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Ethical implications of terminally ill and the current state of Do Not Resuscitate orders

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Abstract

Every human being needs to live with no suffering and to survive a satisfactory quality of life, however in cases of terminal illness or when one is bedridden with machines to maintain organ functions; the dilemma of the decision is arising. Yet, patients may put health care givers in an ethical debate by refusing to obtain care or treatment, regardless of that patients reserve the privilege to do so. This review has attempted to investigate the current debate regarding the DNR orders, discussing the rights of incurably ill patients decided on rejecting medical care apart from the different legitimate and ethical consequences concerning this fussy issue, giving a close picture of DNR in Egyptian Medical Practice and the Middle East. Numerous publications agreed with terminally ill patients in their right to allow the DNR order for them to die in peace. Furthermore, in many cases CPR may not lead to direct clinical benefits as the resuscitation could fail or result in complications, extending the suffering without treating the original disease. DNR should be considered particularly with patients who have worn out all other sorts of therapy modalities where there are multi-organ failure and no hope for a cure. The concept of DNR may seem cruel and intolerable for the patient and his family. Therefore, many authors strongly believe that it would be more appropriate if the term is changed from "Do Not Resuscitate" to "Allow Natural Death."

Keywords: Do Not Resuscitate; Terminally ill; Cardiopulmonary Resuscitation; Allowed Natural Death; Ethics

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Cardiopulmonary resuscitation (CPR)

Cardiopulmonary resuscitation (CPR) is an invasive medical treatment. It was first used to treat patients whose hearts were too good to die. Cardiopulmonary resuscitation is routinely

performed on any hospitalized patient suffering cardiac or respiratory arrest. Health care providers resort to CPR as the last choice. While it can be a life-saving intervention in that context, CPR is not an effective treatment for people who are approaching the end of their natural lives. Though, advanced invasive

procedures and treatments that may sustain life may not confer any predictable benefit and may cause further suffering to the patient and his/her family [1,2].

Terminology and Concepts

Do Not Resuscitate (DNR), also known as no code or allow natural death, is a legal order, written or oral depending on the country, indicating that a person does not want to receive CPR if that person's heart stops beating. Sometimes it also prevents other medical interventions. The legal status and processes surrounding DNR orders vary from country to country. Most commonly, the order is placed by a physician based on a combination of medical judgment and patient wishes and values [3,4].

According to Hussein et al. [5], Terminal illness is an illness from which recovery is not expected. Death is not an ON/OFF event. Z-point (point of no return), and the illness is then called terminal because it is expected to end in death soon. Some illnesses like multiple sclerosis can be called terminal before the z-point because they have a predictable course. The definition of terminal illness is not always accurate; some patients who were told that they were going to die have lived for years, but such cases are few in actual practice. Withholding of life support means not to initiate hopeless artificial life support measures in a terminal or critically ill patient. While the withdrawal of life support means terminating hopeless artificial life support measures in a terminally or critically ill patient [5].

Ethical issues in care for the terminally ill

The terminally ill need physical, psychosocial, and spiritual support. Less aggressive treatment may be advised if the benefits in terms of overall health outcomes are not worth the side effects. Beyond the stage of medical futility, only palliative care and symptomatic treatments are given. The core of palliative care is pain

control, but it can include palliative surgery and palliative radiotherapy that are not expected to cure the disease but to control symptoms and improve the quality of life. Terminal patients continue receiving nutrition, hydration, and general supportive care without discrimination. They also require psychosocial and spiritual support to allay their anxiety. Health care workers can considerably start discussing legal issues, such as advance directives and organ donation [6-8].

Decisions for the terminally ill

Serious decisions with irreversible consequences might have taken by or on behalf of terminal patients. The first and most important is the decision to withhold or withdraw aggressive treatment that has no net benefit that would last for a reasonable time. The second is the decision to withhold resuscitation in case of cardiorespiratory arrest for patients who cannot get a net benefit from. Such repeated resuscitation is useless and should be withheld by a physician order, indicating that in case of collapse, specified resuscitation measures shall not be taken. This so-called Do Not Resuscitate order is a physician decision, but the family must be informed (without seeking their involvement in the decision) [9].

- For patients on artificial life support, a decision must be made about when to withdraw support.
- If brain stem death can be ascertained, the decision to withdraw life support is easy because brain stem death is accepted as a definition of legal death.
- If the patient is in an irreversible coma with intact brain stem function, the decision to withdraw life support is more complicated. Withdrawal on the basis of low quality of life and the continuing expense of intensive care are not usually ethically acceptable reasons because of the overriding concern of preserving life.

- Life support could be withdrawn in definitely futile cases, but this is not an easy decision and is usually a cause of dispute between the family and the health care workers.
- The families of terminal patients may be approached for consent to harvest their organs as soon as clinical death is ascertained.
- A prior decision taken by the terminal patient while still competent will make the work of the organ transplant team easier.

Capacity for decision making

A competent terminal patient must make all decisions regarding his care in fulfillment of the principle of autonomy.

- The effects of the disease or the treatment may affect the decision-making capacity of the patient to varying degrees.
- The health care workers will have to decide whether the patient has the intellectual/cognitive capacity to understand and act on the information he/she is given.
- In most cases, the situation is clear, but in other cases, special tests for competence may have to be carried out by a psychologist (lengthy discussion). For example, the terminal patient may be competent in some matters, but not in others.
- A patient with intellectual capacity may have poor memory without the ability to retain a lot of information for decision making.
- If the patient is competent, he/she will sign a statement of what should be done. If the patient is competent, he/she will sign a statement of what should be done after the loss of consciousness.

Advance directives

Advance directives are documents written during the period in which the patient is competent, and are part of prospective autonomy. They enable the patient to control what is done to him after losing consciousness, or even after death. The common term “living will”. The advance statement has benefits for the patient, the physicians, and the family. The

patient is assured of his prospective autonomy, since his care is carried out according to his/her wishes. The physicians are relieved of the burden of looking for a decision-maker, and of making the decision themselves in the absence of a decision maker. The family is relieved from the tension of looking for consensus and making difficult decisions when their state of mind is not at its best because of the patient's illness. An advance directive must preferably be written and witnessed. It is recommended that each institution develops a specific format to make sure that all legal requirements are fulfilled. An oral directive properly witnessed is effective, but should be avoided because doubts could arise about its authenticity [10].

Withholding artificial life support

The decision to withhold life support in cases of brain-dead or when there is clear evidence that such support will be medically futile. The decision to withhold life support is easier said than done because practical realities condition it. It is difficult for doctors to take such a serious and irreversible decision because of uncertainty in clinical assessment and emotion-laden decisions that families normally resist [11].

Withdrawing artificial life support

Life support theoretically should be stopped as soon as the patient is brain dead, or when it is clearly futile. Clinical signs of brain death are reliable in this matter and confirmation can be by brain encephalography and imaging, as well as laboratory tests. To make sure, the testing for brain stem death should be repeated after 6-12 hours for confirmation. Withdrawal of life support is immediately followed by death in many cases, and the doctor is seen as “pulling the plug.” Often, families oppose pulling the plug and doctors sometimes acquiesce and wait for some time to give the family time to come to terms with the reality and finality of death. Withdrawal decisions can be affected by bed availability in the intensive care unit. In cases

of bed shortage, there are more aggressive and frequent efforts to test for brain stem death [12].

DNR orders versus passive euthanasia

Some authorities deal with DNR order as a form of passive euthanasia. But actually, there is a significant difference between them. DNR order is a legal document and advanced medical decision to undertake extreme artificial life support measures if the breathing or heart stops. But don't affect any other palliative and medical care for the patient. It is practiced in most parts of the world without much legal issues. While Passive euthanasia means withholding and withdrawing all palliative and supportive measures with the deliberate intention of causing the patient's death. Both active and passive euthanasia not legally accepted in many countries and health care workers who engage in them can be sued for homicide. Euthanasia at the request of the patient and with his informed consent is still considered illegal. The distinguishing feature of euthanasia is the intention behind the action, which is to spare the patient further suffering. An action that is considered euthanasia can be deemed legal if the intention behind it is different. Withholding a treatment because it is futile is acceptable, but withholding it to hasten the death of the patient to avoid further suffering is passive euthanasia [13].

Cardiopulmonary resuscitation was approved by the American Heart Association in 1974. Since then, more and more hospitals and professional medical associations have adopted guidelines for DNR orders. While guidelines and policies for DNR orders are ethically sound and defensible now, and while DNR universally means that the patient will not receive cardiopulmonary resuscitation in the event of cardiac or respiratory arrest, DNR orders rarely specify what medical care should be provided to DNR patients before they experience arrest, thus leaving matters open to individual interpretation [14].

So, Chen and Youngner; Breu and Herzig; Mockford et al. [14-16] attempted to put guidelines for medical care of DNR patients before they experience arrest. They mentioned that DNR means not to provide any of the following; cardiopulmonary resuscitation involving chest compression, endotracheal intubation, mechanical ventilation, defibrillation, or vaso-active/ionotropic medication. Health caregiver should notice that Do not resuscitate, doesn't mean, don't treat. However, supportive care that should be provided for all DNR patients are; clearance of secretions (oral, throat, etc) , hydration and nutrition, pain management, antipyretics, and sedation, Supplemental oxygen, antiemetics and relieve of constipation, relief of urinary retention, relief of dyspnoea and cough.

How is the DNR order written? And What if family disagree with DNR order?

According to Perkins et al. [2], Physicians should discuss the resuscitation preferences with the patients /surrogate decision maker. Conversation should be documented in patient's notes. Indicate who were present during the counselling. The final decision should be explicit. DNR Form is filled and signed by all concerned persons. Also, conversation with family members to clarify the benefits and risks of CPR together with reasonable explanation will help to gain their acceptance and resolve any issue in most situations. The family must be informed of the DNR decision, but they cannot interfere with the decision. If they refused, this should be referred to an Ethical Committee.

The DNR decision-making process varies in different countries. The acceptance of the concept of DNR also varies among countries; a lot of studies have been conducted all over the world on this topic. Several of those studies were carried out in the Middle East especially Saudi Arabia and Egypt:

The Fifth International Consensus Conference on Critical Care, held in 2003.

Thompson et al. [17] recommended a shared approach involving the caregiver team and patients' families to guarantee respect for patient autonomy, a pain-free death, and prohibition of treatments specifically designed to hasten death; The purpose of the conference was to provide clinical practice guidelines in end-of-life care. Strong recommendations for research to improve end-of-life care were made. The jury advocates a shared approach to end-of-life decision-making involving the caregiver team and patient surrogates. Respect for patient autonomy and the intention to honor decisions to decline unwanted treatments should be conveyed to the family. The process is one of negotiation, and the outcome will be determined by the personalities and beliefs of the participants. Ultimately, it is the attending physician's responsibility, as leader of the team, to decide on the reasonableness of the planned action. If a conflict cannot be resolved, an ethics consultation may be helpful. The patient must be assured of a pain-free death. The jury subscribes to the moral and legal principles that prohibit administering treatments specifically designed to hasten death. The patient must be given sufficient analgesia to alleviate pain and distress; if such analgesia hastens death, this "double-effect" should not detract from the primary aim to ensure comfort.

Gouda et al. [18] studied compliance with DNR policy in a tertiary care center in Saudi Arabia

They reported that DNR issue was addressed in 65 out of 1468 adult patients admitted to the hospital during the study period. This may be due to the lack of knowledge about DNR policy by patients, their families, and physicians which make the optimization of DNR process difficult. Most physicians wish DNR for themselves and their patients at end of life but only a few of them have advance directives.

They concluded that the most important barriers for initializing and discussing DNR were lack of patient understanding, level of education, and the culture of patients.

Currently, few hospitals in Saudi Arabia have a DNR policy. There is however a fatwa regarding DNR, the fatwa issued by the Permanent Committee for Research and Fatwa in the year 1989, Fatwa No. 12086, in response to the questions raised concerning using resuscitative measures [19,20]:

The First: If an already deadperson arrives at the hospital, there is no need to use any resuscitative measures.

The Second: If the medical file is already carrying the stamp of "Do not resuscitate," according to the patient's or his/her will and the patient is unsuitable for resuscitation, as agreed by three competent specialized physicians, then there is no need to do any resuscitative measures.

The Third: If three physicians have decided that it is inappropriate to resuscitate a patient who is suffering from a serious incurable disease and that his/her death is almost certain, there is no need to use resuscitative measures.

The Fourth: If the patient is mentally or physically incapacitated and suffering from stroke, late-stage cancer, severe cardiopulmonary disease, or had several cardiac arrests, and the decision not to resuscitate has been made by three competent specialist physicians, then it is permissible not to resuscitate.

The Fifth: If the patient had incurable brain damage after a cardiac arrest and the condition is authenticated by three competent specialist physicians, then there is no need for the resuscitative measures.

The Sixth: If resuscitative measures are deemed useless and inappropriate as decided by three competent specialist physicians, then there is no need for resuscitative measures. The opinion of the patient or his/her relatives should not be considered, for either withholding nor withdrawing resuscitative measures and

machines, as it is a medical decision and not in their capacity to make such a decision.

Examples for medical centers in Saudi Arabia supported DNR practice based on the regulations of The Islamic fatwa and The Saudi Commission for Health Specialties [5,21]:

I- King Fahad medical city (KFMC) CPP No 1430-606 Examples for DNR

1. Advanced incurable malignancy.
2. Advanced multi-organ failure.
3. Irreversible, severe, and documented brain damage.
4. Advanced cardiac, hepatic, or pulmonary disease.
5. Inoperable, life-threatening congenital heart disease, fatal chromosomal or neuromuscular disease.
6. Irreversible, severe, mental and physical incapacity.

II- Saudi Aramco Medical Services Organization (SAMSO) MSP 7 Examples for DNR

1. Advanced incurable, end-stage malignancy
2. End-stage organ failure
3. Advanced irreversible brain damage
4. End-stage renal disease if renal replacement therapy is not feasible
5. Inoperable congenital anomalies incompatible with life
6. Fatal chromosomal abnormalities
7. Brain death.

The Islamic Medical Association of North America (IMANA)

IMANA [22] believes that when death becomes inevitable as determined by physicians taking care of terminally ill patients, the patient should “be permitted to die naturally with only the provision of appropriate nutrition and hydration” and any medications and procedures that are necessary to provide comfort and alleviate pain. They do not believe in

prolonging misery on mechanical life support in a patient in a vegetative state, when a team of physicians, including critical care specialists, has determined that no further attempt should be made to sustain artificial support.

According to Saeed et al. [23], Physicians' religiosity may affect their approach to end-of-life care beliefs. They conducted research to evaluate the religious aspects of end-of-life care among 461 Muslim physicians in the US and other countries. Only 58.6% of the respondents believed that DNR is allowed in Islam.

DNR in Egyptian Medical Practice

In Saudi Arabia, Islamic law governs end-of-life legal issues based on specific legal terminology, derived from the Qur'an that is used to settle conflicts in end-of-life care. Egypt, which has much in common with Saudi Arabia and is predominately Islamic, has yet to develop any official state or religious policy for end-of-life medical care.

In Egypt, like Saudi Arabia, Islam, based on the writings of the Quran, explicitly states that the end of life is entirely dependent on judgment by God (Allah). The DNR orders are theologically problematic. Open Discussion of DNR and related issues is essentially forbidden.

These religious norms usually create difficulty in recruitment and completion of an assessment of decision. The DNR medical order is a controversial issue in Egypt as there is no basis for ending therapy. Hospice services are essentially non-existent.

There are no data systemically or objectively collected from Egypt to know whether end-of-life care is used in any local institution or has been considered by medical or non-medical individuals. Many important factors such as patient competence, socioeconomic status and education that influence the decisions on medical care, are not known for the country.

Most studies were unable to discover any formal or informal non index local literature published on end-of-life medical care in Egypt. However, Hassanin et al. [24] have conducted an important study to investigate the acceptance of Do Not Resuscitate order in Egypt. They addressed the most important factors affecting DNR decision in Egypt such as cultural, educational, religious factors, ethical issues and emotional burden on families. They concluded that these were the main reasons for poor communication between staff and family members. Emphasizing the need to continuously evaluate DNR practice in Arab Muslim countries like Egypt. They also reported that 66.8% of Egyptian Muslim physicians support DNR.

According to the study of Hassanin et al. [24], there is number of important questions pertinent in Egypt:

1. Is this issue a professional decision, independently met by a physician?
2. Or it should be based on patient's requests without medical or scientific justification?
3. What is the role of the family and to what extent should family influence the DNR decision?
4. Who has the sole authority to determine that no further treatment measures are taken?
5. Are there legal aspects or traditional and religious issues?
6. And finally, are there issues concerning the waste of medical resources or economic impacts on family members?

Current state of DNR in the Middle East [25,26]

Egypt: There is no formal or informal local literature published on end-of-life medical care. Jordan: DNR is not recognized.

United Arab Emirates: Medical staff is forced by law to resuscitate even if there is a DNR signed form. Saudi Arabia: Patients cannot legally sign a DNR, but DNR is accepted in terminally ill

patients by order of primary physician signed by two other doctors.

Oman: No legislation regarding DNR orders currently exists.

Conclusion

Currently, DNR practice becomes an important part of the medical care. Yet, the knowledge of the physicians and medical care staff about the existing DNR local policies and guidelines is not enough to ensure the optimum medical service for terminally diseased patients. The DNR is a controversial topic usually accompanied by arguments and conflicts. DNR implementation could be complicated as they are reliant on culture, context, policy, persons, and resources. Also, resuscitation decisions involve patients, families, staff, and organizations, raising a storm of emotions and consequences. The need for education of the public is an essential part of DNR practice. Poor explanation to the family has often led to family dissatisfaction in many cases.

In Egypt, the general knowledge and attitudes regarding DNR are present but are still evolving. Although more formal studies are needed, the performed investigation provides objective evidence of the existence of institutional DNR and a significant acceptance of DNR in Egypt by all stakeholders. Improvements in medical and public education on DNR have an opportunity to succeed and improve end-of-life care and reduce the unnecessary economic burdens in Egypt.

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