Implementation of Supreme court Judgment on Advance Medical Directives and “Passive Euthanasia” or withdrawal and withholding of life-sustaining treatment

In keeping with the right to Privacy the Supreme Court has delivered a landmark judgment for patients facing terminal illness. Such patients and their families are often subjected to unwanted medical interventions that serve only to render the dying process agonizing. Medical ethics and standards in such circumstances involve offering the choice of withholding or withdrawing such interventions while shifting the focus of care to providing comfort. Autonomy is a fundamental Right and should therefore extend to the time when the patient is incompetent. This judgment reiterates such Right to all in relation to their bodily and personal integrity while facing death.

The honorable judges have established the moral and constitutional basis of the fundamental right to Autonomy and have also recommended an operational pathway. While we applaud the direction provided by the Supreme Court judgment, as medical professionals with experience in critical and palliative care, we would also like to point out serious practical difficulties with the implementation of the procedure laid down by the Supreme Court. This statement recommends some modifications to this procedure in an attempt to give effect to the spirit of the Supreme Court’s remarkable judgment.

In simple terms this judgment effectively realizes a fundamental common law and constitutional principle. This principle is that any authentic expression of an individual’s wishes with regard to his/her health care, including the refusal of life-sustaining medical treatment, must be respected.

TERMINOLOGY: For the purposes of this note, the resource will be the ICMR document on ‘Definition of terms used in limitation of treatment and providing Palliative Care at the End of Life’ available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5930529/. This is because media persons and legal professionals often use anachronistic and obsolete terms. For instance the term ‘passive euthanasia’ is hardly used anywhere else in the world.

ADVANCE (MEDICAL) DIRECTIVES: A statement made by a person with the decision-making capacity stating his/her wishes regarding how to be treated or not treated at a stage when s/he loses such capacity. Advance directives include living wills or health care proxies and become operational only after the person loses capacity.

WITHDRAWAL OF LIFE-SUSTAINING TREATMENT: On a background of terminal illness, a decision made to cease or remove a life-sustaining intervention presently provided, where the patient’s chances of survival with continued life sustaining treatment is poor with the burden outweighing the possible benefit and the fully informed patient is incompetent, a surrogate on behalf of the patient chooses to cease the life-sustaining treatment.

WITHHOLDING OF LIFE-SUSTAINING TREATMENT: On a background of terminal illness, a decision made not to initiate or escalate a life-sustaining treatment, where the patient’s chances of
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WITHOLDING AND WITHDRAWING LIFE-SUSTAINING TREATMENT (WD/WH-LST):
The Supreme Court has made it clear that the following procedures would apply both to persons who had a valid Advance Medical Directive as well as those without, so that 'cases where there is no advance directive... cannot be alienated'. The process includes the following steps:

1. The initial step is medical opinion confirming the terminal nature of the illness or there is 'no hope of him being cured'.
2. This will be followed by constitution of a Medical Board consisting of the Head of the treating department and at least three experts from various fields each with at least 20 years professional experience, who will examine the patient in the presence of family and will issue a preliminary opinion.
3. This opinion will then be conveyed to the jurisdictional District Collector who will then convene a Medical Board consisting of the 'Chief Medical Officer' of the district together with three experts of the same standing as mentioned above but different from them i.e. not members of the previous board. They will individually/collectively examine the patient and whose opinion will be conveyed to the jurisdictional JMFC.
4. Finally the JMFC will visit the patient and authorize the implementation of the decision of the board.
5. In case the Board/s refuse/s permission, the High Court can be approached.

Again, the difficulties inherent in this procedure are obvious and will make the judgment ineffectual in actual practice. While it does away with a procedure involving the High Court prescribed in the Aruna Shanbaug judgment, it has replaced it with another potentially lengthy procedure. Death and dying in hospitals are common and disproportionate interventions too are commonplace. To have a procedure that involves too many persons and procedure would be cumbersome. Safeguards if too heavy may actually defeat the main purpose- that of caring appropriately for the dying and their families.

To detail the problems:

1. This decision making is largely required for seriously or critically-ill patients who are often admitted to ICUs. This decision-making worldwide takes place within a few hours to usually a maximum of 2 weeks. Because the SC recommended process will be very lengthy to implement, it is unlikely to be usable for most patients in ICUs except for those in the persistent vegetative state which is an exceptional situation.
2. While this decision making is in process, hospital costs will be incurred. These are of the order of tens of thousands of rupees daily for sophisticated care that can keep critically ill patients alive, even on a no-profit basis. Individuals, third party payers and hospital administrations cannot be compelled to bear these costs when medical futility is obvious.

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3. A parallel can be drawn with the Human Organ Transplant Act (THOTA). Earlier THOTA was restrictive and bureaucratic. Now organ transplant decision making is delegated to individual hospitals. As has been done in the judgment, we also suggest a two-tiered process (detailed below) for WH/WD, which is likely to be more timely and more suited to real-life critical care.

4. Two-tier process for WH/WD of Life Sustaining Treatment (LST):
   a. TIER 1: Decisions regarding WH/WD-LST must be completed at the bedside between the surrogate/s of the patient and the treating team. The person designated as the Healthcare Power of Attorney (HCPOA) will be the surrogate. If there is no AMD/HCPOA then the surrogate hierarchy will be the same as in THOTA. The treating team will comprise a minimum of three 'senior' doctors. Preferably it should include a representative of the medical facility administration. Due process will be scrupulously documented by the medical and administrative teams of the facility. WH/WD-LST can then be implemented as per recommendations and treatment guidelines of professional bodies such as the Indian Society of Critical Care Medicine (ISCCM) and the Indian Association of Palliative Care (IAPC).
   b. TIER 2: Each facility that operates an ICU must constitute a standing Clinical Ethics Committee (CEC) or must have access to a standing jurisdictional CEC which may be constituted by the District Collector or Chief Medical Officer. This committee will have adequate representation from outside the hospital/facility including legal experts, patient advocates/NGOs, etc. All cases where WH/WD-LST is carried out must mandatorily be audited post-facto by the concerned committee and their recommendations will be binding on the hospital/facility/local administration within pre-specified time limits. This committee will also be involved from the beginning if there is a lack of consensus between surrogates and the treating team.

CONCLUSION: As stated in the beginning of this note, our effort is to bring to life the spirit of this remarkable judicial effort. In the light of our experience, we believe that there will be significant difficulties in implementing the detailed procedure laid down by the Hon'ble Court. We have recommended procedural alterations largely in keeping with national and international professional consensus and jurisdictions elsewhere in the world.

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