

DISCUSSION

DNAR Guidelines from ICMR: Meeting a felt need

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We note with interest Dr Olinda Timms' comments (1) on the Indian Council of Medical Research (ICMR) guidelines for Do-not-Attempt-Resuscitation (DNAR) published recently (2), and thank her for raising some pertinent issues.

One of the reservations expressed in this editorial is on the lack of details regarding the legality of DNAR decisions in the ICMR document. There is, to date, no clear pronouncement on DNAR in Indian law. That should be no reason not to formulate an ethical and professional consensus to clarify when cardio pulmonary resuscitation (CPR), a medical procedure (3), may not be indicated. Evidence-based practice, grounded in ethics and pragmatism, has always preceded law and legislation. Otherwise it would be a case of the cart before the horse. However, in order to address legal concerns, and to ensure consistency with existing laws, the document was legally validated by three lawyers who were part of the Core Committee and the Expert Group.

DNAR has been an integral part of medical practice worldwide for more than 45 years (4). In the United States, the first of such orders was written in 1974 followed by a codified law only in 1988. The law served to considerably reduce unnecessary CPR as well as unilateral DNAR (5). It is important to mention that outcomes of CPR in critically ill patients are beneficial in less than 5% cases (6). The consequences, to the individual families and to society at large, are highly

adverse, for CPR may result in survival with poor neurological outcomes. In India, despite much avoidable suffering to patients and families, and moral distress to caregivers, there is no formal acceptance of the grim realities, due to which DNAR is considered essential in modern medicine.

CPR, under the circumstances of terminal disease, is therefore usually not acceptable (7). It is pertinent to point out that most of the litigations in the world, around CPR have been for the breach of patients' rights in performing CPR, disregarding advance directives (8). The tenets of respect for autonomy and of weighing benefit vs harm to fulfill the obligations of beneficence and non-maleficence, are ignored, when CPR is performed regardless of the phase of the illness or the patient's choice. The ICMR document aims at defining the ethical standards of care with respect to CPR/DNAR. In any case, legal liability, as with any medical decision, is determined by care standards set by professional consensus. The constitutional validity of treatment refusal and withholding of life-prolonging treatment was well established for India in the *Common Cause* judgment (9).

As noted by Dr Timms, indeed it would be desirable for a professional regulatory authority such as the National Medical Commission to formulate guidelines on matters such as DNAR or an overarching end of life care policy. In the absence of such guidance, the ICMR initiative has answered the long-felt needs of medical caregivers confronted daily, with ethical dilemmas in managing terminally ill patients. It is appropriate that ICMR, the regulatory authority for research ethics, formulates guidelines for DNAR, which has as much to do with ethics as with clinical decision-making.

Due care and diligence went into the formation of the Expert Group to ensure it was truly representative. The core Committee included, apart from the ICMR Bioethics department, several practising clinicians with subject expertise—an intensivist, an anaesthesiologist-cum-palliative care specialist, a neurologist with interest in neuro-palliative care and physicians. The group was drawn from both Public and Private sectors. In recognition of the multi-professional intersections in the field, the core committee and advisory team included legal experts, ethicists and palliative care specialists among others. The consultation process involved:

- four sessions among core group members with multidisciplinary and multi professional invitees;
- the setting up of a round of open public consultation on the ICMR Bioethics Unit webpage for four weeks for comments by patients and the lay public; and finally

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c) a national consultation with a multi professional representation and lay participation.

Participation was kept open through online registration on the ICMR website with 20 slots reserved for patients or any interested citizens. The consultation was widely publicised resulting in the participation of 60 individuals in all. The final document was drafted based on all of the above mentioned rounds. We, therefore, have reason to believe that the document embodies the perspectives of a broad spectrum of stakeholders.

Traditionally, the term “treating physician” denotes the one under whom a patient is admitted. In a unit, it would imply the unit head or an assigned physician. In current times, it is usual for a patient to be looked after by a team. Therefore, even if the patient is attended by a junior physician as a first responder, the overall responsibility and accountability lies with the treating physician. The term “physician in-charge” likewise specifically denotes the Head of the unit. The document thus clearly recommends that the most senior member of the team should take charge of the communication leading up to the decision. In case of transfer of care of the patient to another department, the onus of the DNAR decision, as with overall care, would be transferred to the receiving department.

It is valid and necessary, as pointed out by Dr Timms, that a DNAR decision should be disseminated to the entire care-giving team to avoid inadvertent CPR. Indeed, this is the spirit of a formal process and documentation of a DNAR decision. Errors are prone to occur in a crisis, when CPR is unanticipated and neither the family nor the treating team is prepared. Identification “tags” have been a customary practice but the treating team runs the risk of being suspected of negative stereotyping and discrimination (10). The ICMR document has clarified unambiguously that DNAR does not include decisions to withdraw or withhold other life-prolonging treatments. It is possible to continue with curative treatments while precluding CPR. It is crucial for hospitals to create a culture of ethical decision-making involving the entire team, including the nurses. We believe DNAR decision (“no code”) should be part of the doctor and nursing notes and should be communicated during the hand over as with other clinical details. This should be complemented by promoting end-of-life-care literacy and training.

Privacy and confidentiality in discussing prognosis and the further course of management should be a given. It is clear from the document that no patient or family can demand a procedure, including CPR that is evidently not medically indicated. However, ethical principles behoove the care-giving team to discuss openly and completely as outlined in the flow chart of the ICMR document. Disagreements are to be resolved through multiple sessions and seeking second opinions. Another mechanism for redressal of differences could be referral to an ethics committee. Indian Critical Care and Palliative Care Societies have always recommended setting up of such a committee for the oversight of treatment limiting decisions (11). Such a provision is also recommended

recently in the EOLC policies of the Kasturba Medical College and Manipal group of hospitals (12) and the All India Institute of Medical Sciences (13). In practice, these decisions are made after building a relationship of trust. Therefore, referring to another body of physicians would render the process cumbersome and hamper the primary objective of mitigating patient/family suffering and physician moral distress. Standard guidelines in other countries with long experience of DNAR recommend that caregivers and patient/family work together as a rule and refer to an independent committee only for conflict resolution (7,14).

The word “vegetative” is used for its technical specificity as this guidance is for the professional community. The FAQ in the supplement is meant especially for the lay public. While discussing the clinical state with the family, we suggest the use of euphemistic expressions such as “irreversible coma” while retaining accuracy of the description.

The value of a guideline is ultimately tested by its applicability in the real world. Departure from a habitual but flawed “ritualistic CPR” is expected to take time. At the same time, many physicians will feel empowered to write DNAR orders with more clarity and conviction than hitherto. The process, as recommended by the document, would also ensure that the decisions are reflective, empathic and transparent.

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Centring patient autonomy in DNAR decisions

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The Response from the ICMR team of Dr Mani et al (1) to the *IJME* Editorial (2) on the ICMR DNAR Guidelines (3) provides some answers to the gaps and questions raised, and it is hoped that these will find a place in revised versions of the document. The document Disclaimer said “further revisions” were planned, based on perceptions and experiences of clinicians and the public; an early revision will allow for better acceptance of the Guidelines.

The word “consensus” in the title of the Guidelines conveys the impression that there were wide ranging consultations, but this was not the case. A guideline that applies to all doctors, and can potentially impact every patient, deserves much wider discussion. Such discussion should take place with clinical societies, doctors’ associations, the National Medical Commission, as it is the apical body governing medical practice, and health activist groups. Discussions with patients’ groups, women’s, dalits’ and other underprivileged and discriminated groups are needed to address their concerns about the misuse of the provisions. The ICMR “Bioethics page” may not have been the best location of the call for a broad consultation, as clinicians and non-researchers hardly ever visit the page. Valuable contextual feedback could surely have emerged from circulation to clinical and patient groups.

The Guidelines appear to be scripted from a medical perspective, with process flow and signature sheets that view ethical responsibility through a paternalist lens, describing

clinician’s steps in decision-making and the requirement for consent. In fact the DNAR option is one that is exercised by the patient (or surrogate) after full understanding of the precarious condition and futility of medical efforts, and this option is then executed through a DNAR order written by the doctor. The DNAR decision needs to be centred on the patient and ethically supported by the physician; this aspect was inadequately described in the Guidelines.

Though not provided by these Guidelines, express legal sanction for DNAR orders consented to by patient or surrogate would be crucial to effective implementation of this guideline. ICMR lacks the legal standing to enforce these Guidelines, prescribe punitive measures or arbitrate, as it does not govern medical practice.

Since DNAR refers to CPR only, there is a need to distinguish, right at the start of the Guidelines, between CPR and any other drug or fluid therapy that may have a resuscitating effect.

The response says that “treating doctor” and “physician-in-charge” implies Head of Unit or “senior doctor” but this would have to be made clear. This end-of-life decision by the patient and doctor is important enough to warrant responsible ownership of the process by a senior doctor who would be experienced and accountable.

While the Response acknowledges the role of Hospital Ethics Committees, this it is unfortunately not mentioned in any part of the document, FAQs, or Algorithm chart.

The revised document should also include the important clarification in the Response about sharing DNAR orders with the medical team and nurses, during handing over between shifts.

Since the Response has urged clinicians not to use the term “vegetative” in speaking to surrogates, the word should be removed from the “Surrogate Information Sheet” in the document.

The process described in the document does not give sufficient time for the patient and family to study the implications of DNAR. According to the answer to Q 2 (Annexure 3), the form would be issued when the patient was already in a terminal state. Most internationally reputed hospitals issue the form at the time of admission so that

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