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European Resuscitation Council Guidelines for Resuscitation 2010 Section 10. The ethics of resuscitation and end-of-life decisions

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Introduction

Sudden unexpected cardiac arrest is an event with often devastating consequences to the individual victim, family and friends. While some resuscitation attempts are successful with good longterm outcome, the majority are not, despite significant efforts and some improvements during the last decade.

Healthcare professionals are obliged to do what is necessary to protect and save lives. Society as a whole and especially emergency medical services (EMS), hospitals and other healthcare institutions need to plan for, organise and provide an appropriate response in case of sudden cardiac arrest. This often implies the use of many resources and high costs, especially in the more affluent countries. New technology and medical evidence and increasing expectations of the public have rendered ethical considerations an important part of any end-of-life intervention or decision. This includes achieving the best results for the individual patient, relatives and for society as whole by appropriate allocation of available resources.

Several considerations are required to ensure that decisions to attempt or withhold resuscitation attempts are appropriate, and that patients are treated with dignity. These decisions are complex and may be influenced by individual, international and local cultural, legal, traditional, religious, social and economic factors.^{1–11}

Sometimes the decisions can be made in advance, but often these difficult decisions have to be made in a matter of seconds or minutes at the time of the emergency and especially in the outof-hospital setting, based upon limited information. Therefore it is important that healthcare providers understand the principles involved before they are faced with a situation where a decision to resuscitate or not must be made. For healthcare professionals end-of-life decisions and ethical considerations should be made in advance and in the context of the society. Although there is little science to guide end-of-life decision-making, the subject is impor-

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tant, which is why information for healthcare providers is included in these resuscitation guidelines.

This section of the guidelines deals with some recurring ethical aspects and end-of-life decisions.

- Key principles of ethics
- Sudden death in a global perspective
- Outcome and prognostication
- When to start and when to stop resuscitation attempts
- Advance directives and do-not-attempt resuscitation orders
- Organ procurement
- Family presence during resuscitation
- Research in resuscitation and informed consent
- Research and training on the recently dead

Principles of ethics

The key principles of ethics are referred to as autonomy, beneficence, non-maleficence, justice and further more dignity and honesty.12

Autonomy is the right of the patient to accept or refuse any treatment. Autonomy relates to patients being able to make informed decisions on their own behalf, rather than being subjected to paternalistic decisions being made for them by healthcare professionals. This principle has been introduced during the past 40 years, arising from legislature, primarily the Helsinki Declaration of Human Rights and its subsequent modifications and amendments.¹³ Autonomy requires that the patient is adequately informed, competent, free from undue pressure and that there is consistency in the patient's preferences. The principle is considered universal in medical practice; however, it may often be difficult to apply in an emergency, such as sudden cardiac arrest.

Non-maleficence means doing no harm or, even more appropriate, no further harm. Resuscitation should not be attempted in obviously futile cases.

Beneficence implies that healthcare providers must provide benefits in the best interest of the individual patient while balancing benefit and risks. Commonly, this will involve attempting resusci-

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tation, but on occasion it will mean withholding cardiopulmonary resuscitation (CPR).

Justice implies the concern and duty to distribute limited health resources equally within a society, and the decision of who gets what treatment (fairness and equality). If resuscitation is provided, it should be made available to all who will benefit from it within the frame of available resources.

Dignity and honesty are frequently added as essential elements of ethics. Patients always have the right to be treated with dignity and information should be honest without suppressing important facts. Transparency and disclosure of conflict of interests (COI) is another important part of the ethics of medical professionalism. The importance of this is emphasized by the COI policy operated by the International Liaison Committee on Resuscitation (ILCOR).¹⁴

Sudden death in a global perspective

In Europe, with 46 countries and with a population on the European continent of 730 million, the incidence of sudden cardiac arrest is estimated at between 0.4 and 1 per 1000 inhabitants per year, thus involving between 350,000 and 700,000 people.¹⁵ Approximately, 275,000 persons have a cardiac arrest treated by the EMS in Europe.¹⁶ Out-of-hospital cardiac arrest is the third leading cause of death in the USA.¹⁷ In Europe and USA ischaemic heart disease is considered the main cause of sudden cardiac arrest.

Health challenges look different in a worldwide perspective. In the World Health Organization (WHO) 2002 Annual Report, two extreme findings are found almost side by side: 170 million children in poor countries were underweight, causing over three million deaths yearly, and on the other extreme at least 300 million adults worldwide were overweight or clinically obese with high risk of sudden cardiac arrest.¹⁸ In parallel, the cause of sudden death differs widely across the world. Outside Europe and North America, cardiac arrest of non-cardiac aetiology, such as trauma, drowning or newborn asphyxia, is more important than cardiac aetiology. More than 1.3 million people die yearly in road traffic accidents.¹⁹ In 2008, there were 8.8 million deaths among children less than 5 years old, with considerable inequities between countries. Diarrhoea and pneumonia still kill almost 3 million children less than 5 years old annually, especially in low-income countries. And about one third of deaths among children less than five years of age occur in the first month of life. More than 500,000 women die of complications during pregnancy or childbirth, 99% of them in developing countries.^{20,21} Worldwide, it is estimated that approximately 150,000 people die from drowning each year, and the majority are children.22

In summary, sudden death is a worldwide challenge. Aetiology differs and treatment and prevention have to be tailored to the local problems and resources. The obligation and challenges to protect and save lives are evident both from the local and the global perspective.

Outcome from sudden cardiac arrest

Resuscitation efforts often focus on sudden and unexpected cardiac arrest that should have been prevented. Included in the decision on whether to commence resuscitation is the likelihood of success and, if initially successful, the quality of life that can be expected following hospital discharge. Reliable and valid data are therefore essential to guide healthcare providers. Resuscitation attempts are unsuccessful in 70–98% of cases and death ultimately is inevitable.

Several studies have demonstrated that successful resuscitation after cardiac arrest produces a good quality of life in most survivors. There is little evidence to suggest that resuscitation leads to a large pool of survivors with an unacceptable quality of life. Cardiac arrest survivors may experience post-arrest problems including anxiety, depression, post-traumatic stress, and difficulties with cognitive function. Clinicians should be aware of these potential problems, screen for them and, if found, treat them.^{23–38} Future interventional resuscitation studies should include long-term follow up evaluation.

Prognostication in cardiac arrest

In well-developed pre-hospital systems, about one third to one half of patients may achieve Return of Spontaneous Circulation (ROSC) with CPR, with a smaller proportion surviving to the hospital critical care unit, and an even smaller proportion surviving to hospital discharge with good neurological outcome. Prognostication is of the essence to guide clinicians, and it would be important to be able to predict poor outcome with high specificity to reduce unnecessary burden on the patient, family members and health care providers, and reduce inappropriate use of resources. Unfortunately, there are currently no valid tools for prognostication of poor outcome in the emergency setting, including the first few hours after ROSC. In fact, prediction of final neurological outcome in patients remaining comatose after ROSC is difficult during the first 3 days.³⁹ The inclusion of therapeutic hypothermia has further challenged the previously established prognostic criteria.⁴⁰

Certain circumstances, for example hypothermia at the time of cardiac arrest, will enhance the chances of recovery without neurological damage, and the normal prognostic criteria (such as asystole persisting for more than 20 min) are not applicable.⁴¹

When to start and when to stop resuscitation attempts?

In all cases of sudden cardiac arrest the healthcare provider is being challenged with two main questions: when to start and when to stop resuscitation attempts? In the individual case, the decision to start, continue or to terminate resuscitation attempts, is based on the difficult balance between the benefits, risks and cost these interventions will place on patient, family members and healthcare providers. In a broader perspective, cost to the society and health care system is part of this. The standard of care remains the prompt initiation of CPR. However, ethical principles such as beneficence, non-maleficence, autonomy, and justice have to be applied in the unique setting of emergency medicine. Physicians have to consider the therapeutic efficacy of CPR, the potential risks, and the patient's preferences.^{42,43}

Resuscitation is inappropriate and should not be provided when there is clear evidence that it will be futile or is against the expressed wishes of the patient. Systems should be established to communicate these prospective decisions and simple algorithms should be developed to assist rescuers in limiting the burden of futile and unnecessary costly treatments. One prospective study demonstrated that a basic life support termination of resuscitation rule (no shockable rhythm, unwitnessed by EMS and no return of spontaneous circulation) was predictive of death when applied by defibrillation-only emergency medical technicians.⁴⁴ Subsequent studies showed external generalisability of this rule, but it has also been challenged.^{45–47} Prospectively validated termination of resuscitation rules are recommended to guide termination of prehospital CPR in adults. Other rules for various provider levels, including in-hospital providers, may be helpful to reduce variability in decision-making; but all rules should be validated prospectively before implementation. The implementation of a termination rule will carry a self-fulfilling prophecy, and should be challenged periodically as new treatments evolve.

Who should decide not to attempt resuscitation?

Resuscitation protocols or standard operating procedures should define who has the obligation and responsibility to make the difficult decision not to attempt resuscitation or to abandon further attempts. This goes for the pre-hospital and in-hospital setting and might vary according to legislation, culture or local tradition.

In hospital, the decision is usually made, after appropriate consultations, by the senior physician in charge of the patient or the leader of the resuscitation team when called. Medical emergency teams (METs), acting in response to concern about a patient's condition from ward staff, can initiate DNAR decisions.^{48–50} In the pre-hospital setting, in the absence of doctors, the decision can be made according to standard protocols or after consultation with a physician.

Legislation on who can make decisions about death varies within countries. Many out-of-hospital cardiac arrest cases are attended by emergency medical technicians (EMTs) or paramedics, who face similar dilemmas about when to determine if resuscitation is futile and when it should be abandoned. In general, resuscitation is started in out-of-hospital cardiac arrest unless there is a valid advanced directive to the contrary or it is clear that resuscitation would be futile in cases of a mortal injury, such as decapitation, rigor mortis, dependent lividity and fetal maceration. In such cases, the non-physician is making a diagnosis of death but is not certifying death, which, in most countries, can be done only by a physician.

What constitutes futility?

Futility exists if resuscitation will be of no benefit in terms of prolonging life of acceptable quality. It is problematic that, although predictors for non-survival after attempted resuscitation have been published, none have been tested on an independent patient sample with sufficient predictive value, apart from end-stage multi-organ failure with no reversible cause.⁵¹⁻⁵⁶ Furthermore, studies on resuscitation are particularly dependent on system factors such as time to start of CPR, time to defibrillation, etc. These intervals may be prolonged in any study cohort but are often not applicable to an individual case. Inevitably, judgements will have to be made, and there will be grey areas where subjective opinions are required in patients with heart failure and severe respiratory compromise, asphyxia, major trauma, head injury and neurological disease. The age of the patient may influence the decision but age itself is only a relatively weak independent predictor of outcome.^{56–58} However, high age is frequently associated with comorbidity, which does have an influence on prognosis. At the other end of the scale, most physicians will err on the side of intervention in children for emotional reasons, even though the overall prognosis in children is often worse than in adults. It is therefore important that clinicians understand the factors that influence resuscitation success.

When to abandon further resuscitation attempts

The vast majority of resuscitation attempts do not succeed and therefore have to be abandoned. Several factors will influence the decision to stop the resuscitative effort. These will include the medical history and anticipated prognosis from factors such as the period between cardiac arrest and start of CPR by bystanders and by healthcare professionals, the initial ECG rhythm, the interval to defibrillation and the period of advanced life support (ALS) with continuing asystole, no reversible causes and no ROSC.⁵⁹

In many cases, particularly in out-of-hospital cardiac arrest, the underlying cause of arrest may be unknown or merely surmised, and the decision is made to start resuscitation while further information is gathered. If it becomes clear that the underlying cause renders the situation to be futile, then resuscitation should be abandoned if the patient remains in asystole with all ALS measures in place. Additional information such as an advance directive may become available and may render discontinuation of the resuscitation attempt ethically correct.

In general, resuscitation should be continued as long as VF persists. It is generally accepted that ongoing asystole for more than 20 min in the absence of a reversible cause, and with ongoing ALS, constitutes grounds for abandoning further resuscitation attempts.⁶⁰ There are, of course, reports of exceptional cases that do not support the general rule, and each case must be assessed individually. Ultimately, the decision is based on the clinical judgement that the patient's arrest is unresponsive to ALS. In out-of-hospital cardiac arrest of cardiac origin, if recovery is going to occur, ROSC usually takes place on site. Patients with primary cardiac arrest, who require ongoing CPR without any return of a pulse during transport to hospital, rarely survive neurologically intact.^{61,62}

Many will persist with the resuscitation attempt for longer if the patient is a child. This decision is not generally justified on scientific grounds, though new data are encouraging.⁶³ Nevertheless, the decision to persist in the distressing circumstances of the death of a child is understandable, and the potential enhanced recruitment of cerebral cells in children after an ischaemic insult is an as yet unknown factor. If faced with a newly born baby with no detectable heart rate, which remains undetectable for 10 min, it is appropriate to then consider stopping resuscitation.⁶⁴

Advance directives

Advance directives have been introduced in many countries, emphasizing the importance of patient autonomy. Advance directives are a method of communicating the patient's wishes concerning future care, particularly towards the end-of-life, and must be expressed while the patient is mentally competent and not under duress. Advance directives are likely to specify limitations concerning terminal care, including the withholding of CPR. This may help healthcare attendants in assessing the patient's wishes should the patient later become mentally incompetent. However, challenges can arise. The relative may misinterpret the wishes of the patient, or may have a vested interest in the death (or continued existence) of the patient. On the other hand, healthcare providers tend to underestimate sick patients' desire to live.

Written directions by the patient, legally administered living wills or powers of attorney may eliminate some of these problems but are not without limitations. The patient should describe as precisely as possible the situation envisaged when life support should be withheld or discontinued. This may be aided by a medical adviser. For instance, most people would prefer not to undergo CPR in the presence of end-stage multi-organ failure with no obvious reversible cause, but the same persons would welcome the attempt at resuscitation should ventricular fibrillation (VF) occur in association with a remediable primary cardiac cause. Patients often change their minds with changes in circumstances, and therefore the advanced directive should be as recent as possible and take into account any change of circumstances.

In sudden out-of-hospital cardiac arrest, the attendants usually do not know the patient's situation and wishes, and an advance directive is often not readily available. In these circumstances, resuscitation should begin immediately and questions addressed later. There is no ethical difference in stopping the resuscitation attempt that has started if the healthcare providers are later presented with an advance directive limiting care. There is considerable international variation in the medical attitude towards written advance directives.¹ In some countries, the written advance directive is considered to be legally binding; in others not.

DNAR orders

A do-not-attempt resuscitation (DNAR) order (also described more recently as a DNACPR decision) is a binding legal document that states that resuscitation should not be attempted in the event of cardiac or respiratory arrest; meaning that CPR should not be performed. Other treatment should be continued, particularly pain relief and sedation, as required and indicated, if they are considered to be contributing to the quality of life. If not, orders not to continue or initiate any such treatments should be specified independently of DNAR orders. For many years, DNAR orders in many countries were written by single doctors, often without consulting the patient, relatives or other health personnel, but there are now clear procedural requirements in many countries.⁶⁵

Although the ultimate responsibility and decision for DNAR rests with the senior doctor in charge of the patient, it is wise for this individual to consult others before making the decision. Following the principle of patient autonomy it is wise, if possible, to ascertain the patient's wishes about a resuscitation attempt. This must be done in advance, when the patient is able to make an informed choice. Opinions vary as to whether such discussions should occur routinely for every hospital admission or only if the diagnosis of a potentially life-threatening condition is made. In presenting the facts to the patient, the doctor must be as certain as possible of the diagnosis and prognosis and may seek a second medical opinion in this matter. It is vital that the doctor should not allow personal life values to distort the discussion-in matters of acceptability of a certain quality of life, the patient's opinion should prevail. It is considered essential for the doctor to have discussions with close relatives if at all possible. Whereas they may influence the doctor's decision, it should be made clear to them that the ultimate responsibility and decision will be that of the doctor. It is neither fair nor reasonable to place the burden of decision on the relative.

According to the principle of autonomy, patients have the right to refuse treatment; however, they do not have an automatic right to demand a specific treatment—they cannot insist that resuscitation must be attempted in any circumstance. A doctor is required only to provide treatment that is likely to benefit the patient, and is not required to provide treatment that would be futile. However, it would be wise to seek a second opinion in making this decision, for fear that the doctor's own personal values, or the question of available resources, might influence his or her opinion.⁶⁶

In adult cardiac arrest various studies have addressed the impact of advance directives and DNAR orders in directing appropriate resuscitation efforts. Most of these studies are old and often contradictory.^{67–76} Standardised orders for limiting life-sustaining treatments decrease the incidence of futile resuscitation attempts and should ensure that adult patient wishes are honoured. Instructions should be specific, detailed, and transferable across health care settings, and easily understood. Processes, protocols, and systems should be developed that fit within local cultural norms and legal limitations to allow providers to honour patient wishes regarding resuscitation efforts.

Organ procurement

The issue of initiating life-prolonging treatment or continuing otherwise futile resuscitation attempts with the sole purpose of harvesting organs is debatable.^{77,78} There is variation between countries and cultures about the ethics of this process; at present no consensus exists. If considering prolonging CPR and other resuscitative measures to enable organ donation to take place mechanical chest compressions may be valuable in these circumstances.^{79,80}

Family presence during resuscitation

The concept of a family member being present during the resuscitation process was introduced in the 1980s and has become accepted practice in many countries.^{81–86} Many relatives would like to be present during resuscitation attempts and, of those who have had this experience, over 90% would wish to do so again. Most parents would wish to be with their child at this time.⁸²

Relatives have considered several benefits from being permitted to be present during a resuscitation attempt, including coming to terms with the reality of death. However, this is a choice entirely to be made by the relatives. Several measures are required to ensure that the experience of the relative is the best under the circumstances. This includes allocating personnel to take care of the relatives.^{87,88}

In the event of an out-of-hospital arrest, the relatives may already be present, and possibly performing basic life support (BLS). They should be offered the same choices and appreciation of their effort as bystander offering BLS. With increasing experience of family presence during resuscitation attempts, it is clear that problems rarely arise. Fifteen years ago, most staff would not have countenanced the presence of relatives during resuscitation, but there is an increasingly open attitude and appreciation of the autonomy of both patient and relatives.¹ Cultural and social variations still exist, and must be understood and appreciated with sensitivity.

Research in resuscitation and informed consent

There is an essential need to improve the quality of resuscitation and thereby the long-term outcome. To achieve this, research and randomised clinical trials are crucial, not only to introduce new and better interventions, but also to abandon the use of inefficient and costly procedures and medications, whether old or new. As the ILCOR 2010 consensus on CPR and ECC Science clearly reveals many current practises are based upon tradition and not on science.^{89,90}

There are important ethical issues relating to undertaking randomised clinical trials for patients in cardiac arrest who cannot give informed consent to participate in research studies. Progress in improving the dismal rates of successful resuscitation will only come through the advancement of science through clinical studies. The utilitarian concept in ethics looks to the greatest good for the greatest number of people. This must be balanced with respect for patient autonomy, according to which patients should not be enrolled in research studies without their informed consent. Over the past decade, legal directives have been introduced into the USA and the European Union^{91,92} that place significant barriers to research on patients during resuscitation without informed consent from the patient or immediate relative.93 There are data showing that such regulations deter research progress in resuscitation.⁹⁴ It can be argued that these directives may in themselves conflict with the fundamental human right to good medical treatment as set down in the Helsinki Declaration.¹³ The US authorities have, to a very limited extent, sought to introduce methods of exemption,⁹⁵ but these are still associated with problems and almost insurmountable difficulties.94,96,97

Research and training on the recently dead

Research on the recently dead encounters similar restrictions unless previous permission is granted as part of an advance direc-

tive by the patient, or permission can be given immediately by the relative. The management of resuscitation can be taught using scenarios with manikins and simulators or animal models, but training in certain skills required during resuscitation is difficult. Therefore the question arises as to whether it is ethically and morally appropriate to undertake training and practice on the living or the dead. There is a wide diversity of opinion on this matter.^{98,99} Many, particularly those in the Islamic nations, find the concept of any skills training and practice on the recently dead completely unacceptable because of an innate respect for the deceased. Others will accept the practice of non-invasive procedures that do not leave a mark; and some accept that any procedure may be learned on the dead body with the justification that the learning of skills is paramount for the well being of future patients. One option is to request informed consent for the procedure from the relative of the deceased. It is advised that healthcare professionals learn local and hospital policies regarding this issue and follow the established policy.

Summary

Sudden unexpected cardiac arrest is a global challenge. Some deaths are preventable and some arrests can be treated successfully and result in a very good long-term outcome. However, most resuscitation attempts are futile and death is inevitable. End-of-life decision is an important part of resuscitation.

Scientific evidence does not provide much guidance for endof-life-decisions. Nevertheless, because of the importance of the subject, the ERC has produced this guidance on this important and difficult topic for healthcare providers. End-of-life decisions are complex and may be influenced by individual, international and local cultural, legal, traditional, religious, social and economic factors. Solutions should be tailored accordingly. Sometimes the decisions can be made in advance, but often these difficult decisions have to be made in an emergency and based upon limited information. Therefore it is important that healthcare providers understand the principles involved, the challenges and the need for research in resuscitation. End-of-life decisions and ethical considerations should be reflected in advance through education, discussions and debriefings for health care professionals to further strengthen individual ethical competence.

Acknowledgement

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