, and the former should know how to share this information with the patient. Both aspects are not evident when it comes to CPR.

Assessing CPR Prognosis

By prognosis, we refer to "the probability or risk of an individual developing a particular state of health (an outcome) over a specific time, based on his or her clinical and non-clinical profile" (Moons et al., 2009). Estimating prognosis, in particular the chance of survival and functional outcome, after CPR is essential to determine whether the procedure is medically indicated (van Gijn et al., 2014). Research that investigated the documentation of do-not-attempt-resuscitation orders shows that they are associated with the physician's estimation of a worse prognosis and poorer quality of life (Becerra et al., 2011). These negative outcomes may be associated with older age, comorbidities, cognitive impairment, the general health condition, specific CPRrelated prognostic factors, (Mockford et al., 2015), and patient's level of frailty (Hu et al., 2022).

Though evaluation of CPR prognosis can be facilitated by various risk scores (Becker et al., 2020), prognostication remains tainted with uncertainty (Bloom et al., 2022). Expression of this uncertainty by physicians, however, is equated with ignorance and failure by patients (Simpkin & Armstrong, 2019). Furthermore, documentation of CPR decisions is required at hospital admission when physicians are unfamiliar with patients, rendering the judgment on the medical indication of CPR rather abstract (A. C. Sterie et al., 2021). Lastly, physicians feel ill-equipped to communicate prognostic information and require more adapted training (Bloom et al., 2022). These various factors impact on whether and how prognosis is discussed with patients, and if the latter can integrate this information into their medical preferences.

Prognostic Awareness and Communication. Prognostic awareness is a term used to refer to patients' knowledge and understanding of elements that relate to the prognosis of their disease, such as diagnosis, disease trajectory, life expectancy, and risk of complications (Applebaum et al., 2013). Prognostic awareness is generally low, particularly in patients suffering from advanced illnesses (Chen et al., 2017). Studies equally show that patients have insufficient understanding of CPR outcome and prognosis (Holland et al., 2013; Zijlstra et al., 2016), and that older adults often have inaccurate perceptions of end-of-life medical situations (Meier et al., 2023).

Information about prognosis appears as a necessary step to enable patients to make an informed decision about whether to consider a CPR attempt as relevant. A systematic review reported that while most physicians believed that patients should be informed about their prognosis, the former actually avoided these discussions in practice (Hancock et al., 2007). This is supported by the finding that CPR prognosis is rarely referred to (Anderson et al., 2011) and the vocabulary that physicians use to explain the procedure is generally vague and sparse, for example using euphemisms to refer to the risk of cardiac arrest and not unpacking what CPR consists of (A. C. Sterie et al., 2021; Tulsky et al., 1995).

Communicating prognosis is considered a core competency for physicians. However, difficulties in incorporating and applying this skill into daily interaction with patients highlight the need to integrate it more into communication training (Bloom et al., 2022).

Aim

The aim of this study was to qualitatively explore, using a thematic analysis, the circumstances and ways in which patients and physicians talk about CPR prognosis.

Method

The study was conducted in a university hospital in Western Switzerland, from 2017 to 2019. The project was approved by the regional research ethics commission (2017-00229).

Participants

The participants were patients admitted over 8 months to a 95-bed geriatric rehabilitation facility and the junior physicians who performed their admission interviews. Exclusion criteria included lack of decisional capacity regarding the participation in the study. Participants were screened by a medical practitioner (RJJ and ERT) and were provided with oral and written information about the study by a collaborator (ACS). Participants were informed that the study aimed to investigate communication practices during the admission interview, without specifying the focus on CPR beforehand to avoid bias. They had 24 hr to sign consent forms.

Data Collection

We audio-recorded 51 admission interviews that took place between June 2017 and January 2018. Informed consent from all patients and the 17 physicians who performed their admissions was obtained. The audio-recordings were preceded by 10 days of ethnographic observations (ACS).

Analysis

Data was analyzed using thematic analysis (Clarke et al., 2015). Initially, ACS, a sociologist, and CC, a medical student, identified the conversations in which CPR prognosis was discussed. Transcripts were read by

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Table 1. Description of the Patient Population.

Characteristics (N=43)	Number (%)	
Age (mean)	83.7	
Reason for admission to geriat	ric rehabilitation	
Surgery/trauma	23 (54)	
Infections	12 (14)	
Miscellaneous	14 (32)	

ACS and CC to determine an initial coding framework for identifying (i) who talks about CPR prognosis, (ii) at what point in the conversation, and the (iii) how CPR prognosis was referred to. ACS and CC coded all the data, compared their coding, discussed and resolved dissensions, and created a codebook containing themes, which were then analyzed in depth. The analysis was led by CC in partial response to the requirement of obtaining a Doctorate in Medicine, with CJB (professor in geriatric medicine) as main supervisor, ACS and ERT (a medical doctor) co-supervisors, and RJJ (professor in palliative care, neurologist and ethicist) jury expert. ACS and ERT participated in data sessions for interpreting the data. RJJ, CJB and ERT reviewed the coding framework and contributed to the discussion.

Results

The CPR was discussed in 43 of the 51 admission interviews that were recorded. The mean length of an admission interview was of 52 min 51 s; that of CPR conversations was 1 min 45 s. Patient information is described in Table 1. Overall, 11 patients expressed the wish to receive CPR, 20 refused, and 12 expressed uncertainty.

Prognosis was mentioned in 28 of the 43 (65%) interviews. We identified 50 references to CPR prognosis, 22 made by physicians and 28 made by patients. Reference to prognosis was initiated (first to mention it) by the patient in 16 interviews and the physician in 12.

Physicians Initiate a Reference to Prognosis

Physicians refer first to prognosis either when reformulating or clarifying their own initial question concerning whether the patient wishes CPR (seven cases) or when clarifying a patient's decision to not attempt CPR (five cases).

The first situation is exemplified in Extract 1 (Box 1), in which the physician first asks a straightforward question about CPR, to which the patient avows not being able to answer. The physician then refers to CPR prognosis in an effort to secure a response from the patient.

In this conversation, the physician mentions CPR prognosis after asking for the patient's preference and describing the CPR procedure. Prognosis is referred to in terms of uncertainty, chances of success, prognostic factors (age), generic and specific secondary effects, and mingled with the pathophysiology of cardiac arrest. The

Box I. Extract I: Conversation C7.

hy#2: at:	() Do you want us to resuscitate? It's a question I ask myself. I confess I can't answer. () It's not clear.
hy#2:	Do you have any relatives? ()
hy#2:	Do you know what CPR is?
at:	Well I when someone has a cardiac arrest and has to be resuscitated or not.
hy#2:	Right. So when we resuscitate, we do the cardiac massage, and we use defibrillator machines that produce little shocks to restart the heart. Because when the heart stops, the blood no longer circulates, and the person dies. The problem is that with CPR we never know how it goes. We never know if it goes
at:	Well
hy#2:	Well or not. When people are older, we have a lower chance of success than when they are younger, but you should know that there are also potential secondary effects that can happen. So, when the heart restarts, if the brain hasn't received sufficient blood or oxygen for several minutes, half an hour or even one hour, it suffers, and you can have secondary effects so
at:	Paralysis, things like that
hy#2:	Right, even to become a vegetable. So that's it. Often there are also rib fractures, but that is
at:	I don't know. I can't answer

reference to secondary effects is collaboratively produced by both physician and patient. As the physician pronounces "secondary effects," the patient immediately completes by mentioning "paralysis," showing a recognition of the topic and knowledgeability. The physician reformulates this to becoming "a vegetable," code switching from a technical language to a more vernacular one. Ultimately, the supplementary information about the CPR prognosis, while understood and accepted by the patient, is not helpful for the decision.

The second occasion in which physicians initiate talk about CPR prognostics concerns situations in which they attempt to clarify and explore the reasons behind the patient's refusal of CPR, as exemplified in Extract 2 (Box 2).

In this conversation, the patient's response is concise ("you should let it stop"). The conversation's unfolding shows that some sort of justification is needed to back up the decision. The physician attempts an initial clarification, probing the patient's understanding of the procedure ("you know what resuscitation means?") and questioning the patient's justification ("why don't you want resuscitation?"). The patient eludes the last two. Ultimately, the physician introduces a candidate answer (Pomerantz, 1984), framing the risk of "secondary effects" as a potential reason for not desiring CPR ("You know that there might be secondary effects?"). The extract shows that the physician considers that the patient's decision to refuse CPR should be backed by a

Box 2. Extract 2: Conversation C9.

Phy#2: (. . .) If your heart was to stop, You should let it stop. Pat: Phy#2: All right, you don't want us to try resuscitation? I'm eighty-five years old, I don't expect any Pat: miracles. Right, you know what resuscitation means? Phy#2: Yes yes. No, no, leave it. Pat: Phy#2: All right. Why don't you want resuscitation? Pat: What for? Phy#2: You know that there might be secondary effects when we resuscitate? When we do a resuscitation, you know that there can be secondary effects?

Pat: Yes.
Phy#2: It's just that-

Pat: No but I don't want that!

justification and based on the risk of secondary effects. While this information appears important to the physician (and warrants them going to extra lengths to pursue it), it is not relevant for the patient, who eludes the physician's attempt to obtain it and considers their decision as sufficient without a justification.

When Patients Refer to Prognosis

Patients initiate a reference to prognosis (16/28 conversations) always in relation to their decision to attempt or withhold CPR. In the following extract, the patient decides against CPR and refers to the risk of "becoming a vegetable." (Box 3)

The patient's initial answer is "no futile care"; its justification, followed by a reiteration of the decision to refuse life-prolonging treatment ("if I become a vegetable, then no"), anchors this decision in a context of reflection and patient autonomy. It is confirmed and accepted at face value by the physician.

Physicians did not explicitly follow up on the cue to discuss prognostic elements (as exemplified in Extract 3) in 11/16 conversations in which patients initiated talk about the prognosis.

Type of Prognostic Information

When looking at the type of prognostic information, we identified five themes and several subthemes: (1) factors

Box 3. Extract 3: Conversation C6.

Phy#3 (. . .) If something very serious happened to you, what would you wish the doctors to do or not do?

Pat: I've already answered this question several times.

No, no futile care. That I wouldn't want.

Phy#3: All right, ok.

Pat: If there's nothing to do, if I become a vegetable, then

no.

Phy#3: All right, ok. It's always good for us to know your

state of mind.

determining the prognosis (subthemes: general health, age, duration of cardiac maneuvers); (2) living and survival (subthemes: CPR is life, survival); (3) short-term adverse outcomes of CPR (subthemes: broken ribs, going to intensive care); (4) long-term adverse outcomes of CPR (subthemes: loss of autonomy, suffering a stroke, pain/suffering, generic risks, generic secondary effects, diminished quality of life, futility, uncertainty of CPR outcomes); and (5) being a burden to relatives.

Factors Determining the Prognosis. The general health status as a factor predicting the outcome after CPR was mentioned by physicians in two conversations, once to justify CPR ("your health is not too bad so we can do it [CPR]") and once to justify the foregoing CPR ("you also have quite a lot of diseases so CPR (...) is not harmless"). Age is another prognostic factor and was mentioned four times by physicians. Physicians link older age to poorer CPR outcomes ("CPR is not the same thing when we are twenty, thirty years old or when we are (. . .) your age") as part of the health status. The reference is always found next to a reference to secondary effects of CPR. Only one physician mentions the duration of CPR as having an impact on the CPR prognosis ("The longer we try (. . .) the more possible it is that a secondary effect happens").

Life and Survival. The outcome of CPR was identified as life or survival in 12 conversations. In 11 of these, the reference was made by a patient, as a justification of the desire to be resuscitated ("Oh yes, why not [resuscitate]? I still enjoy living"), thus, revealing an understanding that CPR results in prolonging life. This was also implicitly a resource for referring to hypothetical chances of survival ("As long as there's life, there's hope"). This theme appeared in the physician's reformulated question in only one conversation ("Do you think that your time has come (...) or do you want to keep living?"). Survival rates were mentioned in three conversations, each time initiated by a physician, once in a clarification of the patient's decision ("We have 30%") and twice when reformulating their question about the patient's preference ("The chances of success of CPR are anyway very weak").

Short-Term Adverse Outcomes. Short-term adverse outcomes of CPR were mentioned three times. One physician mentions the risk of rib fractures during CPR, a physician and a patient mention the risk of being intubated or needing intensive care ("Nothing [no CPR]. Because I don't want to be attached to tubes on one side and the other").

Long-Term Adverse Outcomes. Long-term adverse outcomes of CPR were mentioned 33 times in 21 conversations (75%). The risk of handicap and losing autonomy was mentioned by eight patients ("I wouldn't want to be. . . a vegetable") and two physicians ("when the heart restarts you can have a side that is paralyzed"). One patient

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refers to the risk of experiencing a stroke after being resuscitated and another one to suffering. Patients and physicians also refer to adverse outcomes in more generic terms, by mentioning the risk of secondary effects ("It [CPR] can also be accompanied by secondary effects") and the impact on the general quality of life ("I know that if we resuscitate, there's a risk that my quality of life will be worse"). Physicians refer to the uncertainty of the outcome after CPR in seven conversations ("We never know what the result will be afterward"). Patients and doctors refer to "futile care" in 10 other conversations, though without explaining what they mean by that term ("No futile care (. . .) I'm ready to go").

Being a Burden to Relatives. Patients refer to the burden that adverse outcomes would represent for their relatives in three conversations ("No futility (. . .) No if it's to be handicapped. I don't want my son to suffer").

Discussion

Our study shows that discussions about CPR outcomes happened only in about two-thirds of hospital admission interviews, mostly initiated by patients.

The results of this study are important from several perspectives. Firstly, they indicate that physicians do not systematically offer information about CPR prognosis when asking for the patient's preference regarding the procedure. This means that this information is not available from the start of the decision-making process and that the discussion often evolves without it being shared or discussed. This, however, questions whether the type of decision that is reached is truly informed.

A second contribution of our work is to show that information about CPR prognosis is not spontaneously offered to patients, but most often introduced by physicians when reformulating their own questioning, after the patient has already given a decision or has not been able to formulate one (as shown in Extract 1). This occurrence shows that even if information about CPR prognosis is not offered from the start, it is considered as relevant to the patient and used as a resource (a trigger) to obtain a decision. Physicians less often introduce this information in an attempt to clarify the patient's decision to not undergo CPR (as shown in Extract 2). This shows that decisions against CPR need to be backed up by some evidence, such as fear of the risk of unfavorable CPR prognostics, in order to be considered as "receivable."

An additional original contribution of our findings is to provide more insight into the interplay between patients and physicians when discussing CPR. Results show that it is more often patients who initiate talk about CPR prognosis, particularly when justifying refusing CPR. However, patients never spontaneously asked for information about prognosis, suggesting that they do not consider needing more information or, alternatively, that

they do not consider that the physician is a person who can offer it or to whom they can address this request. This observation suggests that physicians should not expect patients to formulate a need for information but should be proactive in offering it.

We identified five themes that relate to the type of information mentioned when discussing CPR prognosis. References to the impact of the main factors determining the prognosis (theme 1), such as age or current health status, provides insight into physicians' strategy of deliberation in assessing whether CPR is medically indicated. It is offered as a given, concrete, medical evidence, about which patients do not have any authority.

Desire to live and appreciate life (theme 2) is a justification for wanting to attempt CPR. This shows that attempting CPR can be equated with a choice of life (as highlighted by previous literature, e.g., (Murphy et al., 1994)). It seems essential for physicians to understand to what point patients would tolerate an alteration of their quality of life.

Short-term adverse outcomes of CPR (theme 3) refer to elements that accompany the overall CPR process, and from which patients might suffer the consequences when conscious (fractured ribs, being intubated). These references are accomplished by way of vivid examples that tap into the patient's imagination and call forth particularly strong emotional reactions. In this way, their use is very similar to that of a nudge (Blumenthal-Barby & Burroughs, 2012), which speaks about the physician's power of influencing patient decisions in the direction of refusing CPR.

References to long-term adverse outcomes of CPR (theme 4) are frequent; they are often vague, holding surprisingly little information about personal prognosis, but are still sufficient to highlight the idea of a risk. They can also be specific, mentioning particularly the risk of becoming a "vegetable," thus, rendering concrete highly undesirable scenarios. The reference to "futile care" by patients and physicians contains embedded a reflection about the overwhelming importance of adverse outcomes, considered here as a reference to prognosis (A.-C. Sterie et al., 2022; Wenger, 2020). These results highlight longterm adverse outcomes as the type of CPR prognosis most referred to and, thus, emphasize their critical importance for decision-making. Therefore, long-term CPR outcomes should certainly be more systematically introduced and discussed by physicians. This is particularly important for older adults who have limited prognosis awareness and knowledge about CPR outcomes.

Lastly, being a burden to relatives due to adverse medical outcomes of CPR (theme 5) highlights the social determinants of medical decision-making. Many patients who suffer from advanced diseases develop a self-perception of being a burden to family (McPherson et al., 2007), in particularly older adults (Lilleheie et al., 2021). Declining life-prolonging treatments can be considered as a gesture of altruism from patients toward

their relatives (Battin, 1985). Our findings suggest that even older patients who are not necessarily in poor health fear becoming a burden were their health state to worsen. However, fear of becoming a burden, especially when leading to medical decision-making, could also reduce the autonomy of the patient and can be experienced as a deep suffering (McPherson et al., 2007).

Our findings generally show that in spite of the clear evidence that CPR prognosis (particularly the risk of adverse outcomes) is an important factor associated with the patient's preferences, physicians do not spontaneously offer information about prognosis from the start of the conversation. This is further complicated by the fact that patients do not ask for information about this topic either. These observations argue toward the need of creating opportunities in which life-prolonging interventions such as CPR can be discussed in a more comprehensive way, such as during advance care planning (Goswami, 2023). Our findings equally shed light on the nature of CPR prognostic information. In addition to confirming that the vocabulary used is vague and that, when existent, details about CPR are scant (Anderson et al., 2011; A. C. Sterie et al., 2021; Tulsky et al., 1995), our results offer an interesting reflection of what can be considered as prognostic for CPR and the layers of this prognostication. We distinguish between long-term and proximal outcomes, and highlight that "life" can be an outcome of CPR that is highly considered by certain patients.

Limitations

A limitation of our study is that we lack contextual knowledge about factors that shape discussions, such as whether patients discussed CPR before or during their stay in acute care, with whom and what this discussion contained.

Conclusion

Cardiopulmonary resuscitation has a high risk of adverse outcomes, and its attempt is considered of little value to patients suffering from multiple co-morbidities. While physicians should not offer interventions that can generate further suffering, this does not mean that the conversation about CPR is futile. Information about CPR prognosis is essential in supporting patients to reflect about what they might expect from such a life-prolonging intervention and attain shared decision-making. Advance care planning discussions can cultivate patients' accurate prognostic awareness that would allow for a more realistic appraisal of whether or not decisions about life-prolonging interventions, such as CPR, are relevant (Goswami, 2023).

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Data Availability Statement

The data that support the findings of this study are available on request.

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