DNR Guideline

Resuscitation is a common procedure performed in hospital for all patients suffering from cardiac or respiratory arrest. This involves lot of manpower efforts, time and expenses without adequate rewards in terms of intact survival. Often short term recovery and subsequent intensive care inflicts physical discomfort for patients and family alike and mental and financial agony for family members. This has been appreciated by healthcare providers across the world and efforts have been made to provide meaningful care and graceful end to life, without painful life pending death for patients and leaving a feeling of guilt among the survivors.

Definitions

Euthanasia: This word is derived from Greek Eu and thanatos meaning good death. In medical parlance it refers to acceleration of death by active intervention to alleviate suffering of a person who is in irretrievable situation. It has been amply clarified that euthanasia is essentially voluntary and any intervention against the will is equivalent to murder. [1]

Active Euthanasia: A deliberate intervention undertaken with the express intention of ending life to relieve intractable suffering.[2]

Passive euthanasia: is different from active euthanasia in that it involves with-holding life support system for continuance of life. [2]

End of Life Care: This refers to care of a person who has received a life limiting diagnosis. It encompasses all aspects of care till the final outcome and care of mortal remains.[3]

Resuscitation: Is the process of restoring the cardiac or pulmonary function back to normal, fully or partially, after a cardiac or respiratory arrest.

Do Not Resuscitate (DNR) order[4]: This is a treatment decision taken prior to event of cardiac or respiratory arrest, with the consent of patient or where that is not possible –proxy consent of next of kin, where care providers will not provided requisite cardio-respiratory resuscitation. This does not preclude or stop to any degree normal care and treatment being given to the patient.

The Legal Framework

The constitution of India, article no 21 provides Protection of Life and Personal Liberty. It states that "No person shall be deprived of his life or personal liberty except according to procedure established by law". However there have been several expansions of article 21 and in its expanded form it assures the right to live with human dignity. Death is universal but dying in a peaceful and dignified manner would

be welcome by every individual.

Some persons interpreted the right to life as including right "not to live" or right to death.[5] However in this judgment, while accepting right to die, euthanasia was not considered viable and was not permitted. Several other judgments have held that right to life as enshrined in constitution article 21 does not confer right to death. [6,7]. In a recent judgment on a PIL, Rajasthan high court two judge bench upheld the PIL and held the Jain religious practice of "Santhara or Sallekhana- a practice of deliberate starvation to death" as unconstitutional and to treat it as suicide punishable under section 309[8].

End of life (EOL) decisions: Why do we Need it?

There may be many situations when patients with irreversible or end-stage diseases (where there are very little chances of recovery) who remain intubated and on assisted ventilation and may continue in the same state for days or weeks or months. This is associated with several conflicts:

1. This results in prolongation of "vegetative life" which may be a source of misery for everyone, especially for the patient and his/her family.
2. There is a lowering of 'dignity of death' due to futile invasive procedures and unnecessary treatment.
3. There may not be any chance of any improvement or survival leading to wastage of resources.
4. It may be a significant burden for the family or society - physically, financially and psychologically.
5. There may be situation where limited resources may be denied to a more "deserving salvageable individual" as they are "in use" for a vegetative individual.

6. Most of the time family members are aware of the final outcome but are usually in a state of conflict and denial and are unable to take decisions of end of life (EOL). An informed, unbiased medical opinion may help them to resolve their conflicts, provide comfort and peace to make a decision.

7. In some Specific Situations there may be need for withdrawing assisted respiratory support e.g in cases of brain-stem death at which all functions of the brain-stem have permanently and irreversibly ceased and is certified by a Board of medical experts.

In spite of the above situations which happen quiet frequently especially in ICU set up and terminally ill cancer patients or in some irreversible chronic conditions, there are no legal guidelines in our country regarding withdrawal of care or EOL decisions. There is also no guideline regarding not to initiate resuscitation in conditions where life may not be meaningful after resuscitation.

End of Life Care

End of Life Care is defined by National Council for Palliative Care UK[9] as "Helps all those with advanced, progressive, incurable illness to live as well as possible, until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support."

This essentially means not taking up intensive care in the event of a cardiac or respiratory arrest but does not deny continued care, nutrition by oral or oro-gastric or naso-gastric route, pain relief, physiotherapy and other comfort care. It does not mean abandoning a patient after an EOL Care decision is taken.

Ethical Principles

While taking decisions for EOL in any critically sick patient, four ethical principles must be followed.[10]

1. Autonomy of the patient
2. Beneficence
3. Non-malfeasance
4. Distributive justice

Autonomy means an individual's rights of freedom and liberty to make changes that affect his or her life. In the Right to self-determination, the informed patient has a right to choose the manner of his treatment. To be autonomous the patient should be competent to make decisions and choices. In pediatric and neonatal patients either the parents or a legal guardian can take such decisions.

Beneficence is acting in what is (or judged to be) in patient's best interest. In critical care, the physician takes care for patients with a high risk of death. As the physician is also expected to act in the best interests of the patient and his family, his responsibility should extend beyond medical treatment to ensure compassionate care during the dying process. The physician's expanded goals include facilitating (neither hastening nor delaying) the dying process, avoiding or reducing the sufferings of the patient and his family, providing emotional support and protecting the family from financial loss. Parents also can be guided for financial help from charitable trusts, free government or insurance schemes.

"The best interest calculus generally involves an open ended consideration of factors relating to the treatment decision, including the patient's current condition, degree of pain, loss of dignity, prognosis and the risks, side effects and benefits of each treatment." [11]

Non- malfeasance means to do no harm, to impose no unnecessary or unacceptable burden upon the patient. This is subject to varied interpretation, as the same act may be construed as harmful or beneficial depending on the circumstances. In practical

terms, it requires the physician not to act contrary to the patient's values and perspectives.

Distributive justice means treating patients truthfully and fairly. Physicians need to take a responsible decision and to make good use of the infrastructure, financial and human resources under their control. The physician may thus provide treatment and resources to one with a potentially curable condition over another for whom treatment may be futile.

In cases of resuscitation of newborn, the autonomy of newborn and to take decision in life threatening emergency situations is both exceptions of general rules of ethics.

Dilemma in EOL decisions

While dealing with a situation which may warrant EOL care decision or discussion, taking abovementioned principles into account, dilemma arise in the mind of treating doctor. These may be summarized as below:

Legal dilemma:

To be certain about prognosis

A reasonable amount of certainty is required to take decisions regarding end of life because the probability of dying is not always clear. In many countries there are set guidelines about when to initiate EOL discussion, however we do not have definite guidelines agreed upon by professional bodies.

There can be questions in relation to which patients can be ascribed as "approaching the end of life". In most situation it is obvious and indisputable. However, many times it may be difficult. GMC guidelines[12] suggest if a person is likely to die in a period of one year, (s)he may be considered as "approaching the end of life". These guidelines hold true for adult and pediatric population.

Ethical Dilemma

Ethical dilemma arises when the opinions are at variance e.g. one child or parent of the diseased may have difference of opinion from the other. It may so happen that the diseased person is a minor, but is old enough to understand and his opinion is different from parent(s). There may be situation where competence of adult may be questionable. In another situation, opinion of the parent(s) may be detrimental to the baby. In such situation, there is no remedy available in India, but countries like US have social set up like child services which can be activated and they in turn can take legal opinion and legal custody of the baby.

Most of this dilemma can be solved with clear thought process, involvement of senior most physicians in the team and good communication with the next of kin, in most

circumstances. However, In Indian social setup, where everyone wants to do "the best" till the end for social reasons, it may still be difficult to achieve consensus among family members. In such situation DNR or end of life care should not be activated till consensus is achieved.

What is DNR:

DNR[13] (Do Not Resuscitate) is a clear concept in most developed countries. It involves not initiating resuscitation in the event of a cardiac or respiratory arrest. It does not involve withdrawing life support system where a patient is already on ventilator or inotropes. It also does not involve discontinuing routine care like oxygen, nutrition, fluids (oral or IV). DNR is like any other treatment decision and must be and adequately documented and communicated to all team members for effective implementation whenever required. In India so far we do not have a clear legal guidelines and accepted method of documentation of DNR.[14]

There are two more terms used in this relation. One is **withhold LST** (Life Sustaining Measures) and **withdraw LST:**

LST especially ventilation, Central line placement, renal replacement therapy etc require consent to initiate these procedures. Except in the event where none from family was available, they should not be initiated.

Withdrawing life sustaining treatment is more difficult and lack clear guidelines. However, it should always be done with clear and repeated discussion, including by senior member of the medical team and written consent, clearly explaining the implications to the parent(s) or next of kin.

Clinical Aspects of DNR

Who are the candidates for DNR:

In one sentence, it can be said that situations where resuscitation is not likely to lead to prolonged and useful survival, are the candidates for DNR. These patients include:

-Where life sustaining treatment is likely to be ineffective or futile.

-Where patient has prolonged unconsciousness which is unlikely to recover.

-Where patient has a terminal condition for which there is no definitive therapy.

-Where patient has a chronic debilitating disorder where burden of resuscitation far outweighs the benefits.

-Where medical treatment appears futile. Futile medical treatment is generally defined as "where treatment is useless, ineffective or does not offer a reasonable chance of survival". [15]

-Such other factor that may be unique to the patient e.g where patient has made an informed living will to refuse CPR.[16]

Who are not the candidates for DNR

DNR should not be activated where

- Patient is unable to pay for advanced care.
- Where the outcome is doubtful (may or may not improve situation).
- Where there is conflicting opinion among the family members.
- Where responsible next of kin is not available for discussion.
- Where written consent is not available.

What is done and what is not done if DNR is activated[17]

Even with DNR orders, a health worker will provide basic support in the form of

- Clear airway
- Provide Oxygen
- Position for comfort
- Splint
- Control bleeding
- Provide pain medication
- Provide emotional support
- Contact hospice or hospital (as hospice facility is hardly available in India)

With DNR orders, a health care worker is not required to

- Perform chest compressions
- Insert advanced airway
- Administer Cardiac resuscitation drugs
- Provide ventilator assistance including non invasive ventilation
- Defibrillate

DNR Issues in Neonates

Neonates are in a special situation with respect to resuscitation and DNR orders. A clinician may face this situation right at the time of birth or subsequently during treatment in a neonatal unit. At the time of birth, condition of the baby may be anticipated or may not be anticipated and arise suddenly. Like in all other situations, social, emotional and cultural environment would affect decisions in relation to DNR decisions.

DNR Decisions at the time of birth

At the time of birth two broad situations may demand a decision on DNR. First is a baby with congenital anomaly or anomalies that are incompatible with life or may be compatible with life but the expected quality of life may be poor or a big drain on resources of family / society. Second situation is where the birth weight and gestational age is such that survival, especially intact survival may be almost impossible. Where congenital anomalies are known before birth and the time permits, DNR decisions should be discussed with parent(s) and other family members, sometimes elders from society including religious leaders or family physician. This will provide a clearer picture on expectation of family and decision to resuscitate or not becomes easier for care provider. If family desires that the baby should be resuscitated and subsequently reassessed for the status with respect to survival and treatment options, this must be honored. Where family agrees with DNR decision, it may be implemented, if the baby is found to have expected situation / problem. The decision of DNR may be reversed if doctor finds baby's condition to be different from what was antenatally expected. This should also be explained to parent(s) during discussion on DNR.

Where there had been no opportunity for discussion on DNR with parents, baby should be resuscitated fully except in gross anomalies that are incompatible with life like anencephaly [18] or prematurity that is not compatible with life. Decision on prematurity depends on period of viability. With survival of even 20 weeks gestation babies in some developed countries and may be in some centers in our country, Period of viability is a definition that has become more difficult. This decision should be based on local survival data and possibility of intact survival in a given setup. However, as a general norm it can be said that 24 weeks gestation babies are regularly surviving[19] in many centers in our country and therefore any baby above this gestation age must be resuscitated and subsequently management options discussed with parents, including transfer to a tertiary care neonatal unit.

DNR decision in Neonatal Units (including NICUs)

DNR issues faced in neonatal units are qualitatively same as faced in other intensive care unit. However, frequency of congenital anomalies in neonatal units is high and is a prominent reason for a DNR order. In a study from Oman[20], lesions that will not allow meaningful survival was the most common reason (18 of 39) followed by

lesions incompatible with life (15 of 39) were the primary reason for a DNR order. Gestation age related reason were only 3 of 39 where babies below 24 weeks gestation were given DNR orders. This study also highlighted that parents were more comfortable accepting non-initiation of ventilator support (14 of 20 cases where it was proposed) than withdrawal of ventilator support (2 of 19 cases). In this study 36% of deaths were preceded by a DNR order. This is far less than some of the western studies [21] where the frequency was as high as 67.9%.

In India, there are hardly any studies on this subject. However, wherever facilities for neonatal care are sparse the requirement will be more and criteria for DNR order should be customized. While customizing and documenting these criteria, one should be cautious that lack of resources or inability to pay is not a criteria for DNR decisions in neonatal units, just as they are not in other neonatal units

Counseling:

Preparations for Counseling

Preparation for counseling involves unanimity in the health care team on appropriateness of DNR decision in the given circumstances[22]. Decision is based on criteria identified above. Decision to invoke DNR order should first be discussed in the treating team including nurses[23]. Once agreed upon within health care team, further steps to initiate a discussion with the patient/ relative(s) or a "person responsible" should be undertaken.

Team needs to decide on competence of the patient to take a decision, in which case discussion should involve patient himself, unless (s)he expresses his unwillingness to discuss matter related to death.[22,23] Where patient is not found competent, other members of the family need to be taken into confidence, a next of kin or "person responsible" should be identified and informed of the need to discuss the issues relating to health of the patient, treatment plan and DNR in the event of a cardio-respiratory arrest. (S)he should be given an opportunity to identify other family members, who should be present during this discussion. Where such members may not be immediately available, a session may be scheduled based on mutual convenience. Such person should also be given an opportunity to identify if (s)he wants specific member of healthcare team to be included in the discussion. In Indian social scenario family may desire to include even a family physician or a doctor not working in health care facility where patient is currently being treated.[24] This should be permitted as it is more likely to be helpful rather than a hindrance in taking

appropriate decision. Pending such discussion, a DNR order should not be invoked and resuscitation carried out in the event of an arrest.

Health care team leader should be aware of all details about patient illness. The records related to patients illness including the days progress notes must be reviewed before initiating a discussion. The diagnosis should be available. Doctor should be aware of the basis of making the diagnosis and any other complicating issues during current admissions. It may be helpful to keep complete records of the patient during discussion, so that the progress (or lack of it) can be discussed based on clinical notes and investigation rather than being seen as the personal opinion of the treating physician.

It is a good social practice to formally introduce the members of health care team present during discussion (including their designations) even though some or most may be known to the family members and the family member (including their relationship with the patient). This helps all concerned in understanding each other's perspective and help in breaking ice initially. Discussion should be initiated with the information on patient's illness (past and present), treatment being offered, future plan and benefits or futility of treatment being given and prognosis of the patient. Presence of a living will (though not really prevalent in Indian scenario) should be enquired about. The family members may be asked "what the patient would have done in such a scenario if (s)he would have been competent. That may provide a clue to the attitude of the patient (and may be the person replying) towards life or death. This may help the "person responsible" in decision making.

Responsibility for Counseling

It is difficult and stressful to undertake a conversation about death even for experienced clinicians. [23,25] Therefore usually the senior most doctor i.e consultant in charge of the case should take the responsibility for initiating and completing this discussion [26,27]. However, there may be situations where another member of the health care team has developed an excellent rapport with the patient.[23,25] This may be junior doctor in the team or even a nurse. In such case responsibility may be given to another member and (s)he should be supported by other members of the team. At the time of initiating discussion with patients, it is important to have complete unanimity in the treating team towards the decision, which is also the responsibility of the consultant in-charge.

Family and Social issues related to our country

Family issues in our country are many. It is imperative for the counseling team to try and understand the social dynamics of the family and identify the decision maker among the relatives present. At the same time others should not be ignored altogether. In case of an old patient, an assessment of conflict of interest among family members should be explored. It is a common scenario to find that one person agrees with the decision of DNR and other(s) do not. In such situation, it is avoidable to press for the agreement. It is prudent to call for another session.

In Indian scenario and that of other developing countries, where hierarchy of community still exists, it may not be possible to give consent out of free will despite constitutional freedom to so. Most often, it is the social harmony overrides and should not be disturbed by the treating team. In fact it may be helpful to engage such individuals for the benefit of the patient. [24]

Financial issues may be involved, where the person responsible for the payment wants such a decision where as others resist. [28] It is not unusual to find a situation where family member agree with the prognosis and futility of intensive treatment but out of social pressures and culture of "doing best possible till the last" do not want to agree.[25] Such situations should be handled with gradual re-enforcement of clinician's view point and discussion on financial involvement in such situation may be help especially where the cost of hospitalization is to borne out of pocket of an individual.

Hierarchy for Decision making [29-33]

There is no description of hierarchy for decision making with respect to DNR decisions. In Indian situation only guidelines available on hierarchy are for inheritance of property. Though not meant for clinical decision making, they do provide some guidance for similar situation, clinical and health related problems may be one of them when it comes to consent by a substitute.[32] However, the hierarchy for consent in various situations are defined in other countries e.g. emergency treatment, clinical research etc are clearly described and are logically acceptable for decision making with respect to DNR decisions as well. This is as follows:

1. Patient himself so long (s)he is competent.
2. Advanced health directive (will seldom be available in actual practice in India).

3. Enduring Guardian (In India there is no law that recognize this kind of arrangement. Therefore, this becomes invalid in Indian scenario)
4. Guardian
5. Spouse
6. Child
7. Parent
8. Sibling (who maintain close contact).
9. Unpaid provider of care.
10. Anyone who maintains close contact.

Same hierarchy could be valid for consent in situation of DNR.

Process of Consent and Documentation

The process of consent taking involves preparation for discussion. Which means that the diagnosis must be certain, records should have been reviewed just before initiating discussion so as to inform the relatives about the latest condition of the patient, all options in relation to possible alternative treatment strategies should have been discussed within the medical team and agreed upon.[22,23,26]

It is useful to have privacy and uninterrupted time for discussion.[23] Phones should either be switched off or handed over to someone outside the room to handle the calls. Sensitivity and empathy are of paramount importance without which it is extremely difficult to achieve desired goal.

Initiation of discussion should be by elaborating patient's current condition which should be followed by a discussion on caregiver preference. Expectations should be clarified and documented. Cultural factors must be taken into account. This helps in deciding the manner in which further information is to be provided. Information provided should be free of jargon, in simple terms and in language that the patient's relatives can understand. Uncertainties should be explained and also the fact that in the event of a cardio-respiratory arrest, there will not be enough time for discussion. Any distressing signal, verbal or in body language should be addressed. Realistic hope should be provided in a manner that is honest but not blunt. Realistic goals of

care that is to be continued should be explained. Questions should be encouraged to clarify the situation. This also helps in assessing the mindset of the relatives.

Finally, after the discussion is over, a summary of the discussion should be documented in the case records of the patient. Summary should include the date, time and place of discussion, names and relationships of the person present with the patient and the decision reached. If DNR is agreed upon the order should be placed in the case records of the patient and the healthcare team should be informed of the same.

A checklist for documenting the summary may be useful. It may be as follows:

- Name of the patient: …….
- Regd No : IP/14/……
- Diagnosis:
- Prognosis:
- Names of persons involved in discussion: ……
- Likely outcome of CPR: Unsuccessful
- Preference of the patient: Against CPR/ Undecided / Not Known
- Views of the "person responsible": Against CPR/ Undecided / Not Known/ Wants CPR
- Reasons for decision of DNR / not advising DNR: ……..
- Goals of treatment: Palliation/ Symptom relief/ Recovery from present episode of illness
- Consultant Responsible for DNR order: Dr……..
- Review Date: dd/mm/yyyy
- Remarks (if any)

Review of DNR orders

Every DNR orders, even where it seems final, should be reviewed at predefined interval and continuation of DNR orders should be documented in the case records of the patient.[23] Usually this responsibility lies with the consultant in charge (The Senior most clinician) of the patient or a person working on his behalf. Where a DNR order is revoked, the reasons for the same should be documented and informed to the relatives, preferably the same person(s) who were present at initial discussion. It is of importance to note that if a patient is being transferred to another facility for care of the patient, DNR orders remains valid. However, it would be a good practice to re communicate the same to the relatives of the patient.

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