Including patients in resuscitation decisions in Switzerland: from doing more to doing better

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Including patients in resuscitation decisions: from doing more to doing better

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ABSTRACT

Background: Decisions regarding Cardio-Pulmonary Resuscitation (CPR) and Do Not Attempt Resuscitation (DNAR) orders remain demanding, as does including patients in the process.

Objectives: To explore physicians' justification for CPR/DNAR orders and decisions regarding patient inclusion, as well as their reports of how they initiated discussions with patients.

Methods: We administered a face-to-face survey to residents in charge of 206 patients including DNAR and CPR orders, with or without patient inclusion.

Results: Justifications were provided for 59% of DNAR orders and included severe comorbidity, patients and families' resuscitation preferences, patients' age, or poor prognosis or quality of life. Reasons to include patients in CPR / DNAR decisions were provided in 96% and 84% of cases, and were based on respect for autonomy, clinical assessment of the situation as not too severe, and the view that such inclusion was required. Reasons for not including patients were offered in 84% of cases for CPR and in 70% for DNAR. They included absent decision-making capacity, a clinical situation viewed as good (CPR) or offering little hope of recovery (DNAR), barriers to communication, or concern that discussions could be emotionally difficult or superfluous. Decisions made earler in the patient's management were infrequently viewed as requiring revision. Residents reported a variety of introductions to discussions with patients.

Conclusion: These results suggest progress in patient involvement. However, they also point to potential side-effects of implementing CPR/DNAR recommendations without in-depth and practical training. This should be part of a regular audit and follow-up process for such recommendations.

Decisions regarding Cardio-Pulmonary Resuscitation (CPR) and Do Not Attempt Resuscitation (DNAR) orders are increasingly considered a necessary part of hospital practice, but remain demanding.[1] These decisions are complex, with CPR/DNAR orders remaining frequently misunderstood.[2] Moreover, although most patients would like to be consulted on these decisions,[3] and despite consensus that such inclusion is ethically required in most cases,[4-6] including patients in these decisions is hard.[7] Such conversations can be emotionally laden and potentially conflictual,[8] and come up against public misconceptions of the efficacy of resuscitation.[9] As a result, hospital doctors are often uncomfortable about whether, why, and how to include patients in CPR/DNAR decisions. Education on such issues is often lacking in hospital training.[10]

To date, almost all studies designed to understand the practice of decisions regarding CPR/DNAR orders have been conducted in the United States of America. Little information is available in Europe,[11] despite recognition of CPR/DNAR orders as a frequent cause of ethical difficulty;[12] and only three studies have been conducted in Switzerland.[1, 11, 13, 14]

The Clinical Ethics Committee at the Geneva University Hospitals issued a recommendation on CPR/DNAR prescriptions in 2001.[15] This topic was addressed because discussion with patients on their preferences regarding CPR remained exceptional, many patients were nevertheless the object of DNAR decisions, patients in palliative management often did not have a DNAR order, orders were often decided by a single person without discussion between doctors or the health care team, CPR/DNAR orders were seldom revised in light of changing circumstances, rarely documented and even more rarely explicitly justified in the patient's chart. Reasons identified for these problems were that discussing CPR/DNAR decisions with patients is difficult. A further difficulty was that guidelines regarding CPR/DNAR are inevitably complex since a position whereby any patient who hadn't explicitly refused CPR would be resuscitated would be ethically untenable. As a result, the Council recommended that the default position should be to resuscitate patients, except in cases where a competent and informed patient refuses CPR, or when the patient is in end-of-life care, or where CPR would be considered futile. It further recommended systematic discussion of CPR/DNAR prescriptions for all patients between at least two doctors and information of the health care team, the inclusion of patients in such decisions except at the end of life, as well as systematic documentation and regular review of CPR/DNAR prescriptions.[15]

The definition provided for “end-of-life” is “death is expected in the following days”. Futile is defined as: “any treatment which does not enable the restoration of a patient’s vital functions, or enable him to recover an acceptable quality of life, as defined based on the patient’s own appreciation criteria”. This position further states that patients should be included in CPR/DNAR decisions, unless they are incapable of decision-making, or in end-of-life care, or if CPR would be futile in their case. A further exception to patient inclusion is that a CPR order can be given without patient inclusion in cases where the disease is not serious and cardiac arrest is highly unlikely. An example of such a situation provided in the ethics committee recommendation is: “a young patient admitted for acute appendicitis and who might be a victim of an allergy in the peri-operative period”. Following this position statement, the General Internal Medicine Service implemented a policy on CPR/DNAR prescription, requiring first a specific form for each patient, and at a later stage a systematic computer-based prescription.

In this setting, we conducted a study to assess the prevalence and factors associated with CPR/DNAR orders and with patient inclusion in these decisions, physicians’ justification for CPR/DNAR orders and their decisions regarding patient inclusion, and how discussions with patients had been initiated. In this paper, we report participants’ reported reasons for CPR/DNAR prescriptions, their reasons for including or not including patients in these decisions, and the way in which they reported initiating these difficult discussions. Prevalence and factors associated with CPR/DNAR orders and with patient inclusion have been described elsewhere.[16]

PARTICIPANTS AND METHODS

Participants

Residents were identified based on a weekly screening of CPR/DNAR prescription forms in 6 wards (approximately 100 patient beds) of the General Internal Medicine Department of the Geneva University Hospitals in Switzerland. Medical records of admitted patients contain a specific CPR/DNAR prescription form, to be completed during admission in order to specify for each patient whether in his/her case a CPR or a DNAR order applies in case of cardiopulmonary arrest. All available forms were included. In order to explore factors associated with CPR or DNAR orders, we more closely examined a sample of consecutive cases containing approximately equal numbers (about 50 cases) of patients from four categories defined on the basis of the resuscitation order, and of whether or not the decision had been discussed with the patient. These groups were: discussed DNAR, undiscussed DNAR, discussed CPR, and

undiscussed CPR. Patient cases were included if the resident in charge of the patient was available in his/her office and consented to filling in a short face-to-face questionnaire.

Data collection

Questionnaire items were based on a literature review of factors associated with CPR or DNAR orders, and with patient participation in end of life decisions. Two versions of the questionnaire were used, taking into account whether the patient had been included in the CPD/DNAR decision or not. Survey items were further described elsewhere.[16]

In all questionnaires, open-ended questions addressed justification provided for the CPR/DNAR order by the resident. In cases where a discussion with the patient took place, residents were asked the justifications for discussing the decision with the patient as follows: “What were your reasons to discuss [this] with the patient?”. They were then asked how that discussion had been initiated: “If [you initiated the discussion]; how did you start?”. In cases where such a discussion did not take place, residents were asked the justification for not discussing the decision with the patient as follows: “What were your reasons for not discussing [this] with the patient”?

Closed-ended questions addressed whether justifications for prescriptions had been discussed within the medical team, who had initiated the discussion when patients were included, and resident demographics. Questionnaires were administered face-to-face, and responses noted by the research assistant. The full questionnaire is available on request.

To minimize recall problems, residents who consented to participation were asked to fill in the questionnaire 1 to 6 days after the patients’ admission to the ward. Data collection was open during twelve months, from April 2004 to May 2005.

Protection of human participants

Participation was voluntary and responses were made anonymous before analysis. Questionnaires and answers were kept strictly confidential, the research assistant was an advanced medical student with no power over residents, identities were kept from senior members of the research team who worked in the surveyed department, and this was made clear to respondents. This study was submitted to the chair of the hospital research ethics committee who designated it as quality control and exempted it from full ethics committee review.

Data analysis

Descriptive statistics were used for closed-ended responses. Responses to open-ended questions were transcribed and coded for content. Codes for the participants' justification for CPR/DNAR orders, their decisions regarding patient inclusion, and how discussions with patients had been initiated, were developed and refined, and grouped into first-level categories. Quotations presented in this article are translated from the original French.

RESULTS

Respondents

Weekly screenings resulted in the inclusion of 1446 records (47% of the 2911 admissions during the study period). Of these, 21.2% contained a DNAR prescription, 61.7% a CPR order, and 17.1% gave no indication. From this sample, we selected 100 CPR orders, of which 51 had been discussed with the patient and 49 had not, and 106 DNAR orders, of which 56 had been discussed with the patient, and 50 had not, for the resident questionnaire. Almost all approached residents consented to participation (98%). Refusal was due to time constraints in three cases, and one resident answered an insufficient number of questions to be included. The 206 patients were treated by 61 different residents with postgraduate clinical experience ranging from 1 year to over five years. 89% of residents reported general training in ethics during medical school, and 31% specific training on CPR/DNAR orders. The mean number of cases per resident was 3.3.

Reasons given for CPR/DNAR orders

Justifications were given for 38% and 59% of CPR/DNAR respectively. They are outlined in Table 1. Residents gave four major justifications for DNAR orders: important comorbid conditions, patient or family resuscitation preferences, patient age, poor prognosis or quality of life. Diseases most frequently reported as determining a DNAR prescription were cancer, mostly described as untreatable, advanced, or terminal, heart disease, or the presence of multiple disorders. For the CPR patients the residents indicated the same factors in reverse as justifications: patient younger age, patients' resuscitation preferences, or causes for optimism

such as an ongoing therapeutic plan. A good quality of life as assessed by residents was also a salient justification. Cancer and heart disease were also the most frequent diseases reported as determining a CPR order. In such case, however, cancer was rarely described as terminal, advanced, or untreatable. Reasons for CPR/DNAR orders were discussed within the health care team in 55% of DNAR and 32% of CPR orders.

Reasons given to include or not include the patient

Justifications given for including –or not including- patients in decisions regarding CPR/DNAR prescriptions are outlined in Table 2. Reasons to include patients were based on routine (topic is always discussed), diagnoses other than cancer or neurodegenerative disorders, changes or prospective changes in the patient's health status, previous occurrence of 'close calls' , as well as ethical considerations (respect for patient autonomy)

Reasons given for not including patients included previous discussions with family members or in other healthcare teams, communication barriers or emotional difficulties, judgment that inclusion was superfluous, and neurodegenerative disorders.

A good quality of life or poor prognosis were included as justifications both to include and not to include patients in decisions regarding CPR/DNAR status.

Introducing the discussion

Descriptions of how the discussions to include the patient in CPR/DNAR decisions were initiated are outlined in Table 3. Respondents reported starting by telling the patient that this discussion was always included in admission work-ups, by asking what the patient did or did not want from a stated list, by focusing on the patient's present state of health, or on the risk of it worsening. Other reported starting with a discussion of a recent health event, or previous advance care planning, and making the initial question about CPR/DNAR a follow-up. Participants also reported announcing that this would be a difficult discussion or asking patients if they had already deliberated, either alone or with their primary care doctor, on what they did or did not want. Discussions regarding DNAR orders were initiated by residents, first residents, and patients in 68%, 2%, and 16% of cases, respectively. Discussions regarding CPR orders were initiated by residents, first residents, and patients in 86%, 2%, and 8% of cases, respectively.

DISCUSSION

Our study provides insight into residents' reasoning regarding CPR/DNAR decisions and into why, and how, they include patients in these decisions. Such findings are important both to tailor post-graduate and continuing education to doctors' perceptions and needs, and sometimes to revise or adapt ethical recommendations to fit with pitfalls of clinical practice.

Residents used arguments based on respect for patient autonomy and decision-making capacity, as well as arguments based on their own clinical assessment of the situation, to justify including or not including patients in CPR/DNAR decisions. In view of efforts made to improve a situation where patient involvement was exceptional, this represents encouraging progress. Other studies where recommendations for end-of-life care were implemented showed mixed results, with an increase in advance care planning[17] and end-of-life management[18] reported by some, but little effect on patient involvement reported by others.[19] Some justifications, such as reports that previous refusals or an unstable clinical situation are a reason to discuss treatment preferences, or that these discussions happen because they always should, also suggest a heightened awareness of the importance of patient involvement.

Residents, however, also reported several justifications for not including patients which may give cause for concern. Communication barriers were invoked, even when they were based on language or on an absent dental prosthesis. Decisions made at earlier stages in the patient's management tended not to be viewed as requiring revision. Finally, residents seem to operate with a much broader definition of a patient who is 'too well' or 'too sick' for DNAR to be discussed than the Ethics Council recommendation. They reported patients with a diagnosis of advanced cancer, but whose death was not expected in the next days, as sick enough for a DNAR order to be considered, and for it to be prescribed without patient consultation. In reverse, their reports suggest that patients with many different kinds of clinical situations are deemed too well for their treatment preferences to be discussed.

This discrepancy between residents' thresholds and the Ethics Council's threshold for allowing a decision, either CPR or DNAR, without patient involvement, was also found in previous studies,[20, 21] including in Switzerland,[14] and can be interpreted in several ways. First,

residents may be rationalizing situations where their true reason for not including patients is the anticipation of emotional difficulties with the discussion. They may underestimate the number of patients who want to discuss DNAR status with their doctor, even when they state that they would find such a discussion distressing.[3] Second, as suggested by other findings from this study, residents may underestimate the differences that can exist between their own assessment of the patient's interest, and this patient's wishes and priorities.[16] Third, this discrepancy may be associated with the thresholds of medical indication and futility, with their attendant difficulties,[22] and misuses.[23]

Among the different thresholds proposed for futility, the Ethics Council recommendation took a position which required the intervention itself to lack the prospect of restoring vital functions, and any quality of life considerations to be based on the patient's own appreciation. Residents, in contrast, considered factors such as patients' age, or likelihood of recovery could be included in the assessment of futility as regards CPR. This would be consistent with the extension of the 'end of life' label to patients with an incurable disease threatening their lives in the foreseeable future, rather than in the next few days. It would also be consistent with the fact that residents also tend to evaluate patients' quality of life themselves and include this consideration into CPR/DNAR decisions.[16]

Residents reported using a variety of introductions to discussions to include patients in CPR/DNAR decisions. These included stating that the discussion was systematic, explaining the patient's present state of health, outlining the risk of getting worse, and asking what the patient wanted or would agree to. Some discussions were initiated by following up on a complication or on a previous discussion, or asking if patients had previously thought about their treatment preferences. These reports illustrate a great diversity of strategies and experience. While some examples show sensitivity to context and to the difficulties associated with such discussions for both doctors and patients, some examples are concerning or might be misunderstood. Given public misconceptions of CPR, asking if a patient wants doctors to 'start it up again' following cardiac arrest may play into excessive expectations. Some examples of how discussions are started are technical, and cast the patient in an inappropriate expert role regarding CPR techniques. Other examples show asymmetry between CPR and DNAR orders in the manner in which discussions are initiated. While this study's sample and recruitment does not allow us to search for association, it is intriguing that patients told not to worry all ultimately had CPR orders, as did most of those told that this discussion is routine or that the discussion could be

difficult. These exploratory findings raise questions as to whether such introductions cue the patient's answer. In a recent Canadian study, patients with CPR and DNAR orders to which they had personally agreed understood these orders very differently. Patients with DNAR orders 'described resuscitation in graphic concrete terms that emphasized suffering and futility, and DN[A]R orders in terms of comfort or natural processes.' Patients with CPR orders, in contrast, 'understood resuscitation in an abstract sense as something that restores life, while DN[A]R orders were associated with substandard care or even euthanasia.'[24] It is credible that doctors' choice of words could influence such perceptions. An alternative interpretation could be that residents may adapt their wording to their sense of the patient's state of health, and write CPR/DNAR orders based on similar considerations. In either case, greater awareness would contribute to better conversations.

Several of these aspects suggest that additional and more in-depth as well as practical training of residents regarding how to reach CPR/DNAR decisions, as well as when and how to include patients, would be useful. Calls for such training have already been made elsewhere.[6, 10] Although training on CPR/DNAR could take place in many settings, it is also a missed opportunity that the reasons for CPR/DNAR decisions were rarely discussed within the medical team. Also, there are potential side-effects of implementing CPR/DNAR recommendations without simultaneous practical training. Although each of these points would require further study, patient reaction to discussions regarding their treatment preferences might be influenced by the manner in which they take place, varying from surprise, shock, or confusion, to information, respect and support. This is further reason why regular audit and follow-up of such policies should be welcome.[25]

Our study has several limitations. Our questionnaire sample included only 206 cases, which were chosen with the purpose of recruiting as many different residents as possible. This allowed us to explore different views on CPR/DNAR orders and patient inclusion, as well as experiences with such discussions, but as a result our findings reflect diversity and salience within our sample rather than frequency in clinical practice. As previously outlined,[16] we were dependent on the availability of residents and despite our efforts we may have selected residents who were more interested in ethical questions than those who might have tried to "escape" the attention of the research assistant. Our sample included a number of temporary residents who were substituting and who are less experienced than their more stable colleagues employed for a period of several years during residency. However, this is likely to have been attenuated by our broad sampling

strategy. As in other questionnaire studies, a bias could exist towards obtaining socially accepted answers. We tried to reduce this bias by guaranteeing complete confidentiality regarding respondents' identity and their answers, especially towards the clinical hierarchy. That residents did report socially/professionally undesirable attitudes, such as failing to include patients because they did not dare to do so and admitted ignorance as to why orders and resuscitation preferences were not discussed with patients, indicates that this bias was low. Finally, as with any exploratory single centre study, any generalization to other contexts should be cautious.

CONCLUSION

These results represent encouraging progress in patient involvement. However, some also provide cause for concern. Reasons to leave patients out of CPR/DNAR decisions included barriers to communication, previously made decisions, or a sense that the discussion was emotionally difficult or might be superfluous. Although the Ethics Council took a restrictive view of the cases in which futility would warrant a DNAR order without patient inclusion, residents seem to operate with a much broader definition of these cases, leading to more restrictive patient inclusion in DNAR decisions. Such results point to potential side-effects of implementing CPR/DNAR recommendations without simultaneous in-depth and practical training. This should be part of a regular audit and follow-up process for such recommendations.

Competing interests: none.

Table 1-A: Residents' justifications for CPR/DNAR prescriptions

	CPR (N=100)		DNAR (N=106)	
Reasons given for the prescription	**Disc N=22**	**≠ disc N=16**	**Disc N=29**	**≠ disc N=34**
Important comorbid conditions				
Cancer			5	10
Heart disease			2	1
Sepsis			1	
Polymorbidity			4	4
Futility / patient described as terminal		1	2	1
A decision was made for palliative management			2	2
Preferences				
Patient request	11		11	
Previous patient request				1
Family request			1	3
Advance directive				1
Patient's age	3	4	5	9
Cause for optimism				
Lack of futility / described as non terminal	3	1		
Situation is uncertain	1	2	3	
Ongoing therapeutic plan	1	1		
Possibility of recovery	1			
Disease is stable				1
Lack of comorbidities		1		
Prognosis and quality of life				
Prognosis is good				
Prognosis is poor			3	12
Patient's quality of life is good	3	5	1	2
Patient's quality of life is poor		1	2	1
Other reasons				
Patient is unable to communicate				10
Patient previously underwent an invasive procedure				1
Patient had a negative experience with treatment			1	
Decision by health care providers			2	1
There was no reason		1		

Table 1-B: Residents' justifications for CPR/DNAR prescriptions

	CPR (N=100)		DNAR (N=106)	
Disease described as determining the prescription	**Disc N=42**	**≠ disc N=37**	**Disc N=50**	**≠ disc N=52**
Several coexisting diseases (linked or not)			5	12
Cancer	11	12	18	28
Described as metastatic, advanced, or untreatable	2	2	5	15
Previous cardio-respiratory arrest				1
Heart disease	13	14	10	13
Stroke		2	1	3
Coma				1
Multiple organ failure	1			
Infectious disease (incl. sepsis, HIV)	4	3	1	1
Renal disease	3		4	3
Pneumonia*				3
Other lung disease	5	1	5	3
Liver or other digestive disease	3	1		2
Diabetes*		2		1
Obesity*	1			
Anorexia		1		
Smoking*			1	
Alcohol		2		
Bedridden or cachectic			2	1
Psychiatric*(including dementia)				2
Brain death				1
Neuro-muscular disease		3	1	1
Thrombo-embolic disease				2
Diagnosis described as uncertain	4			
Graft rejection		1		
Foot necrosis				1
Age	2	1	1	2
None		1		4

*Only mentioned along with other diagnosis

Table 2: Residents' justification for including, or not including, the patient

	Patient included (N=99)		Patient not included (N=107)	
Reasons given for the decision	**CPR N=43**	**DNAR N=48**	**CPR N=39**	**DNAR N=49**
Topic is always discussed	10	4		
Inclusion respects patients' autonomy				
To know the patient's wishes	9	4		
Patient's request		10		
Previous refusal by patient	2	8		1
Topic previously discussed with patient	1	1	1	4
Inclusion requires capacity				
Risk of loss of capacity		1*		
Decision-making capacity present		2*		
Decision-making capacity absent				7
Dementia/other CNS disease (incl psy)			4	13
Communication barriers			5*	6
Difficult conversations				
Avoid demoralizing / scaring the patient			1	1*
Patient is in denial / doesn't collaborate				3
Resident is embarrassed to broach the topic			1	2*
'Superfluous' conversations				
Patient already knows his prognosis is poor				3*
Right decision is self-evident			9	4
Discussions with others				
Discussion with family/proxy				2*
Discussion with first resident			1	
Disease makes the issue relevant				
Cancer	3	3		10
Other non CNS disease	10	10		1*
Polymorbidity	8	2		2
Severe state of health		3		
Good general health / functioning	2	2*	16	
Elective admission			1	
Changes				
New diagnosis		1		
Risk of worsening state of health	7	8		
Change in CPR/DNAR status	1*	1		
An intervention is planned	1*		1	
Situation is uncertain				1*
Close calls				
Previous ICU admission		1		
Previous C-R arrest	2			
Patient's age	16	17	15	7
Prognosis and quality of life				
No treatment option			2*	5
Prognosis is poor	3	2	1	7
Prognosis is good			7	
No expectation of C-R arrest			1*	
Quality of life is good	2	1*	2*	
Quality of life is poor		3		
Hospital processes				
Ongoing palliative management		1		5
A decision was made previously			2	5
To have a prescription to transmit				1

*Only mentioned along with other reason

Table 3: Initiating the discussion

	CPR (N=100)	DNAR (N=106)
	N=44	N=39
This discussion always takes place	15	7
DNAR: "On admission, we always discuss DNAR and CPR with patient"		
CPR: "This is a question we ask all patients. Don't worry."		
What do you want?	17	17
DNAR: "If your heart stops, do you want us to make it start again?"		
CPR: "If you heart was to stop, do you want resuscitation, cardiac massage, intubation, intensive care?"		
Agreement with a default	4	7
DNAR: "Do you want to be resuscitated?"		
CPR: "Your heart could stop. We would tend do everything for you. Do you want that?"		
Your current state of health	7	9
DNAR: "The disease is progressing. How do you see yourself in the near future?"		
CPR: "Explain the seriousness of the situation, ask if he's already thought about it, then ask questions on resuscitation, intubation, etc"		
If your health worsens	13	14
CPR: "If something bad happens while you are here…"		
DNAR: "If something serious happened, what would be your wish?"		
After this complication		
DNAR: "We've been very scared for you, and given your state of health do you want to be resuscitated if there is a serious problem or if your heart stops?"	4	5
CPR: "If it happens again like yesterday, do you want to return to intensive care or do you want us to be less aggressive, less interventionist?"		
This is a difficult discussion	6	1
CPR: "This question may seem shocking to you, but we need to know"		
DNAR: "There is a topic we'd like to discuss …"		
Let's pick it up where we left off	3	3
DNAR: "Do you still refuse intensive care? Dialysis?"		
CPR: "The last admission, it was DNAR. Have you thought about the code status? Do you want to change?"		
Don't worry	4	-
CPR: "This is a question we ask everyone. Don't worry"		
Have you already…?	1	4
DNAR: "Have you already talked with your GP about…?"		
CPR: "Explain the seriousness of the situation, then ask if he's thought about it, then ask questions"		

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