Withholding information from patients regarding do-not-resuscitate (DNR) decisions – a moral evaluation

(Swedish title: Undanhållande av information till patienter angående beslut att avstå från hjärt-lungräddning (ej HLR-beslut) – en moralisk värdering)

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Table of contents

Introduction.................................................................................................................................................. 3
CPR and DNR decisions.................................................................................................................................. 5
Withholding information and other forms of deception............................................................................... 7
Information and patient self-determination ............................................................................................... 9
Reasons for deceiving.................................................................................................................................. 10
Reasons for withholding information regarding DNR decisions................................................................. 11
  Protect the patient and avoid harm .......................................................................................................... 12
  Keeping the patient in blissful ignorance .................................................................................................. 13
  Decisionally impaired patients and patients prone to misunderstanding............................................. 14
Reasons for not withholding information regarding DNR decisions.......................................................... 15
  Patient self-determination ...................................................................................................................... 15
  The (philosophical) right to information and informed consent ............................................................ 17
  Promote one’s own personal interests ..................................................................................................... 18
  Trust and power balance in the patient-physician relationship .............................................................. 18
  The risk of proliferation ........................................................................................................................... 20
Patient participation and shared decision-making....................................................................................... 20
Summary .................................................................................................................................................... 22
Introduction
In modern health care, at least in the western countries, it is commonly assumed that patients should be offered the opportunity to participate in important decisions regarding health care and medical interventions, thereby respecting their autonomy or self-determination. This requires thorough information about the disease, the prognosis and the interventions that are considered indicated and those that are considered futile or harmful.

In the case of cardiopulmonary resuscitation (CPR) and the do-not-resuscitate decision (DNR), the Ethical Guidelines for Cardio-Pulmonary Resuscitation (2013) from the Swedish Society of Medicine, the Swedish Society of Nursing and the Swedish Council for Cardio-Pulmonary Resuscitation do not prescribe that the patient always should be involved in, and sometimes even informed of, this decision. It is, according to these Guidelines, a question for the individual physician to decide whether or not to disclose this information to the patient and/or relatives, and for what reasons. This could stand in conflict with the Patient Act from the Swedish Riksdag, which prescribes that patients should take as active part in health care decisions as possible, and therefore be subject of criticism from a legal point of view. In this essay, I will approach this question philosophically, and specifically from a moral point of view. If I were to write a policy document regarding decision-making and patient participation in DNR decisions, I am well aware that I would have to consider all the relevant legislation concerning the case. For this analysis, I will limit my study to the policies regarding information to patients regarding DNR decisions in the Swedish guidelines regarding CPR. When it comes to the legal aspects, I will limit myself to compare the guidelines and practice with formulations from the Swedish Patient Act, which offers one of the frameworks even for the ethical analysis of the question.

My aim is to study the moral implications of the praxis in Swedish health care regarding DNR decisions, with a special focus on patient autonomy. I will study the DNR decision as a suitable example of a decision which is often made in health care, and where the ethical guidelines provide a wide space for individual interpretation regarding what, if any,

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1 Tom L. Beauchamp & James F. Childress, *Principles of Biomedical Ethics*, New York, Oxford University
3 Ibid.
4 Swedish Riksdag, Patientlagen (Patient Act), Svensk författningssamling 2014:821, ch. 4 §1 and ch. 5 §1.
6 Swedish Riksdag, Patientlagen (Patient Act), Svensk författningssamling 2014:821, ch. 4 §1 and ch. 5 §1.
information should be given to the patient regarding the decision, which is being made. The results of this study may potentially be of relevance to other areas of health care decision-making, but however plausible this may be, it is not within the scope of this essay to study other decisions in health care, and their consequences for patient autonomy. The moral situations described in this essay are confined to health care. It includes only patients that have the sufficient capacity to understand and handle information, since there is a totally different moral evaluation of cases where the patient is decisionally incapacitated.

I will not specifically touch the subject of information to relatives, since this is a somehow different moral question, although it is for different reasons important to provide relatives with information even in some cases where the patient has full decision-making capacity.

The DNR decision is frequently made in everyday health care, there are written recommendations for it, and it has to be well formulated and documented in the patient record. Both the decision to perform CPR and the DNR decision involve great consequences for the patient, and therefore they are high-stake decisions that should be handled with great care. The conversation between physician and patient regarding DNR decisions normally includes information about the medical condition of the patient, the predicted future quality-of-life, and the prognosis for survival. It should also include a statement about what treatments will be offered to the patient, and what treatments are considered futile. The conversation that should be held in these situations can be difficult for both physicians and patients. For patients, it could be a moment when important but hard facts are revealed about the bad prognosis of their disease. When the subject of CPR is brought up, it could make patients think about their close death, even if death is not imminent. The information can be misunderstood and there could be a sense of mistrust in the physician in charge or in health care in general if a DNR decision is being made, thereby indicating that health care will not do all it can to save and prolong the life of the patient. Physicians can feel the burden of having to break bad news to patients.

There can be moral reasons to protect patients from this potentially harmful information, thereby withholding important facts about their future life and the aim of the medical treatment, which sometimes is curative, but more often can be only life prolonging or merely offering symptom relief. My thesis is, that it is morally wrong for a person in the role of primary care giver (medically responsible physician), to intentionally withhold relevant information from a patient regarding his or her disease and prognosis and the treatments that are considered futile, given that the patient does not decline or refuse this kind of information.
This is true also, or even principally, in case this information could contain something that is conceived as negative for the patient, and regardless of whether it creates a state of worry or sadness in the patient. According to this thesis, it is morally wrong to abstain from giving the patient the *necessary means* to understand the decisions regarding what treatments are considered adequate and what treatments are considered futile, including DNR decisions. The one who is responsible for offering the patient this kind of information is not subject to blame if the patient, out of cognitive difficulties or other factors that impair his or her decision-making capacity, cannot participate fully in the decision, as long as the necessary means are taken to provide the patient with information that is adapted to his or her personal condition.

I will analyze the arguments *for* withholding information from patients regarding DNR decisions in order to study if these arguments can be valid, thereby challenging my thesis. I will not consider the basis for the DNR decision, or whether it is the right decision for a certain patient. I will instead begin by studying the process of decision-making and information to the patient at the point when the decision is being made, regardless of the reasons for it. However, in order for the reader to understand the reasons and potential consequences of either a decision to perform CPR or a DNR decision, I will shortly explain these in the following section.

**CPR and DNR decisions**

In this section, I will give a short introduction about CPR and the consequences of resuscitation for different kinds of patients, something, which will be important to take into account when reading the subsequent argumentation regarding the moral dimensions of the decision to be taken whether or not to offer the patient CPR in the case of cardiac arrest.

A situation with cardiac arrest can arise in a patient as a consequence of severe underlying disease. It can also occur as an emergent situation in a person who does not have a serious comorbidity. The longer the duration of the cardiac arrest, the more side effects occur as a result of a diminished blood flow, for instance to the brain and kidneys. If the patient is previously healthy, survival with preserved functions and quality of life can be achieved, although in the majority of cases the patient has a slight cognitive dysfunction after being resuscitated. In patients with severe underlying disease/comorbidity, the consequence can be both brain damage with a poor functional status and advanced kidney injury, both of which

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have a great impact on future quality of life. Despite technical advances, CPR is effective in a quite low percentage of cases and the efficiency is highly dependent on the duration of cardiac arrest and the precondition of the patient.

The decision not to perform CPR in case a patient suffers from cardiac arrest is assigned as a DNR order. Because of the low statistical probability for survival, some even question the term DNR and would rather name it DNAR (do not attempt resuscitation). The prediction of success or failure of a medical intervention is always difficult, and in the case of CPR, the decision either to intervene or not to intervene has serious consequences for the patient. CPR can restore life, but at a cost of great suffering or a prolonged dying, while a DNR decision will mean that a cardiac arrest is seen as the natural end of life of a certain patient, and something that the medical staff should not interfere with. According to Jeffrey P. Bishop, the policy of making DNR decisions arose in medical history as a response to the presumed consent to CPR among patients, in an era when the technical advances were considered as unlimited in controlling life and death. At some moment, the death of the patient must be accepted, and excessive but futile treatment avoided. For health care staff, and especially for the physician who has to make the CPR/DNR decision, it is however a high-stake decision which implies a great responsibility. It is difficult to translate statistics into the prognosis of particular patients. In these decisions, it is good to acknowledge the uncertainty of the decision, that it is often based on intuition rather than hard facts.

In Sweden, the DNR decision has to be made by two licensed health care workers, of which one has to be a licensed physician. The decision must be clearly stated and motivated in the patient record, and reevaluated whenever there is a change in the condition of the patient and for each new care event. According to Swedish medical legislation, it is mandatory to perform CPR in all patients with a cardiac arrest, unless a DNR decision has been made. There is a recommendation, although not mandatory, to inform the patient and/or relatives

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8 Ibid.
9 According to statistics performed by the American Heart Association, for 2016 the survival rate is 12% when cardiac arrest occurs and CPR is initiated out of hospital and 24,8% when cardiac arrest occurs and CPR is initiated at the hospital. http://cpr.heart.org/AHAEC/PRAndE/General/UCM_477263_Cardiac-Arrest-Statistics.jsp accessed 15/10/2016. According to Swedish statistics, these numbers are approximately the same.
11 Ibid.
13 Bishop et al. (2010).
14 "Ethical Guidelines for Cardio-Pulmonary Resuscitation (CPR)” (2013).
15 Ibid.
about this decision when it is made.\textsuperscript{16}

According to the principle of patient self-determination described in the Patient Act, the patient always has the right to deny CPR, even if he or she is not suffering from a terminal disease and also if CPR is considered to be effective.\textsuperscript{17} The conditions for this right are that the patient has decision capacity, is well informed and accept the consequences of that decision.\textsuperscript{18} If a conversation regarding this is considered relevant, it should take place under psychologically good conditions. If the patient is considered to lack decision-making capacity, the Swedish guidelines recommend that the patient’s former wishes are inquired, and if the patient has not made these known in advance, relatives are questioned about the patient’s assumed wishes.\textsuperscript{19}

When there is a poor prognosis for survival, if survival is estimated likely but with a poor quality-of-life, or if cardiac arrest is caused by a progress in the underlying diseases, CPR can be judged futile and the physician is not obliged to perform it. Rather, it could be considered as a pseudo-option for that particular patient, and it could be morally better to abstain from performing it.\textsuperscript{20} If CPR is considered medically futile, the physician can make a DNR decision without informing the patient and/or relatives and irrespectively of what the patient would have wanted.\textsuperscript{21} The information about the DNR decision in these cases could be well received by the patient (positively, with relief) but it could also be frightening or cause worry. These potential negative effects of the information have given rise to a recommendation of not always informing the patient and/or relatives of the decision, which, besides being legally dubious when considered in the light of the Swedish Patient Act, also has important moral implications that I want to address in this essay.\textsuperscript{22,23}

**Withholding information and other forms of deception**

Withholding information regarding DNR decisions will necessarily touch the problem of deception, which could be caused either by lying, misleading or withholding of information. I will not enter in detail into the potential moral difference between these forms of deception. I will use the definition of deception as suggested by Roderick M. Chisholm and Thomas D.

\textsuperscript{16} Ibid.
\textsuperscript{17} Swedish Riksdag, Patientlagen (Patient Act), Svensk författningssamling 2014:821, ch. 4 §2.
\textsuperscript{18} "Ethical Guidelines for Cardio-Pulmonary Resuscitation (CPR)" (2013).
\textsuperscript{19} Ibid.
\textsuperscript{20} Bishop et al. (2010)
\textsuperscript{21} "Ethical Guidelines for Cardio-Pulmonary Resuscitation (CPR)" (2013).
\textsuperscript{22} Ibid.
\textsuperscript{23} Swedish Riksdag, Patientlagen (Patient Act), Svensk författningssamling 2014:821, ch. 3 §1.
Feehan and reviewed by James Edwin Mahon in the Stanford Encyclopedia of Philosophy:

“To deceive =df to cause another person to acquire a false belief, or to continue to have a false belief, or to cease to have a true belief, or be prevented from acquiring a true belief, or to allow another person to acquire a false belief, or to continue to have a false belief, or to cease to have a true belief, or be prevented from acquiring a true belief.”

In this sense, deception through withholding of information is to “allow another person to continue to have a false belief(...) or be prevented from acquiring a true belief.”

Deception, for instance through withholding information, can sometimes be unintentional, which makes it difficult to evaluate morally. For this analysis, I will therefore presume that withholding of information is the intentional omission to transmit information that the recipient may reasonably deem relevant, and that is in possession of the communicator, who has a professional role that includes communicating the information to the recipient. The communicator is so to say in a warranting context, where sincerity is expected.

There could be reasons to believe that lying is morally more problematic than withholding of information. Lying is the intentional transmission of false information, while withholding of information is the intentional concealment of relevant information from the recipient. Among other differences between deception through lying and through withholding information, the first can be seen as an act and the latter as an omission. According to some philosophers, an immoral act is worse than an immoral omission, but this is a highly debated theory.

Furthermore, Jennifer Mather Saul stresses the convincing argument that, regardless of our psychological intuitions that lying is worse than withholding information, the consequences of withholding information can sometimes be the same or even worse than when lying. Even if consequences do not make up the whole moral evaluation of an act or omission, at least it is an important aspect to take into account when determining whether it is morally more problematic. In merely withholding information, the trust in the relationship can have a greater chance of being maintained, because the one who withholds information can defend this strategy and evade criticism through different arguments, for instance, that the

25 Ibid.
28 Saul (2012), ch. 4.
information must be timed in order to be received in a good way. However, when looking at the other consequences of withholding information, it is not clear how these aspects that lessen the impact of withholding information would therefore make it morally permissible.

In the following sections, I will not take into account either lies or intentional misleading through words or gestures, but only intentional withholding of information to patients regarding DNR decisions, and its moral implications.

**Information and patient self-determination**

In modern medicine, patients are considered to have the right to information about their disease and treatment through the principle of autonomy, or self-determination. To the greatest extent possible, they should therefore be offered shared decision-making regarding important treatment options, if there are not strong reasons that speak against it or when the right to receive information does not come into conflict with another, and stronger, principle or value. The intentional withholding of information from the patient by a physician can be seen as an infringement of the patient’s right to receive certain information that he or she may reasonably deem relevant – the decisive information about the status of disease, the prognosis, the treatment options that can be used in order to improve the situation, and the treatment options that are considered futile and/or harmful.

It is important to make an individual judgment regarding the patient’s need of information regarding his or her condition, possible outcomes of treatments that can be offered, and treatments that are not considered to benefit him or her. Reasons for not disclosing full information to the patient can stem from cultural, religious or simply personal needs.

The question then arises whether truthfulness or honesty means giving all the information, or just not giving the wrong information, as in lying and misleading. This implies an analysis of what amount and type of information that the patient could have an interest in receiving, an interest great enough to outweigh the possible negative effects of that information for the patient. For withholding of information to be morally relevant, I consider that some requirements should be fulfilled: that the recipient should have a sufficient interest in

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29 Beauchamp & Childress, ch. 3.
30 Ibid.
receiving the information through being the subject of it, that the information is easily accessible, and that the communicator is in position where it may be expected of him or her to give that information to the recipient. Furthermore, it should be the relevant amount and detail of information in order to make a decision.

Shared decision-making is a model that has been elaborated in order to increase patient participation in medical decisions. According to a theory suggested by Lars Sandman and Christian Munthe, shared decision-making in health care can be divided into several different models, depending on the capacity of the patient to receive information and participate in the decisions regarding his or her treatment options. The models proposed by Sandman & Munthe intent to balance the different values at stake in the decision-making in health care: patient best interest, patient autonomy, and effective decision in terms of patient adherence. 34 The definition of the models are so to say included in the designation of each of them: Shared Rational Deliberative Patient Choice, Shared Rational Deliberative Paternalism, Shared Rational Deliberative Joint Decision and Professionally Driven Best Interest Compromise Model. The third model mentioned is, according to Sandman & Munthe, the ideal model for shared decision-making, while the fourth can be used when patients cannot receive information or cannot participate in the decision in some other way. 35 In the section on patient participation and shared decision-making, I will enter into two of these models in more detail and develop their potential use in DNR decisions.

Reasons for deceiving
What could then be the reasons for deceiving someone? A common belief is that deception in order to save innocent lives is morally acceptable, at least when one judges the morality of the action by looking at the consequences. 36 Sissela Bok comments that some equate deception and violence, when it comes to self-defense and to save the lives of others. This means that deception, as well as violence, would be morally permissible if a situation were to arise when life is under threat, either the life of the one who deceives/uses violence, or of others. 37 Deception can also be motivated by a wish to benefit oneself or others, or to avoid harm. 38

35 Sandman & Munthe (2010).
37 Bok (1999), p. 29.
38 Ibid., pp. 78-81.
A paternalistic reason to deceive is driven by the wish to benefit someone or protect him or her from harm, disregarding the preferences and wishes of that person.\(^{39,40}\) This paternalistic form of deception has historically found a place in the patient-physician relationship, but could remain present also today in some areas of medicine and regarding some decisions. One area of paternalistic deception, often present in the form of withholding information, is when the physician does not want the patient to be told about his or her state of disease when there is a poor prognosis, since there is a danger that the patient would not be able to handle this negative information. In some cultures and some areas of care, there could even be a presumed consent to this kind of paternalism.\(^{41}\) One reason for this form of deception is that the knowledge of a poor prognosis may have negative effects on patient survival and quality-of-life, something which several authors dispute, saying that this is not the case.\(^{42}\) Some patients respond differently and really want this information and are unjustly deceived through this concealment. One way to handle this kind of problem would be to investigate how much information the patient wants.\(^{43}\)

**Reasons for withholding information regarding DNR decisions**

I can think of several reasons for withholding information from a patient regarding DNR decisions. The reasons that are often brought up are that the patient is not judged to be capable of participating in the decision or that the information about the DNR decision would cause harm to the patient through the reactions of worry, anxiety or sadness it can provoke.\(^ {44}\) There can be a worry about formulating the information such that the patient and/or relatives do not misunderstand it and thereby think that the physician will not provide the patient with other and more appropriate treatments or care. The decision not to inform the patient could also potentially be made when there have been many previous DNR decisions and the physician in charge does not consider it appropriate to bring up the question again, or when the timing is considered to be bad, postponing the information for another and more suitable moment, which perhaps will never occur.

One reason that can be brought up is that we make many other decisions regarding to treat or not to treat without informing the patient. I consider this a bad reason, because it contains

\(^{39}\) Ibid.
\(^{41}\) Bok (1999), p. 215.
\(^{42}\) Ibid., pp. 236-7.
\(^{43}\) Ibid., p. 241.
\(^{44}\) "Ethical Guidelines for Cardio-Pulmonary Resuscitation (CPR)” (2013).
something that could be a circular argument, not really defining why an existing practice would morally justify the inclusion of all situations where this practice can be performed. At least we would have to be able to give arguments for those other decisions we make without informing the patient. Besides, the wish to avoid any psychological harm to the patient could perhaps give an excuse for routinely not informing patients about bad news regarding their disease and prognosis, which I suggest is a morally dubious approach, which does not consider the individual needs of the patient.

Beside the reasons of withholding information to the patient, there are some excuses or psychological motives that influence our behavior: the lack of time for having a conversation with the patient, external pressure for making a quick decision or the desire to avoid conflict with the patient and relatives in case they do not share the view of the health care professionals. I will not enter in detail into these psychological motives, since they are normally not part of a rational and moral process of decision-making, even if they can influence the decision. Some reasons for lying to the patient that I judge clearly not morally justified are the egoistic motivations of gaining something through misleading or just avoid transmitting information to the patient out of laziness.45

Reasons that more directly focus on the best interest of the patient can be used to justify withholding information, while the decision could also have been caused by other and less altruistic motives. Below, I will list some of the most important rational moral reasons for withholding information to patients regarding DNR decisions and the arguments that can invalidate these reasons when it comes to moral permissibility.

**Protect the patient and avoid harm**

One of the most frequent arguments in favor of withholding information from patients is that information can be harmful. This is a benevolent reason, even if patient autonomy is disregarded. The reason to withhold information that is based on the wish not to harm the patient is often based on the supposition that truthful information will cause patients to lose hope and become depressive or anxious, which according to several authors is often not the case.46,47 The question is if the benevolent moral reason of protecting the patient from harm makes withholding less morally blameworthy than if the motivation is egoistic or to harm the patient. According to T.M. Scanlon, the permissibility of an action could depend on the

46 Gold (2004)
reason for acting, because the reason can define the meaning of the action. In line with this view, when an action is done with the aim of hurting someone, the action gets a clearly negative meaning and is therefore not morally permissible. An action that is done out of a benevolent reason can be morally permissible, but the predictable consequences of the action should not be disregarded. There is a negative effect of concealment that is clearly predictable, besides protecting the patient from potentially harmful information. This effect consists in not respecting autonomy and promoting the interests of another rational being, and I think this consequence should be given priority in the moral evaluation.

Even if the disclosure of information to patients could indeed cause harm in the sense of anxiety or depression, I argue that this harm could be accepted because of the greater good we achieve when patients are informed about their disease, the treatments that are available to them and those that are considered futile. Truthful information, even if hard to “digest”, can often bring more serenity and provide the patient a possibility to prepare for the end of life. Avoiding harm should furthermore not be a principle that overrules other and potentially more important principles. In health care, many interventions cause good effects at the price of some harm. What we should do instead of merely avoiding harm is to compare the good and the harm offered to a patient through a certain intervention, to decide whether the good outweighs the harm that the intervention causes as a side effect. The reason not to “harm” the patient in the sense of giving truthful information, could even justify other and more serious forms of deception, such as lying and misleading, implying negative moral consequences. Withholding of information from the patient can also do harm in the sense of limiting his or her autonomy or self-determination. It is of importance for our well-being to be in possession of relevant information about ourselves, in order to defend our own interests and plan for the future. Even if the benevolent reason of avoiding harm could thus modify the moral assessment of the person who withholds information, it does not change the moral judgment of withholding information in itself, which I consider morally wrong.

**Keeping the patient in blissful ignorance**

If we would principally focus on well-being in the sense of a situation devoid of worry or sadness, we might be driven either to withhold or modify the information given to the patient in order not to cause these “negative” feelings. Without this potentially “harmful”

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49 Ibid.
information, a person could perhaps feel well since he or she lacks the information about a
disease and/or a bad prognosis, but this well-being would not be in accordance with his or her
true condition. According to this reasoning, the relationship between true well-being or
happiness and the truth regarding the subject of that well-being comes into play. I would
argue that well-being or happiness, which is not caused by a true state or condition, is not true
well-being or happiness. My argument is in line with the argument against hedonism offered
by Robert Nozick through his thought experiment of the *Experience Machine*. According to
this thought experiment, Nozick argues, quite successfully according to my view, that well-
being based on an untruthful condition is not real well-being. The opposite side of the coin
would probably be that it is better to accept reality with all its constituents, including the
necessary amount of difficult or painful situations, rather than to live in a pleasant situation,
which is disconnected from reality. This would require that we consider living unaware of
one’s real condition as qualitatively inferior to living in a condition of awareness of one’s
situation and prognosis, which in turn leads to a greater amount of self-determination. An
informed patient is a patient who is given the cognitive, factual, basis for different decisions.
I suggest that giving a patient the sufficient amount of self-determination, through the
necessary information, is preferable to keeping the patient in a situation of unawareness but
artificial well-being, a blissful ignorance. The well-being which comes from ignoring a
disease or a bad prognosis would, accordingly, not be preferable to the potential sadness that
truthful information can give rise to.

**Decisionally impaired patients and patients prone to misunderstanding**

The reason to withhold information, based on the incapacity of the patient to understand and
handle the information, can be presented in case the patient is considered not to be in
possession of the sufficient cognitive function needed to participate in the decision. I would
think that this assumption is not always in line with the patient’s real decision-making
capacity. A possible cognitive defect does not imply that the patient has lost his or her right to
information – it only makes information more difficult because it has to be adapted to the
patient’s possibilities of understanding. Many patients could participate in the decision, if
the information would be given in a way that is easy to understand. This forms part of the
important capacity of the physician to adapt the information to a specific patient.

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51 Ibid.
52 Da Silva (2003)
Withholding information to avoid causing misunderstanding and conflict could also be evaded through this adaptation to each patient. I do not think that the fact that information can potentially be misunderstood is a valid argument for withholding information. Misunderstanding can possibly arise in all sorts of communication, but nevertheless it is important to give the necessary information to each individual and not withholding it without very good reasons to support it.

In the following section, I will comment and develop further some of the arguments for not withholding information from the patient regarding DNR decisions, primarily patient self-determination, the patient’s right to information, offering the means for defending the patient’s own personal interests, and the right power balance in the patient-physician relationship.

**Reasons for not withholding information regarding DNR decisions**

The reasons for not withholding information could be that it restricts patient self-determination which is already limited in relation to the DNR decision, the patient’s philosophical right to information and the opportunity for the patient to promote his or her own personal interests. Another reason could be the harm it causes to the relationship between physician and patient - even if it is not discovered - as well as the redistribution of power from the patient to the physician who in this way acts paternalistically. According to John J. Palmieri, deception causes complex emotions and the feeling of not being of importance. It can also give rise to a wider loss of trust and faith in the one deceived. The potential consequences for the recipient can be getting important facts wrong, which could lead to a limited autonomy through impairment of his or her decision capacity. The Swedish legal framework states that medical interventions as far as possible should be planned and performed in consultation with the patient, and that patient self-determination and integrity should always be respected. The praxis of routinely withholding information from patients about important decisions regarding their health and planned treatment therefore stands in conflict with the law, something I will not develop further but focus on the moral perspective.

**Patient self-determination**

In the case of CPR and many other treatments offered in Swedish health care, patient self-determination involves the right to deny treatment. It does not involve the right to be

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53 Swedish Riksdag, Patientlagen (Patient Act), Svensk författningssamling 2014:821, ch. 4 §1 and 5 §1.
54 "Ethical Guidelines for Cardio-Pulmonary Resuscitation (CPR)" (2013).
given the treatment, regardless of the medical indication, based on science and proven experience and is therefore from the start quite restricted.\textsuperscript{56} If information about a decision regarding future available treatments is withheld from the patient, out of any reason, then the self-determination can be diminished not only in relation to that concrete decision but also to other decisions regarding his or her future life. The information that is withheld from the patient can be of crucial importance for the capacity to plan and prioritize between different options at the ultimate stages of life. Withholding information can therefore cause a more serious restriction of patient self-determination than one could easily foresee.

Besides causing negative consequences for the one who is deceived, deception can also have negative impact on the one who deceives, for instance through personal discomfort, anxiety, changed personality, loss of integrity and an impaired capacity of judgment.\textsuperscript{57} Honesty is an attitude, which preserves the autonomy at the same time of the communicator and of the recipient.\textsuperscript{58}

If information is disclosed in a truthful way and in a patient-physician relationship based on trust and the sense of not being abandoned by the physician, then I suggest that it may be more likely that the patient could cope with information without it causing that much harm. There is, therefore, a greater moral responsibility of the physician than providing facts to the patient about his or her condition. The physician also has a responsibility to nurse the patient, to promote trust and security in the patient through continuity in care.

It is worth noting that decisions are not only based on cognition, but also on emotions. The information given and the way it is given can have effects on both, which is important to be aware of when striving for patient participation in decision-making. It is therefore important to decide both what amount of information is appropriate for the patient, and how to transmit this information. If a physician only focuses on the cognitive part of the process, he or she can miss the potential emotional impact of the information that is given, an impact that can highly affect the decision-making capacity. The right to information will thus not require that all the information be given at the same time and in the same way to all patients. This approach would not respect the self-government of patient, because the accumulation of information that is not handled in an effective way can also cause more harm than benefit to the patient.\textsuperscript{59}

\textsuperscript{55} Swedish Riksdag, Patientlagen (Patient Act), Svensk författningssamling 2014:821, ch. 4 §2.
\textsuperscript{56} Ibid., ch. 7 §1.
\textsuperscript{57} Bok (1999), p. 23-8.
\textsuperscript{58} MacIntyre (1994), p. 355.
\textsuperscript{59} Gold (2004).
It should instead be adapted to each patient’s capacity to handle and cope with the information. The patient should be given the means to control how much information is given and at which pace.60

The (philosophical) right to information and informed consent

The information regarding CPR and DNR should involve realistic information about survival and future quality-of-life, and this is something that might be problematic for the physicians to bring up in a conversation with the patient, out of reasons explained above.

Informed consent is legally and ethically requested in case the patient is about to receive a certain treatment.61 It is understood as consent to certain actions that could harm the integrity of the patient in some way, give rise to complications or even just discomfort.62 There are several reasons for this informed consent: protection of the patient, prevention of abusive conduct, autonomy/self-ownership/non-domination, personal integrity and trust.63 The amount and the formulation of the information load which is offered to the patient has to be evaluated and it will always be a relevance problem how much of the information the patient needs in order to participate in a decision.

In DNR decisions, instead of deciding to do some intervention, the decision is made to avoid some intervention either because of futility or because the intervention can cause more harm than benefit for the patient. Since a DNR decision is such a high-stake decision, I consider it a right of the patient to receive information, when the physician considers that the decision has to be made. It does not imply that the patient has the right to resuscitation, but the right to know when the physician considers it futile.

It can in some cases be necessary to withhold important personal information through confidentiality, if there are strong moral reasons to support it.64 Sissela Bok, who has written much about the ethics of concealment, suggests that withholding information can be morally acceptable in case it leads to preservation of autonomy, promotes human relations and the keeping of promises, and provides other benefits for individuals and sometimes the whole of society, than would be the case if this information had been revealed.65 Bok considers it

60 Ibid.
63 Eyal (2012).
65 Bok (1983), ch. IX.
morally negative when it leads to harm or serves to protect professions or companies from the necessary transparency needed to promote the good of society. I agree about the fact that there are situations when information can be withheld from people for the good of society. However, the common denominator of all these cases is that the information does not regard anyone personally, and the potential recipient of the information is not supposed to act upon that information, as is the case with the information to a patient about a serious condition where CPR is considered futile.

Relatives do not have a legal right to know about the patient’s health and future life situation, but at least in Sweden there is a recommendation that they should be involved in the health care planning and performance, as long as it is considered adequate and that regulations concerning confidentiality are not infringed. In a moral sense, it could severely hurt relatives to be unaware of a DNR decision in case they think that the health staff will perform attempts to resuscitate the patient, and if they retrospectively get to know that this was not done, without knowing the reasons for it. Honest information is important for patients as well as relatives.

Promote one’s own personal interests
In the DNR decision, one of the decisive aspects is to promote the best interests of the patient. Normally, this is made from some kind of reference, often what the patient has expressed as valuable, but perhaps more often what the physician considers to be in the patient’s best interest. It is, however, important to consider the patient as an individual, with his or her own personal interests or preferences, that no one else can easily find out about without asking the patient. There could be unanimity between the patient and physician on what is to be considered as most valuable, but one cannot assume that this is always the case. Physicians and patients can have different priorities, and it is important to identify the occasions on which the physician strives to fulfill an objective that the patient does not share, and enable increased patient autonomy in this sense.

Trust and power balance in the patient-physician relationship
The issue, which I aim to analyze in this essay is closely associated with truth, honesty and

66 Ibid.
67 Swedish Riksdag, Patientlagen (Patient Act), Svensk författningssamling 2014:821, ch. 5 §3.
veracity in the patient-physician relationship.\textsuperscript{69} I consider that we should regard truthfulness and trustworthiness as important and even the foremost value in the patient-physician relationship. This makes it morally unacceptable to deceive patients regarding their situation. Deception creates mistrust, and a redistribution of power to benefit the one who deceives at the expense of the one who is deceived, who is deprived of autonomy.\textsuperscript{70,71} Persons who deceive often think that others deceive them, and this creates a serious breach in the trustful relationship between people.\textsuperscript{72,73}

Historically, the physician was regarded as having some kind of therapeutic privilege to decide over the patient.\textsuperscript{74} This was a paternalistic version of the decision process in the relationship between patients and physicians. Even if we have moved from the openly paternalistic way of deciding over the patient, still there is a difference between the physician and the patient regarding the knowledge they have about the medical condition of the patient, his or her prognosis and the expected result of different interventions. This imbalance in knowledge and experience makes the physician a good decision-maker from a medical perspective, which however must be combined with the patient’s views, wishes and preferences.\textsuperscript{75} Both medical knowledge and experience, and the patient’s personal preferences should form part of the decision-making. The decision, which is ultimately made, should ideally be the one that the patient would make if he or she had the same knowledge and experience as the physician.\textsuperscript{76} There is a difference between this view of the physician as the one who decides, and the classical paternalistic model, since the paternalistic model would not include anything about patient preferences or wishes, but would entirely be guided by the medical indications, science and experience of the physician.

In withholding important information, the trust between the patient and physician can be hurt in a way that has a severe impact on the relationship and future information situations.\textsuperscript{77} The patient can possibly think that the physician can withhold other important information, if such information as the futility of resuscitation is withheld from the patient. There is a need to

\textsuperscript{69} Lisa I. Iezzoni et al., ”Survey Shows That At Least Some Physicians Are Not Always Open Or Honest With Patients”, \textit{Health Affairs} 2012;31(2):383-391
\textsuperscript{70} Bok (1999), p. 20-22.
\textsuperscript{71} MacIntyre (1994), p. 354.
\textsuperscript{72} Ibid., p. 319-20.
\textsuperscript{73} Bok (1999), pp. 23-8.
\textsuperscript{74} Da Silva et al. (2003).
\textsuperscript{75} Sandman & Munthe (2010).
\textsuperscript{76} Ibid.
foster honesty in the patient-physician relationship and counteract paternalism, aiming at individualized information and decisions. The trust in the relationship is highly dependent on the trustworthiness of the concerned parties in the relationship, and above all the trustworthiness of the physician because of his or her advantage position in terms of knowledge and experience, but also of being in a professional role and not a dependent position as the patient is.

The risk of proliferation
One of the most serious problems with deception is, according to Bok, the potential for proliferation, through a general acceptance of the praxis of concealment and, equally, a general loss of trust between people. In health care, the danger of proliferation would arise if withholding information were to be considered as morally unproblematic, from the paternalistic argument that it spares the patient from important but somehow harmful information. In the patient-physician relationship, this could lead to serious consequences, because it breaks the treatment alliance and creates a relationship of mistrust where there should be trust and trustworthiness.

Patient participation and shared decision-making
In case the patient would be entitled to receive certain information, that the physician conceals, the moral problem gets clearer if we see it from the perspective of the patient. Often, it is the one who deceives who defends deception, while the one who is deceived has no opportunity to speak for his or her interests. I assume that, on some occasions, the patient would object to being deceived through withholding of information if this were to be revealed afterwards, since a feeling of deception would arise, which is mostly of a negative quality. Bok suggests that there can be morally valid forms for deception, but that these should be agreed to in advance, be judged as good by rational persons and especially that it is considered acceptable by the one who is deceived. Following a norm of promoting patient autonomy in health care, the patient should be given the possibility both to decide whether or not to be informed, how much information to be given and participate in the decision as far as possible. This can be realized through a process called shared decision-making.

The difficulties exposed above regarding communication and decision-making stresses the

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78 Ibid.
81 Bok (1999), pp. 20-2.
82 Ibid., ch. VII.
need for policies or routines to follow in DNR decisions and conversations with patients. These should involve patient participation, communication, expression of treatment preferences, decision, and agreement on the decision, which is made. In the best-case scenario, patients are fully capable of participating and agree with the physician on the treatment plan, which he or she suggests. In these cases, we can use the shared decision-making model proposed by Sandman & Munthe: Shared Rational Deliberative Joint Decision. There are indeed cases when the patient is sufficiently rational in order to deliberately participate in joint decision-making with the physician, and in these cases they should be allowed to do so. There are cases, when the medical indications and the decision of the physician is not in accordance with what the patient would prefer, or the patient is not able to participate fully in the decision-making process. Then we can use another of the models suggested by Sandman & Munthe: the Professionally Driven Best Interest Compromise Model. These two models serve to maintain patient autonomy, patient best interest, patient adherence and the continued trustful relationship between patient and physician. I consider that they do this in spite of not giving patients the full liberty of choosing treatments.

As explained above, I suggest that the Professionally Driven Best Interest Compromise Model proposed by Sandman & Munthe would be possible to use also in cases where the patient lacks the capacity to participate fully in the information and in the decision. What is needed is not full cognitive capacity or full self-determination, but the information should be adapted to each individual patient, as well as the space given for their own personal decision within the treatment plan. When the patient is not fully autonomous or in possession of complete self-determination, the major responsibility of the decision falls on the physician. However, the physician is not through that fact dispensed from giving information both about the condition of the patient, the expected prognosis, the treatments, which will be given and those that are not considered indicated.

One should not forget that the conversation about the CPR or DNR decision involves the necessary information, which is to be given to the patient, and that the patient has an opportunity to bring up many questions that would perhaps never be brought up in the case the conversation would not be offered. The one who is medically responsible for the DNR decision is the physician, but in this decision-making there should also be an aspiration to

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83 Sandman & Munthe (2010).
84 Ibid.
85 Ibid.
86 Ibid.
satisfy patient preferences.\footnote{Ibid.} This requires that both patient and physician work together to process the best decision. The reason why the Professionally Driven Best Interest Model better preserves patient autonomy than a traditionally paternalistic decision-making process, is that it is an open strategy which is made known to the patient, and the patient receives information about the decision that is taken.

Is there then any condition, where withholding of information regarding DNR decisions can be morally permissible? Considering the right to receive relevant information and the legal and moral norms for informed consent in health care, I think there is only one independent condition, when withholding of information regarding DNR decisions can be considered a reasonable option and be morally permissible: When the patient does not want to be informed. The patient can clearly choose not to be informed and this wish should be respected. This right to refuse information has also been defended by Carlos Henrique Martin Da Silva et al.\footnote{Da Silva (2003).} For withholding of information to be morally unproblematic, it should be agreed upon in advance by both the patient and the physician. Even if this also creates a power imbalance, this is accepted in advance by the patient and is therefore in line with patient autonomy.

**Summary**

In the ethical analysis of different reasons for informing, or withholding information from, patients it is possible to find arguments both for offering and not offering to the patient information about his or her disease, prognosis and DNR decisions. When weighing these arguments, I have come to the conclusion that the principle of self-determination should be the principle that outweighs the principle of avoiding harm through withholding information from patients regarding DNR decisions. Deception is also a form of harm, since it limits self-determination and the possibility to defend one’s own interests, and it does not lead to true well-being or happiness. The harm caused by sad but truthful information does, in the majority of cases, not outweigh the harm of being deceived, since this is a harm which perhaps is necessary in order to come to a future state of increased peacefulness, true well-being and trust. One should neither forget that the patient often could be the one who has the most pessimistic view of the disease and prognosis, and just to receive truthful information can reduce the anguish of uncertainty.

When thinking of potential possibilities of including patients more fully in the DNR decision, the models of shared decision-making described by Sandman & Munthe can be of great use,
especially the Shared Rational Deliberative Joint Decision and the Professionally Driven Best Interest Compromise Model. Patients can, through these models, participate more fully in the important decision regarding CPR or DNR. It does not deprive the physician from making the decision out of medical indications, but the patient is given the means to participate in the decision-making process through transmitting his or her ideas the priority of values. In that way, these models help the physician to maintain patient autonomy and strive for patient’s best interest even if the decision to perform or not to perform a certain intervention is made by the physician, through his or her knowledge and experience in the medical field.

There are several questions that could be explored further, for instance concerning the decision per se, and the way of giving information to the patient. When it comes to giving information, this can be done in a way so as to minimize the negative consequences and, instead, making the patient more involved in the care, calmer and more satisfied with the treatment offered.

An interesting solution to the problem of informed consent to DNR decisions is proposed by Bishop. His suggestion consists in a reversion of the decision. Instead of deciding not to resuscitate, physicians together with patients and relatives should decide to attempt resuscitation in case it is considered medically effective. There is, so to say, a change from opt-out to opt-in regarding CPR, which could make decision and the information to patients much easier, at least in some patient groups where CPR is seldom or never considered effective. This idea would give rise to another essay, and I will just mention it here as an opening for a future analysis.

If a treatment plan is made early, in the form of advance care planning, then the step to a DNR decision may not be that great. A patient who has been informed early in the disease progress about the possibility that some treatments will subsequently be considered futile, will probably cope better with the DNR decision and the reasons that motivate it. The physician should be attentive to the individual needs of information or objection to information of patients. Framing and timing of information are of great importance in order to preserve hope and optimize the patient’s coping possibilities and participation in the decision.

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89 Sandman & Munthe (2010).
90 Bishop (2010).