THE CENTRE FOR
BIOETHICS
Improving health care through Bioethics

THE BIOETHICS BULLETIN

Volume 2, Issue 2

Editorial

In this issue we look at some of the ethical issues related to the end of life. We have touched upon only a few areas in these articles. Coming face to face with death is always a humbling experience and Dr. Christina's article reminds us that though death is the final enemy and we always feel rightly that we are violated, there is much we can learn from it. Dr Santhosh writes an article from personal experience of journeying closely with a loved one through the valley of the shadow of death and gives much practical wisdom on how a care giver can compassionately facilitate the whole process. His article touches upon many issues that can crop up in these situations and will be a helpful resource for one who has to care for a loved one with a life limiting illness. Withdrawal of supports and life sustaining measures is always a painful decision and the article by Shobha gives useful guidelines and perspective. We have an article by Jubin from the background of working among disabled children, and this raises some difficult questions for which we offer no easy answers. There are 2 other articles by Dr Jameela and Dr Ashu which throw light on the decision making process in end of life dilemmas. These decisions are not easy and so knowledge of guidelines can greatly help us wade through these stormy waters and quicksand. Above all, let us remember that we are not alone in all this and the One who has the power to raise a person from the dead is also one who sheds tears beside the sorrowful family that grieves.

Dr Satish Thomas

DEATH – THE END OF LIFE?

-Dr. Christina Marie Joseph

“Seeing death as the end of life is like seeing the horizon as the end of the ocean”; It's a beginning of another journey of existence in the presence of God. As the Bible says in John 3:16-17; For God so loved the world that he gave His only son, so that everyone who believes in Him will not perish but have eternal life.

I recall a patient of about 50 years of age. She had been admitted to our hospital 3 years ago for complications developing after an open cholecystectomy done elsewhere. At that time she was diagnosed to have biliary peritonitis presumably due to a bile duct injury for which she was re-operated here. She had been lost to follow up ever since. This time she presented to us with severe abdominal pain and symptoms suggestive of a biliary bronchial fistula. Investigations and preliminary work up revealed that she had a sub-diaphragmatic abscess and multiple biliary calculi. She was admitted in the Intensive Care Unit for conservative management of shock and sepsis.

I took great interest studying the case in detail and chose to present this patient at the doctors meeting on the morning following my emergency duty. The management plan was extensively discussed and it was finally concluded that special investigations (MRCP-Magnetic Resonance Cholangiopancreatography) would be necessary to decide the future action plan. The prognosis and fatality of her condition and the need for higher centre care was explained to her relatives.

Despite being fully briefed about the condition of the patient and our limitations with regard to the investigations and management needed; owing to financial constraints the family was still adamant that they had no desire to seek treatment elsewhere. I was frustrated no end knowing that in the given circumstances, her chances of survival and cure were rather bleak. Also, as a doctor working in a rural set up, I felt that there was not much more we could offer from our side other than supportive care.
Having said this much, I went through a lot of trouble locating her earlier patient record files and did an extensive internet search. I was shocked to note the paucity of information on the subject. Indeed her's was a rare condition with very few published reports world-wide. This motivated me no end. My mind was made up. I would work feverishly on, leaving no stone upturned and publish this case report with the help of my consultants.

Day after day I carefully went about editing data and making meticulous entries in the progress chart. Then one evening, some 3 weeks later, I could see my paper slowly taking form, barring a couple of clarifications from the patient. Mechanically, I briskly walked towards bed number 7 in the ICU; my sole intent to fill in the blanks in the history sheet and progress record for the case report, otherwise perfect in every detail. She who had survived for 3 long years hoping for a sure cure as she answered each question unwaveringly, patiently, smilingly; whilst for me I thought I was a step nearer to making a publication. I looked enquiringly at the nurse. Where had they shifted my patient?. I stared blankly at the newly made bed and the absent case papers --which said it all. The nurse put it very simply; “ Oh, she expired this morning.”

To say that I was stunned would be an understatement, I felt myself sinking deeper and deeper into an invisible black hole as the guilt overwhelmed me. And even as I saw my so called “brilliant” case study go up in smoke; I reflected on her life of those 3 weeks and how profoundly it had impacted me. First of all the thought of her dying so soon had never occurred to me. She must have been in a lot of pain but courageous as she was, she never once showed it. Nor did she ever lament over her pitiable plight. She had been brought to this Christian hospital knowing that she would be treated compassionately even if all else failed; And fail I did, oh, so hopelessly!

I had learnt this lesson well over 7 years ago. It was a time when I, as a patient had shared a hospital room with a little girl half my age who was diagnosed with Acute Lymphoblastic Leukemia. I remember all too well that it was this little selfless child with alopecia, hemiparesis and a million other setbacks who had brought a new meaning to my life. She parted with her most prized possession, a golden haired doll claiming that its hairstyle resembled mine; hence it ought to be in my possession. Her action left me speechless.

God works in strange ways they say. I was 16 then and overnight I had made up my mind .... I wanted to be a doctor. Until that day my purpose in life was focussed solely on personal achievements – medals, certificates and academic awards galore. I knew then that God had a special plan for me just as He had for that brave little girl who had changed my life so dramatically.

As doctors, nurses or medical staff, in dealing with terminally ill patients, how often do we seek to find that road of compassion that makes death a fulfilment rather than a loss to deal with? How often do we realize that the reward lies in the journey of finding that road rather than giving up on ourselves and patients and waiting for death to take its course?

Standing by her bed, I further reflected on those past 3 weeks, my patient and I, though for entirely different reasons had kept each other's hopes alive. But, like a flash of lightening and a break in the wave, one stroke of God's mighty hand had made all the spirit and glamour of the case vanish into thin air.
Those history sheets now seemed so lifeless as they slipped through my fingers onto the floor. I stared once again at that empty bed; Then all of a sudden , the vision of a brightly lit face of an 8 year old, the tired, wrinkled yet courageous face of a woman fighting a rare disease and then God's mighty love, the thought of compassion and eternal life with the Lord at the end of it all gave me in return a new hope...

Christine Marie Joseph is a Junior Medical Officer at the Herbertpur Christian Hospital, Uttarakhand

A Care Giver's Role in Life limiting illness

Dr Mathew Santhosh Thomas

The road on which a person and his / her family, diagnosed with a life limiting illness and approaching the inevitable end of death, passes through is laid with multiple rough patches and the journey is often a challenging one. The care providers' primary role is – as much as possible, to smoothen out the rough patches, and accompany and journey alongside much beyond the inevitable end, till such a time that the family is able to stand without this support.

A care giver, whether professional non- related care giver or family member, in this journey of accompaniment, will need to hold multiple roles and responsibilities, and switch these, on a dynamic basis, as the disease progresses and needs and contexts undergo various changes.

The primary role of the care provider will be one of being a **“Communicator”**. From the time of diagnosis, and into months after the demise of the person, this role of being an effective but compassionate communicator remains the role which will bring hope in the midst of a seemingly hopeless situation and comfort in the context of distressing events.

Communicating the diagnosis, the potential progression and the inevitable end, succinctly but with sensitivity and compassion, to the patient, close relatives, and the rest of the family, is a difficult challenge which has to be taken up early in the course of the journey. Ongoing supportive verbal and more often nonverbal presence is what could facilitate the individual and close relatives to move from denial to acceptance, anger to peace and helplessness to hope. Equal or more time will need to be spent with the close relative or spouse, whose emotional upheaval might be more than that of the patient. If the disease is one which affects the cognitive functions, the communication becomes much more complex, and many a times challenging and stressful to the care provider. The content of the communication will go through constant evolution, as the disease progresses and patient goes through various exacerbation and remissions.

Treatment plans should primarily focus on making life as comfortable as possible, in the midst of the progressing life limiting illness. The balance between palliative or curative treatment modalities, or palliation which could worsen the quality of life or hasten progression versus just enough palliation to make the patient comfortable, is difficult but definite decisions will have to be taken. As the days draw close to the end, facilitating the family to come together and prepare to support each other and enjoy their loved one's potentially short presence becomes a role the care provider has to take up.

Preparing for the disease progression and inevitable end, anticipating and **planning** for potential crises or rough patches, need to be part of the **care planning** from the initial days itself. If the disease is a slow progressive one this preparing and planning becomes easier initially but at the same time more complex as the days prolong; the challenge being, keeping up hope when the way ahead is uncertain and long. Such **ongoing support** is inevitable in slow and prolonging disease situations.

Setting up systems for care, support and treatment is yet another key role of the care provider. This will involve setting up systems of medical, emotional, social, financial and spiritual care, both for the individual and the family. Setting up these systems will involve **facilitating a community of caring** people, who can contribute to these needs, coming alongside the patient and the loved ones. This will also include having conversations which we are generally not comfortable with, or tend to avoid. Conversations around death, funeral, life after loved ones death, issues like preparing a living will, sorting out financial, legacy and succession issues, might be inevitable.

At every stage there will be **ethical dilemmas** the care giver will face. Individual autonomy Vs families' and close relatives' desires and needs, individual confidentiality vs shared confidentiality, what and what not to communicate, are challenges one would face. If the illness is one which affects the cognitive functions, then the autonomy and communication issues become more challenging.

Not to do harm in the midst of balancing issues like prolonging life vs facilitating peaceful death, treatment decisions which could hasten progression or reduce quality of life or interventions which could unnecessarily prolong suffering, are other challenges one would need to grapple with.

Beneficence of the individual vs family will be yet another constant issue one will have to consider and balance. The issues of justice will emerge as treatment decisions are considered.

Some guiding principles to help the care giver to grapple with these challenges are

- Recognizing that the individual's autonomy is in the context of the desires of a loving and caring family and community who want the best for the individual.
- Holding on to the fact that God is the Giver and Taker of life, and that the patient and all involved are His creation carrying His image.
- Understanding care providers' role as a facilitator of a hope and comfort giving journey, using his or skills and available resources.

Dr Mathew Santhosh Thomas is a physician with the Emmanuel Hospital Association in mission hospitals located in rural parts of North India for more than 2 decades. Currently he is the Executive Director of EHA and Treasurer of TCB

WHEN THE END IS WELCOMED BY PARENTS AND EASED BY DOCTORS

Jubin Varghese

A 7 years old boy with cerebral palsy was part of the Anugrah program for 3 years. He had contractures and was dependent on his mother for all his needs. His speech was limited and he was intellectually compromised. We visited him once a week to provide respite to the mother and to help with some therapy. During one home visit, we realized that he looked very sick and was having breathing difficulties. His mother said that he had been sick for four to five days but her husband would not allow her to bring him to the hospital. We spoke to the family and they said that they would bring him to the hospital. When they did not bring him that day, we sent a vehicle to pick them up. But by the time they brought him to the hospital, he was gasping and he died in the hospital emergency of untreated pneumonia.

A girl, 6 years old, on the autistic spectrum had been with us for a couple of years. She came everyday to the center and was undergoing specific therapy for her autistic behaviors. She was making some progress and had started relating with the therapist. She went home one Friday and did not come back on Monday. We called up to find out what had happened and the family informed us that she died over the weekend. She had had repeated seizures over the weekend and the family did not take her to the doctor. They did not even inform us though they knew that we would have helped with the costs of the treatment.

In the stories mentioned above, the families were not too poor and they were aware that we would have helped if they had just contacted us and yet, they chose not to. It appears as if the family was tired of looking after the children and the fathers (as they made the decision) saw no reason to spend money on children who will not get better.

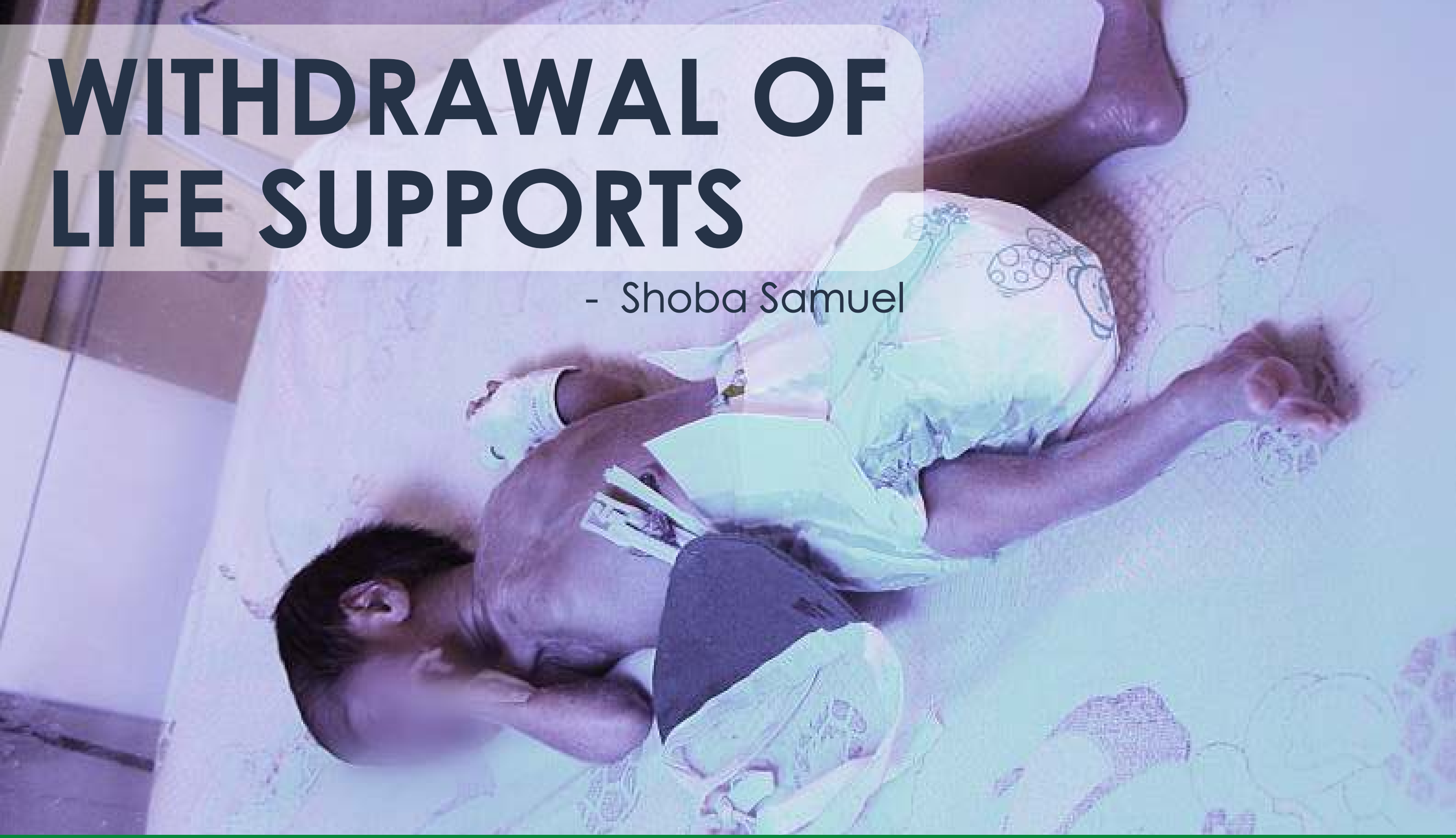
We also have stories where parents refused treatment because of the financial burden and because the medicines were making no difference to the medical problem (seizures/breathing difficulties due to muscular dystrophy) of the child.

A child with multiple disabilities was brought into emergency with breathing difficulties. The emergency doctor talked about the quality of life of the child as he grows older and actively encourages parents to ease the child's suffering. The doctor works on easing the child's journey from this world rather than cure the treatable medical condition.

Editor's note:

This article raises difficult questions: does a person have a right to refuse treatment, even in terminal illness? Is it ethically justifiable for a parent to take such a decision for his/her child? Are withholding and withdrawing life sustaining treatment ethically the same? Is it ethically justifiable in certain cases, because of the nature of the underlying illness, to switch goal of therapy from curative to palliative (comfort care)?

Jubin Varghese is a clinical psychologist and is program manager of disability program of the Emmanuel Hospital Association. She is based in Herbertpur Christian Hospital.



WITHDRAWAL OF LIFE SUPPORTS

- Shoba Samuel

Critical care can be a stressful and frustrating experience, not just for the patient and families, but also for the treating intensivist and other professionals involved in the care of the patient, especially when outcomes appear undoubtedly futile. A feeling of helplessness prevails for the ICU personnel but much more so, for the families of these patients.

When intensive care does not appear to lead to recovery, continuing it would only result in prolonging the dying process. Withholding resuscitation and discontinuation of life sustaining treatment during or after resuscitation, are ethically equivalent but may not be legally the same in some countries, unlike many Western countries. Some countries consider withholding intermittent therapy (intubation, surgery, dialysis, administration of blood products, chemotherapy, radiotherapy) and withdrawal of continuous therapy (mechanical ventilation, inotropic support) acceptable and legal, but as oxygen, food and fluids are considered as basic human needs, they cannot be withheld[1].

It is still debatable if the process should be immediate or gradual. Several practices involve immediate withdrawal of all supports including ventilator supports, catheters, tubes and drains, as the goal is removal of treatments that are no longer desired or indicated, and that do not provide comfort to the patient[3]. This process can be emotionally demanding not just for the families of the patient, but also for the clinician and medical professionals involved. Some practices exclude withdrawal of ventilator supports from immediate withdrawal, as this is the final step preceding and leading to discomfort and death, preferring rather to wean ventilator supports[2]. Still others include gradual weaning of all continuous therapy[1].

All such decisions should be made keeping in view the expressed desires of the patient, or the family member who acts as a surrogate decision maker in the best interests of the patient.

Prevailing Reasons for considering Withdrawal of Supports

Although futility of therapy is the ideal reason for withdrawal of supports, we have often faced other situations such as, financial constraints of the family, of the patient receiving treatment in a private hospital/mission hospital, whereupon withdrawal is considered. Finances contribute to decisions of on-going care of critically ill patients. Often, the family sells whatever little asset they have to be able to support the treatment of the patient till all resources are exhausted. Critical care being expensive, the institution is limited in offering financial aid when the treatment duration is long term and outcomes could be poor. A consensus decision needs to be made based on the outcome of therapy and options of non-escalation of therapy can also be considered should the patient deteriorate. The family needs reaffirmation of their efforts in having done their best to support the treatment of the patient. Emphasis needs to be made on the poor outcome resulting in decisions of non-escalation, allowing the disease to take on its natural course. Much wisdom is needed in dealing with these situations. Options of transfer to a government treatment facility need to be offered which also depends on the status of the patient if financial constraints are the only limitations to treatment. It is also essential to establish if the information pertaining to the family's socioeconomic status is genuine based on which the family can further be guided to make ethically sound decisions.

Also if clearly indicated that a poor outcome is inevitable, it is the responsibility of the treating team to begin preparing the family for poor outcomes and decisions on withdrawal, rather than be unaffected by the struggles of the family as they continue to exhaust their resources one after another without any gain of the patients' life.

Should financial constraints be the only limitation in continuing life supports in potentially salvageable patients, the institution needs to consider supporting the on-going treatment of the patient based on available resources honouring the sanctity of life? Each human being is precious in the eyes His Creator.

Often, decisions on discharge against medical advice are made, leading to withdrawal of supports due to the family's inability to commit to care for prolonged treatment, as the family member might be a daily wage labourer and the sole bread winner of the family. We find in India, standardised systems are not in place to continue to cater to the health needs of individuals, despite the unavailability of the family of the patient.

Quality of life also plays a major role in decisions to withdraw supports. According to the WHO report on Measuring Quality of life, there are several domains such as physical health, psychological domain, level of independence, social relationships, environment, spirituality/religion/ personal beliefs that are indicative of the quality of life. Ideas of quality of life is also subjective, and it is found that decisions for withdrawal of supports is offered and/ made early during the treatment process based on the subjective opinion of the clinician or the patients family, on quality of life. The family will require clear information on possible outcomes, to understand the value of life, to realize that they have the capacity to care for their own family member who depends on them and be encouraged to do so. It would be futile to aggressively manage the patient only to be left uncared for at home. However I find most often, families requesting that the patient be “given back” just their life, vowing to look after and care for the patient as they would a baby, even though there is absence of meaningful neurological recovery. For them, the very comforting presence of the patient would be worth the efforts.

Clarity also needs to be provided for family members who believe that, life supports mean suffering for the patient thereby causing them to decide on withdrawal of supports. Here, lack of awareness must not be mistaken for lack of commitment. There needs to be information on, efforts to minimise discomfort and promote recovery, explained, for the family to perceive the complexity of critical care. Most families are receptive and show eagerness in continuing treatment once they have a clear understanding of the same.

The Experience of Withdrawal of Supports

Decision to remove life supports from the patient can be a very traumatic experience for the family. I have often faced instances when the family struggles to grapple with the fact of withdrawing or withholding life supports from the patient. The basis of their struggle is the sanctity of life, wherein they fear and believe that, by so doing, they are preventing treatment and taking away the life of the patient. Sensitivity is needed to empathise, perceive their motive, and explain to them the difference in providing help to someone who needs it, from ceasing to provide the same for someone who cannot take it any longer because of the progressive/incapacitating nature of the illness. Family members wish to allow nature take its course rather than actively taking life. Withdrawal allows a natural process to take place; and the family feels reassured when they understand this fact and also that the patient will be kept as comfortable as possible during this time.

Withdrawal of supports as a decision should be made when the significant members of the family have all their doubts clarified and have provided a consensus on this decision. It necessarily does not require a written consent signed by the family, but a clear communication between the clinician and the family, of the decision made which needs to be documented by the clinician, as some families find it distressing to provide a written consent.

The family will greatly be benefitted from learning of their right to remain by the bedside of the patient, providing them the need for privacy during this time, but allowing them to choose whatever is comfortable for them. I can safely say that the process of withdrawal of life sustaining supports have been smooth and satisfying, for those families who, had all their doubts clarified, understood the reasons for withdrawal, were provided time and a listening ear to grieve, were allowed to bid farewell to the patient in their own ways, were provided unrestricted time to be by the patient's bedside and, were reassured by the empathy and supportive behaviour of the ICU personnel.

Nevertheless, each time, when much care is taken to enable the patient have their rights exercised for them, in dying, this question looms in my mind, “Where is he/she going to spend eternity??”

All these efforts will have no eternal value for them if, having known of The way, The Truth and The Life, it was *Withheld* from being shared/discussed with them, had there been the opportunity to act in season and out of season...

Refrences

1. John G, Subramani K, Peter J.V., Pichamuthu K, Chacko B, 'Ethics and Ethical Analysis', Essentials of Critical Care, 8th Edition, Published by Division of Critical Care, CMC, Vellore.
2. Rubenfeld G. D., 'Principles and practice of withdrawing life-sustaining treatments', Critical Care Clinics 20 (2004), 435-451, Elsevier Publications.
3. Stacy K. M., 'Withdrawal of Life-Sustaining Treatment', Critical Care Nurse, Vol 32, No. 3, June 2012, Published by American Association of Critical Care Nurses, California.

Shoba Hannah Samuel is a Social Worker in the Medical Intensive Care Unit at Christian Medical College, Vellore.

Role of Surrogacy in End of Life Decision Making

- Ashu and Satish Thomas

Dr BK, an 80 year old lady, was admitted in the ICU with lower respiratory infection, cardiac and renal failure. She was unstable at admission and required multiple interventions to keep her alive. This included need for dialysis, multiple high end antibiotics and mechanical ventilatory support. Before her current illness, she was independent, leading an active life, practicing general medicine in her OPD. Her children were extremely caring and desired the best possible care for their mother. However, after a month of intensive care, she showed little signs of improvement and seemed to be ventilator and dialysis dependent. She was in a 'locked in' state, non-communicative, yet aware of pain and noxious stimuli. Though there were no advance directives from the patient regarding end of life care, the family members were increasingly of the opinion that she would not have wished to be subjected to prolonged and distressing therapy. After several rounds of family meetings and discussions, her family decided to opt for palliative treatment. She was moved into a private room and all aggressive, invasive therapy except ventilatory support were discontinued. Pain relief and relief of symptoms were ensured. She died a few days later, surrounded by her family and loved ones.

The vast majority of critically ill adults do not have the capacity to make treatment decisions.[1] When patient autonomy has to be upheld in these situations, there has to be alternative measures to the normal process of informed consent. These are advance directives by the patient or decision making by a proxy appointed by the patient or a surrogate identified by the health care providers. A living will is an instructional advanced directive, written by the patient at a time of competence and free of duress, which instructs providers as to the patient's preferences in the event of an illness which impedes their ability to speak for themselves. However, in many instances, especially in the Indian context, this may not be available. The next crucial question asked in these situations is what the patient would have liked.

When patients have not identified a person formally to be their healthcare agent (termed proxy), then the health care providers have to identify a valid surrogate to make decisions.[2] The most common surrogate chosen is the next of kin, the spouse, parents, or eldest surviving child, in that order. However the biological or legal relationship may not always translate into the most intimate knowledge of the person. A valid surrogate will be one who knows the patient's goals, values, and preferences and is willing to make decisions that are consistent with what the patient would have wanted.[2]

The surrogate's role would be to choose on behalf of the patient, as the patient himself or herself would have chosen. This can be a difficult proposition. There is a stepwise hierarchy of standards in the surrogate decision making process – patient's stated preferences, substituted judgments and patient's best interests. In this tiered system, the patient's stated preferences always have the primacy of place. This may be in the form of an **advance directive** or a living will clearly stating the patient's preference. If this is not available then the role of the surrogate is to be the voice of the patient, to choose as the patient would have liked, not as the surrogate would have. This is called **substituted judgment**, and is exercised by the surrogate relying on known preferences of the patient to reach a conclusion about medical treatment.[3] If the surrogate is not able to make decisions on substituted judgment, then together with the health care providers, he/she is asked to make decisions in the patient's **best interests**. Though the term best interest sounds lofty, it must be recognized that it is the lowest standard[4] as it is the one most removed from patient's autonomous choice. However for children and developmentally disabled adults, it may be impossible to make decisions based on advance directive or substituted judgment and so the best interest judgment is the only option.

In the Indian context, several social, cultural, economic factors add complexities to the concept of end of life care and decision making. While many physicians appear to favor limitation of therapy in patients with futile prognosis,[5] their practice is severely hampered in practice by the lack of safeguards in the form of legal guidance. In addition, physicians often have a paternalistic approach towards patients, with less emphasis on autonomy of the patient. Medical training in our country still is largely focused on curing the disease rather than understanding and accepting the need for palliative care. Discussing palliation might be perceived as a sign of weakness, of giving up and the physician might be fearful of being accused of providing sub-optimal care or of possible criminal liability of limiting therapies. It would appear, based on small surveys that legal anxieties have been the most important factor[5] to obstruct appropriate discussions on end of life care and “good patient death”. Physicians may then tacitly endorse the practice of “left against medical advice (LAMA)”as the only way to prevent perceived social and legal complications of an end of life care decision. However, in a recent development, the Indian Law Commission published a draft bill on “Medical treatment of terminally ill patients (for the protection of patients and medical practitioners)” in 2006.[6] Some of the important observations of the bill include,

- Euthanasia and physician-assisted suicide remain criminal offences, but are clearly distinct from withholding and withdrawal of life support.
- Adult patients' right to self determination and right to refuse treatment is binding on doctors if based on informed choice.
- The State's interest in protecting life is not absolute.
- The obligation of the physician is to act in the “best interests” of the patient.
- Refusal to accept medical treatment does not amount to “attempt to commit suicide” and endorsement of FLST by the physician does not constitute “abetment of suicide”
- Applying invasive therapies contrary to patient's will amounts to battery or in some cases to culpable homicide

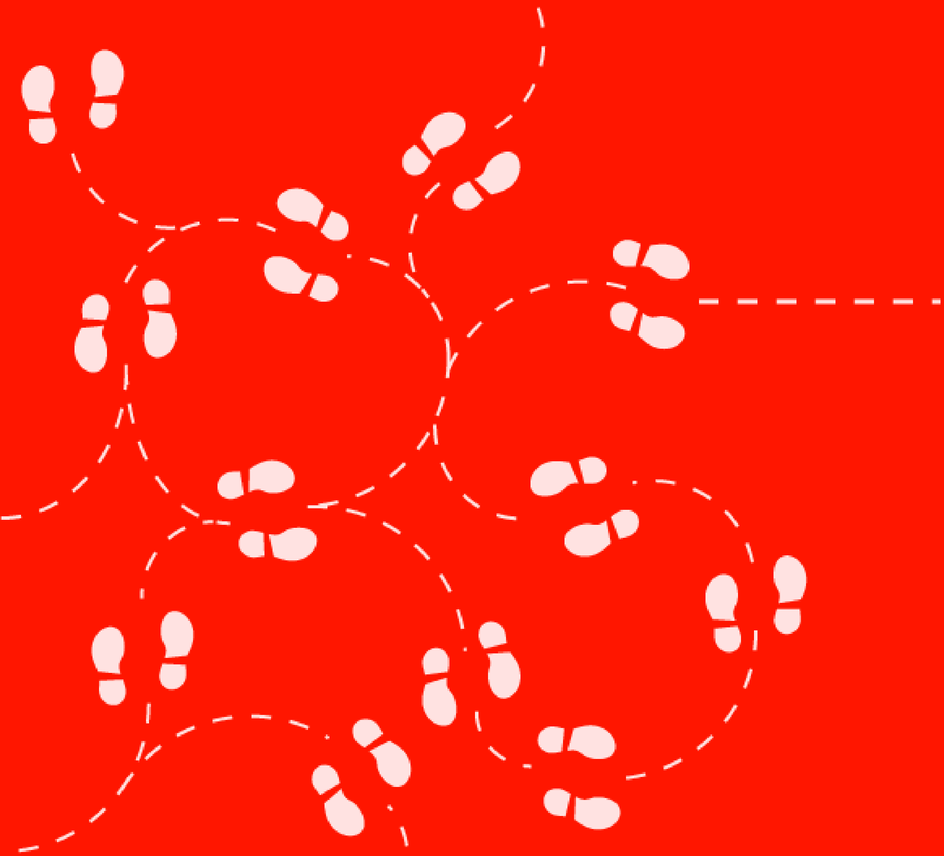
While absolute certainty in the anticipation of death is impossible, mortality prediction is central to communication and decision making in the critical-care setting. Therefore, the physician must initiate discussions with the patient and surrogate decision makers early. Waiting, watching, and postponing discussions on prognosis may be more stressful to the family as well as the ICU staff. For the family to make an informed decision, it is important that they understand the prognosis, including the uncertainty in the treatment, in a language and in terms that they most clearly understand.

Even with all these various options available, it is worth noting that we do not have a fool proof method of upholding the patient's true wishes when her decision making capacity is compromised. Even when a patient has an advance directive, it might not always correspond with the choice she would possibly make when faced with the actual situation. Research suggests that many patients change their minds over what they want regarding end of life care when confronting a real life situation rather than a hypothetical situation. This would make the ability of surrogates to predict accurately what patients want at a particular point questionable. In fact many patients actually prefer that family members and physicians make decisions for them as opposed to a surrogate making decisions solely based on patient's prior stated preferences.[1] Therefore a surrogate's substituted judgment standard cannot always be taken at face value and must be discussed against other sources of information.[3]

REFERENCES

1. Hester DM, Schonfeld T, eds. 2012. *Guidance for HealthCare Ethics Committees*. Cambridge, UK: Cambridge University Press.
2. Lo B. 2009. *Resolving Ethical Dilemmas: A Guide for Clinicians*. 4th ed. Philadelphia, PA: Lippincott Williams & Wilkins
3. Jonsen AR, Siegler M, Winslade WJ. 2010. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine.* 7th ed. New York, NY: McGraw-Hill. .
4. Orr RD. 2009. *Medical Ethics and the Faith Factor: A Handbook for Clergy and Health-Care Professionals.* Grand Rapids, MI: Wm B. Eerdmans.
5. Barnett VT, Aurora VK. 2008. Physician beliefs and practices regarding end of life care in India. *Indian J Crit Care Med*.12:109–15.
6. Law Commission of India. 196th report. Medical treatment of terminally ill patients (for the protection of patients and Medical practitioners). Available from: http://lawcommissionofindia.nic.in/reports/rep196.pdf

Dr. Ashu Thomas is an Intensivist and Professor of Anesthesiology & Critical Care at Christian Medical College, Ludhiana. Dr Satish Thomas is Professor of Ophthalmology at CMC, Ludhiana and is currently pursuing Masters in Bioethics from the Trinity International University, USA.



ADVANCE DIRECTIVES IN HEALTH CARE

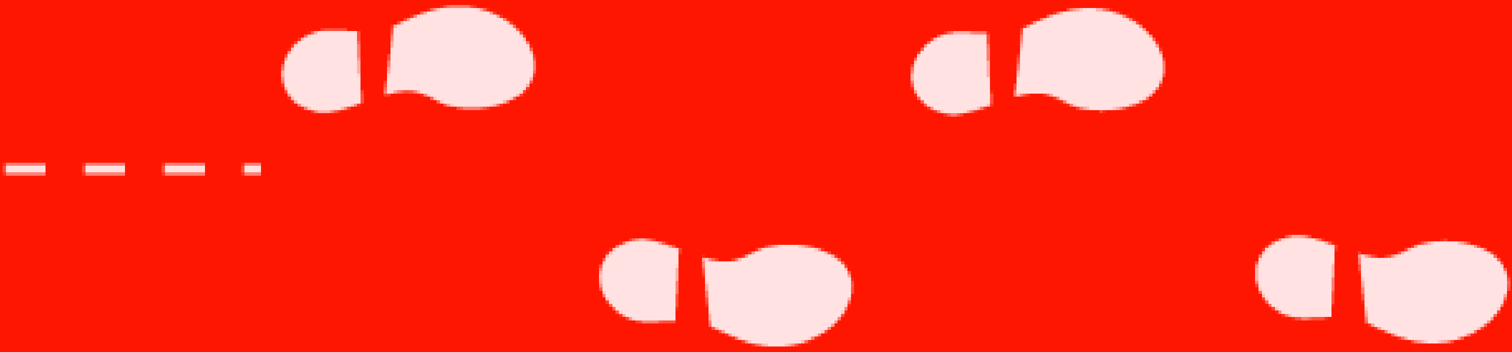
Dr Jameela George

Advance Directives in health care . Recently living will has come up for discussions in Supreme Court. This is in relation to cases of those who are terminally ill or in a vegetative state with no hope of recovery. India Constitution judge panel of five judges have been asked to look into this. The High Court said the Constitution panel will study all aspects of the issue before framing guidelines (1).
In the west, autonomy (self-determination) of an individual is vital regarding one's treatment. This is possible when one is competent to make decisions. Advance directive focuses to a large extent about the care to be given/ not to given at the end of one's life. In order to enable the healthcare provider and designated power of attorney to be appropriate advocates for the patient to accurately carry out their care preferences at the end of life, advance directive must be clearly addressed and described prior to an acute event when the person is fully competent to make decisions. Carrying out clearly documented advance directives will assure that the family feels comfortable and confident that they have carried out the preferences of their loved one. In the absence of such, other options are available.

Living will:

A living will usually provide specific directives about the course of treatment that is to be followed by health care providers and caregivers. The living will is used only if the individual has become unable to give informed consent or refusal due to incapacity. A living will can be very specific with details of use of dialysis and ventilator, resuscitation if breathing or heart beat stops, tube feeding or very general. It may also be used to express wishes about the use or foregoing of food and water, if supplied via tubes or other medical devices. It gives instructions about end-of-life care preferences *without* appointing an agent.

An example of a statement sometimes found in a living will is: “If I suffer an incurable, irreversible illness, disease, or condition and my attending physician determines that my condition is terminal, I direct that life-sustaining measures that would serve only to prolong my dying be withheld or discontinued.” Historically, living wills allowed patients to direct healthcare providers to withhold or withdraw life-sustaining treatment if they became terminally ill.



Durable power of attorney and health care proxy:

This is a legal document that allows an individual (principal) to designate a person (principal's agent) to make medical decisions for them if they are unable to do so. The DPAHC is less specific than a living will and applies to all situations in which patients are incompetent and unable to make their own decisions. He/she is legally bound to execute the patient's wishes if the individual is rendered mentally incapacitated. This is substituted judgement. The proxy can be a family member / guardian / close friend. The primary benefit of this second-generation advance directive is that the appointed representative can make *real-time decisions* in actual circumstances, as opposed to advance decisions framed in hypothetical situations, as recorded in a living will.

Limitation of treatment:

There is a right to refuse treatment, a right to be left alone. The decision made by the patient should be made known to other individuals involved in care of the patient.

The common situations are “Do not resuscitate (DNR)”, “Do not intubate (DNI)” and “Do not transfer” that is, don't move the patient to a higher level of care, say from hospital ward to ICU.

Moving From DNR to AND:

The 1990 Patient Self Determination Act (PSDA) has encouraged healthcare providers to ask patients about their advance directive and establish whether the patient requests a *do-not-resuscitate* (DNR) order. Currently there is a new trend emerging for healthcare providers to encourage patients to declare an *acceptance of natural death* (AND) request when medical interventions are deemed medically futile.

Surrogate decision maker:

When the patient is unable to decide for himself/herself, a surrogate decision maker such as “next of kin” - a relative or guardian could decide about one's treatment. He /she is expected to substitute his or her judgement for that of the patient. The idea is that the person who knows the patient best, and is familiar with his or her values or wishes, is in the best position to make decisions that would be consistent with what the patient would choose if he or she would be able.

Ethics Committee and case consultation:

As the process of consultation by committees was found to be too cumbersome, case consultation was used. A few members of the committee from different disciplines go to the patient, review the chart, speak with relevant individuals and render an opinion.

Legal situation by country:

A very few countries have laws pertaining to these. In the **Netherlands**, patients and potential patients can specify the circumstances under which they would want euthanasia for themselves. Currently **Germany** has a law on advanced directives, applicable since 1 September 2009. Such law, based on the principle of the right of self-determination, provides for the assistance of a fiduciary and of the physician. **Italy** currently lacks living will legislation, though there are laws that allow patients to refuse life-sustaining medical treatment. The new law permitted a judicially appointed guardian to make decisions for an individual. In **Switzerland**, there are several organizations which take care of registering patient decrees, forms which are signed by the patients declaring that in case of permanent loss of judgment, all means of prolonging life shall be stopped. Family members and these organizations also keep proxies which entitle its holder to enforce such patient decrees. Establishing such decrees is relatively uncomplicated. However, in Switzerland, a patient decree has, as of November 2008, no legally binding effects, whether concerning civil or criminal aspects.

The practices in **India** regarding end of life issues are varied. Decisions are not necessarily made by the individual, but by the family and or the one footing the bill. There are instances where, in spite of DNR being displayed, at the request of relative, every effort is taken by the health care professional to resuscitate the patient. Law in India does not yet recognise advance directives. The process is on to have discussions to develop guidelines. This will be towards legalising end of life treatment options, including euthanasia.

1. http://www.upi.com/Top_News/World-News/2014/02/25/India-Constitution-judge-panel-to-look-into-legalizing-euthanasia/UPI-36661393327722/#ixzz2uLTGcdT6

Dr. Jameela George is Member secretary of EHA Research Committee and is currently the Executive Director of TCB. She has a Masters in International Research Bioethics from Monash University, Australia

Aims & Objectives of TCB

1. To be a Christian voice on ethical issues based on Biblical values

2. To analyze, interpret and engage with the existing and emerging bioethical issues pertaining to health care and research

3. To facilitate upholding the sanctity of life and dignity of humans in medical practice and research

4. To promote ethical medical practice

5. To build leadership in the field of Bioethics, in the areas of Medical education, Medical practice and Medical research

Prayer support:

TCB needs constant prayer support of churches and individuals alike for the success of its mission and we request all our like-minded believers to kindly uphold us in prayers for God's leading and wisdom. We will appreciate you being in touch with us through face book, website, email or post.

Contacts:

Dr. Jameela George
Executive Director
The Centre of Bioethics, India
Mobile: +91-9312795987
Email: jameelageorge@eha-health.org

Dr. Satish Thomas
Editor, Bioethics Bulletin
Professor of Ophthalmology
Christian Medical College, Ludhiana
Mobile: +91-9646001314
Email: ashusatish.thomas@gmail.com