Clinical decision making in cardiopulmonary resuscitation

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Chapter 8

General discussion

Survival probability

Expected survival probability of resuscitation appears not to be an independent explanatory factor of decisions to withhold resuscitation at pre-hospital and hospital ward levels. The result is not surprising since in our hospital this decision turned out to be associated with other end-of-life decisions. Nevertheless, it is essential to be able to predict survival with sufficient confidence. The generally proposed Pre-Arrest Mortality (PAM) score and the Probability After Resuscitation (PAR) score are based on an aggregated score of morbidities being present or absent (Chapter 8). There scores may not be able to predict survival under all circumstances. The new prognostic score presented in Chapter 5 is based on the dynamics of pre-arrest morbidity. With our prognostic model we could identify a subgroup of patients at risk for a poor outcome (inventor probability 90 percent or less). This does not imply that our model can be used as a formal decision model on the level of the individual patient. There always will remain patients who survive against the odds. As yet, the prediction of survival that leaves much to be desired. Furthermore, there is no consensus about when probability of survival resuscitation is no longer worthwhile to undertake. Still, we consider our model useful for decisions in discussions about the patient's prognosis. We think that our survival information is essential because many doctors, nurses, patients and their partners have no realistic expectation about survival after resuscitation and their preferences for treatment depend to some extent on survival information (Chapter 7).

Quality of life after resuscitation

Using survival as an indicator of "successful resuscitation" can be misleading because it is not a synonym for good quality of life. Studies have shown that survival can mean an independent life at home, dependence life in a nursing home or a vegetative state. Such a differentiation is important, relevant for patients. The knowledge about more refined quality of life outcomes after resuscitation is rather global. This because quality of life in this kind is mostly assessed by clinical judgements, not by formal instruments (Chapter 8). We measured the quality of life of patients after resuscitation and showed that the common fear that resuscitation frequently leads to a long-term poor quality of life is unjustified (Chapter 8).
We studied essential elements of decisions to terminate and to withhold cardio-pulmonary resuscitation in hospitals. These are: the survival probability and quality of life after resuscitation, and the patient’s prospects without cardiac arrest, in terms of expected life time and quality of life. Our results will be discussed in this context. Furthermore, we shortly address the issue of costs, discussions with patients and highlight some aspects of decision making. Finally, some suggestions are made for future research.

Survival probability
Expected survival probability after resuscitation appeared not to be an independent explanatory factor of decisions to withhold resuscitation (Chapter 3). This result is not surprising since in our hospital this decision turned out to be associated with other end-of-life decisions. Nevertheless, it is essential to be able to predict survival with sufficient confidence. The generally proposed Pre Arrest Morbidity (PAM) score and the Prediction After Resuscitation (PAR) score are based on an aggregated score of morbidities being present or absent (Chapter 3). These scores may not be able to predict survival under all circumstances. The new prognostic score presented in Chapter 4 is based on the dynamics in pre-arrest morbidity. With our prognostic model we could identify a subgroup of patients at risk for a poor outcome (survival probability 10 percent or less). This does not imply that our model can be used as a formal decision model on the level of the individual patient. There always will remain patients who survive against the odds. As yet, the prediction of survival thus leaves much to be desired. Furthermore, there is no consensus about which probability of survival resuscitation is no longer worthwhile to undertake. Still, we consider our model useful for doctors in discussions about the patient’s prognosis. We think that our survival information is essential because many doctors, nurses, patients and their partners have no realistic expectations about survival after resuscitation and their preferences for resuscitation depend to some extent on survival information (Chapter 7).

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Using survival as an indicator of ‘successful resuscitation’ can be misleading, because it is not a synonym for good quality of life.
Studies have shown that survival can mean an independent life at home, a dependent life in a nursing home or a vegetative state. Such a difference is, no doubt, relevant for patients. The knowledge about more refined quality of life outcomes after resuscitation is rather global. This because quality of life in this field is mostly assessed by clinical judgements, and not by formal instruments (Chapter 5). We measured the quality of life of survivors after resuscitation and showed that the common fear that resuscitation frequently leads to a long-term poor quality of life is not justified (Chapter 6).
Interestingly, the most important explanatory factors for an impaired level of quality of life after resuscitation were patient characteristics known before the arrest, such as older age and noncardiac reason of admission. These findings may be particularly helpful when informing patients and taking decisions about resuscitation. In view of the findings, we feel no need to make quality of life after resuscitation a prominent issue in discussions with patients, other than for those who are at risk for a poor quality of life after resuscitation.

**Prospects without cardiac arrest**

The patient's prospects without cardiac arrest in terms of life expectancy and quality of life, is frequently uncertain. However, it is biological not plausible that resuscitation will improve the prospects. At best the patient's present condition remains unchanged. A resuscitation attempt in patients with an expected short life expectancy and a poor quality of life seems therefore disproportional, because there are no likely health benefits. Resuscitation should thus be in balance with the prospects without cardiac arrest.

In Chapter 3 we showed that, besides age, the patient's prospects in terms of reduced life expectancy and dependency had a clear impact on the decision to withhold resuscitation. Whether these and other aspects of quality of life were of different importance to doctors, nurses, patients and their partners remained, however, unknown. Therefore, we investigated the impact of various prospects without cardiac arrest on the preference for resuscitation, and demonstrated that doctors, nurses, patients and their partners had indeed different perspectives in some matters (Chapter 7). For example, an expected short life expectancy influenced the preference for resuscitation of patients, but doctors were significantly more influenced by this aspect. Differences between patients and doctors also concerned the importance of emotional distress and social isolation. The trade-offs between life expectancy and aspects of quality of life were found to be complex and preferences between individual respondents could be very different. This suggests that there is no consensus about which aspects of life make resuscitation senseless.

In this chapter, we also showed that 14% of doctors, 20% of nurses, 34%, and 18% of partners always favored or opposed resuscitation, regardless the prospects without resuscitation. Apparently besides the investigated factors, other aspects play a role, such as religion, social circumstances and personal views. That personal views influence decisions of patients can be illustrated by the following case. A well-educated and competent patient wished to have a do-not-resuscitate order. She had cared for her mother who lived in a nursing home and wanted to avoid a similar life after a potential resuscitation. It was explained to her that with her condition the risk for such a life was small, and that death or survival in her current state of health was more likely. She understood this information, but still preferred death above the small chance
of a life in a nursing home. This illustrates that decision making is a highly individual matter and can be driven by a variety of issues and risk attitudes.9

**Costs**

When taking care of the patients, doctors should be aware of the consequences of their clinical actions for future patients, in terms of financial costs, resources, time and energy. In this respect, particularly the use of life prolonging technology near the end of life has become a concern.10,11 Costs involve choices at a macrolevel, whereas the cost issue has hardly any place in discussions at a microlevel, where choices concern individual patients.

We showed in Chapter 3 that for 32% of the patients with a life expectancy of less than three months resuscitation and other life prolonging technology were still available (Table 3.4.). We do not judge such a policy, but it illustrates variations based on value judgements, problems of setting limits to care or unstructured care. Although doctors have no obligation to provide futile care, it remains difficult to determine when resuscitation is futile. If the consequence is that always the patients must decide whether resuscitation is worthwhile, the financial impact of fully granting this autonomy can be great. On the other hand, we have demonstrated that patients are in general not more inclined to resuscitation than doctors (Chapter 7), and the financial consequences of generally granting patient’s autonomy in resuscitation seems thus only a potential, but not an actual problem.

**DISCUSSIONS WITH PATIENTS**

Hospitalized patients may expect that resuscitation is initiated in case of a cardiac arrest, unless the doctor informs the patient about the opposite.12-16 Nevertheless, and as said before, not all patients prefer to undergo resuscitation and discussions with patients are needed to be informed about their preferences. Research revealed that in the United States the subject was not discussed in 75% of the cases.17 Even in seriously ill patients resuscitation was discussed with only 10 to 30% of the patients. Research in the Netherlands has focussed on the presence of do not-attempt resuscitation orders, and not on routine discussions with patients about resuscitation. However, we have no evidence that resuscitation is more routinely discussed in the Netherlands than in the United States. Six percent of the total Dutch hospital population has a do-not-attempt resuscitation order (Government Commission Remmelink),18-20 but only 14% of these patients were informed about the presence of such an order. Of course, because of cognitive deterioration or coma, a do-not-attempt resuscitation order cannot always be discussed with patients,
but the Dutch commission concluded that in about one third of all patients a discussion had been possible, but was not undertaken.

How do patients react when the subject of resuscitation is brought up? Most patients have positive feelings: they feel to have control over things (71%), feel relieved (53%), and feel cared for (53%). A minority becomes nervous (22%), feels sad (16%) and thinks that the doctor is giving up (6%). If information on disease prognosis would distress patients and hamper their recovery, a doctor can withhold this for therapeutical reasons and make autonomous decisions. How often doctors call upon this ‘therapeutic exception’ is unknown, but care should be taken that the doctor’s reluctance to bring ‘bad’ news to patients, is a substitute for the opinion that for many patients it would be better to be ignorant about their future.

From Chapter 3 we conclude that do-not-attempt resuscitation orders were closely related to withholding other treatments as well. Well considered, there is no reason to link discussions about resuscitation to other treatment limitations. Cardiac arrest is an acute event and may occur in relatively healthy patients. Discussing resuscitation thus concerns in fact all patients. But should we really discuss resuscitation with every patient in the hospital? The current Dutch law Medical Treatment Agreement (Wet Geneeskundige Behandelings-overeenkomst) regulates the obligation to inform patients.

The law also sets limits to the use of the ‘therapeutic exception’. The explanatory memorandum states that an expected impaired recovery of patients by providing information is not sufficient ground to withhold such information. According to the memorandum, a call on the ‘therapeutic exception’ is (only) justified when there is a reasonable risk of suicide. Doctors can object this statement by saying that many patients have a low probability of getting a cardiac arrest and that for those patients the issue is not relevant, or is unnecessary frightening. Furthermore, they may reason that the major medical goal is prolonging life, this can be achieved with resuscitation and such efforts will be expected by their patients.

A practical argument of doctors can also be that it is time consuming to discuss the topic with every patient, indifferent to the probability of a cardiac arrest. Some philosophers may also oppose a discussion about resuscitation with every patient. They argue that the reason for seeking the opinion and consent of patients is a way to promote their autonomy, and that respecting autonomy does not mean that one seeks the opinion of patients in matters that are very unlikely to occur. In contrast, jurists can refer to the Dutch Law and consider resuscitation just as any other treatment and argue that a doctor has to get consent from a patient before instituting a treatment, and argue that a doctor has to get consent from a patient before instituting a treatment, certainly if risks are involved.
From the studies presented in this thesis and in the literature, we learned that cardiac arrest occurs in a rather unpredictable heterogeneous population of patients, that most patients have wrong expectations about survival after resuscitation and that they have a wide variability of preferences. Moreover, most patients prefer that the topic is discussed, but often don't take the initiative to talk about the subject. In this field of tension, we feel that there still are good arguments for having a general policy about informing relevant patients about resuscitation.

DECISIONS

Decisions by patients
If resuscitation is discussed with patients, do they really want to make decisions themselves? Unpublished data of our study presented in Chapter 7 revealed that 80% of the patients in our hospital wanted to be involved in resuscitation decisions. Fifty percent of these patients wanted to share their decisions with the doctor; whereas 40% preferred to take decisions all by themselves. Only 10% preferred that doctors alone took such decisions. A recent study concluded that contrary to doctors themselves, patients prefer a more active role for doctors in both discussion of end-of-life care and decisions. This does not imply that doctors should make first decisions not to resuscitate, and then inform their patients or solicit approval from their patients and their partners. In this approach, the discussion with patients is not very open.

Decisions by others
What happens if patients cannot be consulted or are not able to make a choice, and a decision about resuscitation cannot be postponed? If a patient has already and competently expressed preferences with sufficient clarity, these
preferences can be extended to situations of incompetence.\textsuperscript{26} If there is no evidence about previous wishes, resuscitation can be withheld if no survival is expected or if the burdens of the patient’s life with treatment clearly outweigh the benefits of that life. The persons who should balance these benefits and burdens are generally speaking the partners of patients, the doctors and the nurses. In our hospital, partners are, as yet, no substitute decision makers for the patients, but are very important advisors of the doctor who carries the responsibility for the decision about a do-not attempt resuscitation order. Although the information of partners can certainly play a decisive role, it is our opinion that doctors remain responsible to safeguard the patient’s best interest.

In about 30 to 40\% of the cases inconsistencies are reported between the choice of a patient and the predicted choice by surrogate decision makers.\textsuperscript{27–29} To minimize the possibility of such inconsistencies, all participants in the decision making process should take the patient’s expected preference under the given circumstances as starting point, and not their own preferences. In that respect, it is essential to have a good picture of the patient’s personal background and goals in life.\textsuperscript{23}

**No decisions**

As yet, resuscitation requires no prior consent of a patient, and without a do-not-attempt resuscitation order it will be applied even without strict doctor’s orders. If a cardiac arrest occurs, a resuscitation team is called. This medical fire brigade has no time for deliberations about the sense or desirability of the resuscitation attempt, and will hardly be able to judge this in the context of an ongoing resuscitation attempt. Decision making becomes a matter of rules (Chapter 2) which concentrate on the survival probability. In that respect, the decision making process during resuscitation has a smaller basis.

If no decisions are taken, and a resuscitation attempt is performed in an unavoidable deathbed, futile care is given and the patient’s dignity is jeopardized. If this attempt turns out to be not preferred by the patient, his or her autonomy has not been respected. Such a situation is undesirable, leads to conflicts during and after resuscitation and is not necessary. Nevertheless, in view of the acuteness of the event and goals of medicine, we do not recommend a change of the current hospital policy in such a way that a patient should give explicit consent for resuscitation and that a resuscitation attempt can only be initiated under this condition.
DIRECTIONS FOR FUTURE RESEARCH

To improve the probability of survival after resuscitation, directions for future research concern the improvement of the in-hospital Chain of Survival. With the development of semi-automated defibrillators for use out-of-hospital by relatively lay people (e.g. police officers), one can think of the application of these defibrillators by nurses. The evaluation of such practice should concentrate on the efforts made versus the effectiveness, the incidence of shockable cardiac rhythms in a hospital, and trainability and retention of skills required for the semi-automated defibrillator. Another amelioration of the in-hospital Chain of Survival can come from new strategies to treat post-anoxic encephalopathy, such as experiments with hypothermia.

With regard to the quality of life after resuscitation, a firm core of knowledge about the relation between resuscitation and the outcome is still required. Differences in quality of life between similar patients with and without a cardiac arrest and subsequent resuscitation is still a relatively unexplored area. We expect that more information about the condition of the patients before resuscitation will lead to a more complete explanation of their quality of life after resuscitation (Chapter 6). Our results suggest a difference in physical functioning of resuscitation survivors over time. This may imply that the outcome ‘quality of life after resuscitation’ depends on the timing of assessment. When investigating changes in quality of life over time, a longitudinal study design is required, with repeated measures and control over mortality as a potential selection bias. Aspects of adaptation of patients to less favorable conditions after resuscitation and how this influences the quality of life measurements need also further research.

Concerning the decision making during resuscitation, we propose the development of improved guidelines to terminate resuscitation (Chapter 2). Furthermore, the prognostic model presented in Chapter 4 needs further research in terms of its reliability, and discriminative ability, as well as internal and external validity.

In this thesis, we have not investigated the optimal information strategy to avoid harm to the patient and guarantee well-balanced decisions. Not all patients can be considered adequate decision makers. To prepare them, there should be a proper climate for discussing resuscitation. There are many factors which can influence the patient’s feelings, their readiness to decide, and their final decision. One can think of the time of the discussion in the clinical course (e.g. outpatient clinic, the first day of admission), the type, the amount and the order of the given information. Of course, also the information...
provider is a factor to be investigated. One might hypothesize that the professional background of the provider (doctor or nurse) may also influence the patient's preference for treatment. For example, doctors talk with patients about resuscitation within the context of disease, treatment and prognosis, whereas nurses talk with patients about resuscitation within the context of general care.

All in all, we believe that there are good reasons for an early discussion with patients about resuscitation. Patients also expect an active role of health care professionals. Ideally, a do-not attempt-resuscitation order is discussed with relevant patients upon admission, and after clinically relevant changes in health during admission. Such a discussion should neither give the impression, nor imply that the maximum medical and nursing care is withheld. Decisions should include information about survival probability, quality of life after resuscitation, as well as the patient's prospects without cardiac arrest.

Proper conditions are necessary to make patients adequate decision makers, and decision makers should be fed with adequate information about the outcomes after resuscitation. When doctors have to decide about resuscitation without knowing the patient's preference, they can balance their decisions with information from the partner and nurse about the patient's views and social history. Nurses can have other information about the patient and they nearly always have to start the resuscitation attempt. For a well-accepted resuscitation decision, and to avoid that resuscitation is performed half-heartedly, the support of nurses is indispensable.

A practical approach for all those involved in decisions about resuscitation is finding an answer to three questions: (1) what is the chance of survival, (2) what is the sense of a resuscitation attempt in terms of quality of life after resuscitation and prospects without cardiac arrest, and (3) what is the patient's (expected) preference? Bringing up the subject of resuscitation with patients has the advantage that it can also enlighten their general attitude to other invasive medical treatments. Experiences with well-balanced decisions about resuscitation may be expanded in the future to other treatment choices, such as those for intensive care, mechanical ventilation, and dialysis.
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