THE CENTRE FOR BIOETHICS
Improving health care through Bioethics

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Editorial

Greetings everyone! Finally we have been able to roll out another issue of the Bioethics Bulletin. In this issue we thought we would focus on stories of end of life issues from personal experiences. This was in the light of the recent Draft Bill on "Medical treatment of the terminally ill patient" which was put up by the Ministry of Health and Family Welfare for comments.

Many of our contributors wrote about their experiences with a loved one. Invariably, the accounts remind us that death is the great equaliser. Whether a person is a medical doctor or even an intensivist, when it comes to facing death of a loved one, the choice is for the human touch. A good death respecting the wishes of the dying one, in the company of loved ones, with dignity, and if possible with relief of pain is always preferred over dying alone, all wired and hooked up to machines. And yet, how many are being offered this kind of care at the end of their lives in our secondary and tertiary hospitals? While death is our enemy, let us also remember that our Lord has conquered this enemy. The Palliative care and hospice movement has brought about a much needed corrective to an ill-conceived attempt by science and technology to conquer the final frontier. I believe these articles will bring us perspective and remind us of what is truly important in medicine – to cure where possible, but to care and bring comfort and healing in all situations.

Dr. Satish Thomas

Facing Death

Dr. Roopa Verghese

Death is a natural occurrence. Death, for many or mostly, is the enemy. We come to work ready to conquer it or, at the very least beat it back, beat it down for another hour or another day. There is no battle with death, not really. It has allowed us to think we have won other battles but it was only a trick of the ego, our ego, as death was never truly in those fights. When death has truly come there is no beating it back, there is no winning. Death was never wanted, never welcomed but neither was it the enemy nor the ultimate loss in a battle of good vs. evil.

We live in what is sometimes described as a “culture of death.” Abortion on demand has been practiced for decades. Some seriously propose infanticide. And euthanasia is promoted as a viable means of solving various social and financial problems. This focus on death as an answer to the world’s problems is a total reversal of the biblical model.
It was in our first year orientation classes where we were talked about the topic of “ breaking bad news”. It was just another class then until just before graduation that we talked about it in detail - what to do when a patient is dying. A single hour seminar with a group of specialists; well at least it was mandatory in both times for attendance sake to attend them and to listen to them.

As young physicians, we have spent years in medical schools sharpening our history-taking skills, learning to recognize heart murmurs, memorizing the drugs used to treat high blood pressure, diabetes, even cancer. In the final months of school, we worked in the ICU, taking care of critically ill patients who required breathing tubes and life-sustaining machines. We learned how to perform intubations and place central lines. We marveled at how much we were able to do to help sick people. Nearly all of us became doctors to keep patients alive, to treat them. Most of us thought: The ultimate treatment failure is death.

I too graduated from medical school and moved on. Except for a cadaver in my first-year anatomy lab, I hadn't really seen or rather dealt with a dead body until the second month of my medical internship. When I finally did, a nurse called and said I needed to "come pronounce dead in room 211." My heart sank. I wasn't precisely sure what pronouncing a patient dead entailed. When I reached room 211, I entered to find a frail woman Mrs. X lying still on the bed. She was surrounded by family members young and old, and, to my amazement, they were smiling, chatting, even laughing with one another. I mumbled a greeting, then crossed to the bed, where I proceeded shakily through the pronouncement.

One of Mrs. X's daughters touched my hand. "This is my mother; she was a wonderful woman but had a long battle with cancer and it was time for her to go," she said. "She just wanted to be comfortable in the end.” The other family members nodded in agreement and went on talking about how much they had loved Grandma’s biriyani. Mrs. X's family and friends, who had gathered around her to say goodbye, moved me. Mrs. X had had the forethought to tell them how she wanted to pass away, and they were by her side until the end. I had never before pondered the idea of a "good death," but that night I walked out of that room with a smile on my face, because, somehow, I had just witnessed one.

About a week later, I found myself back in the ICU, no longer a lowly medical student but as an intern with real responsibilities. Patients in an intensive care unit are very sick; they require the highest level of monitoring and interventions that a hospital can provide. This particular unit was lined with patient care bays featuring sliding glass doors, glaring white walls, blinking monitors, and little natural light. Alarm bells rang constantly, and the smell of bleach disinfectant made my eyes water.

Checking in on my patients and learning about those who had been admitted overnight, I came in to a commotion. There were several nurses scurrying around a new patient's bed, and the night residents were huddled in a corner, with concerned looks on their faces. Before I had a chance to ask what was going on, a loud shout went ahead, and the team of doctors descended upon the patient. I peered into the room, and underneath the breathing tube and profusion of lines, I saw an elderly man. The senior resident called out orders. The intern hopped up on a stool next to the bed and began performing rhythmic chest compressions that cracked the man's ribs. The nurses pushed various medications into his IV and watched the heart monitor intently. I stared at the spectacle in front of me. This was my first time seeing a code situation. For 30 minutes I watched strangers in masks and gloves race around an unconscious old man, trying everything they could to keep him alive. But after the heart rhythm monitor fell into a flat line, the team pronounced him dead, removed their protective garb, and walked out of the room.

I later learned that an ambulance had brought in the old man for heart failure. His heart could no longer effectively pump blood to his organs, and he had been drowning in fluid that backed up into his lungs. On arrival, he was immediately intubated and rushed to the ICU. His family members were only a servant who used to stay with him to take care of him, and he had not come with any advance directive stating his wishes. This was not his first trip to the hospital. He had been admitted five times in the previous one year. During his first hospitalization, his records showed that he and his family had wanted "everything done" to keep him alive. Despite multiple readmissions, the question was never revisited. I wondered whether they knew what "everything" meant.

During our journey as doctors going up the hierarchy, we acquire methods for analyzing large amounts of data so that we can accurately assess, down to the minute, what is happening with our patients. But we spend almost no time at all learning about illness in the context of our patients' lives, or how to heal people when modern medicine provides no cure. We are rarely schooled in how to break bad news compassionately, or how to sit in silence with a grieving family member, or even how to make recommendations for appropriate end-of-life care. Today's physicians are spread thin. We have more responsibilities than ever before and are often tethered to a computer screen instead of our patients' bedsides.

Maybe it's easier to just give someone more treatment instead of stopping and telling her that she's dying. These conversations are never easy, no matter how many times you've had them. They can be enormously difficult even under the best circumstances, and often the circumstances are more like a patient (or, more often, his family) arguing, denying what's going on and demanding to see another doctor. Maybe we just don't want to go through it. Or maybe we hide behind more tests and procedures to make ourselves feel better — as if we're still fighting, as if we haven't failed yet.

Thinking about all of these down the years, I have changed my opinion a bit -I don't see it that way. As doctors, we dedicate most of our time in medical school to learning about the physical body, how things can go wrong and how modern medicine can fix them. I have become disheartened by the number of patients who received invasive treatment in the final days and hours of life. So many spend their final moments hooked up to tubes and lines in the ICU, alarms beeping in the background, hidden away from the people who care about them.

Modern medicine is always poised to offer another procedure or therapy for prolonging life, but it often does so without considering the quality of that life. How much suffering is five more weeks worth? Or five days, or five hours? "I believe we owe it to our patients to have open, honest conversations about what the future holds including the debt the families will be settling for ages.

Patients and families need to be informed in order to make decisions that are in line with their values. My patients have all taught me valuable lessons about what a "good death" might look like. Each one has reminded me that there is more to medicine than placing a line to monitor the heart, or performing an intubation. Just because more tests and procedures exist, it does not mean that we should perform them all each time. Sometimes the most powerful healing of all comes through the simple act of sitting and listening to our patients with compassion. Doctors sometimes actively choose to forgo the suffering that takes place in our ICUs, because we've seen it and we know better. I felt my goal many a times is to close this gap, to educate my patients about their options based on open, honest communication. I no longer see death as a failure but as a place we are all headed at some point — and if I can help someone live the fullest to the very end, I have practiced the best medicine.

The Christian will attempt to preserve life, but there is a difference between preserving life and prolonging death. Artificially maintaining a semblance of life functions, simply because someone has a hard time “letting go” would indeed be “playing God.” Death comes at the “appointed” time (Hebrews 9:27). When a patient’s body begins shutting down, when medical intervention will not heal but only prolong the natural process of dying, then removing the machines and allowing that person to die is not immoral. This calls for wisdom. Actively speeding up death is wrong. That would be “playing God.” Withholding life-saving treatment might also be wrong. But allowing life to run its course, providing palliative care, and permitting a person to die in God’s time is the best one could do.

Life is a sacred gift from God (Genesis 2:7). When given the choice between life and death, God told Israel to “choose life” (Deuteronomy 30:19). Sometimes God allows a person to suffer for a long time before death occurs; at other times, a person’s suffering is cut short. No one enjoys suffering, but that does not make it right to determine that a person should die. Often, God’s purposes are made known through suffering. “When times are good, be happy; but when times are bad, consider: God has made the one as well as the other” (Ecclesiastes 7:14). Romans 5:3 teaches that tribulations bring about perseverance. God cares about those who cry out for death and wish to end their suffering. God gives purpose in life even to the end. Only God knows what is best, and His timing, even in the matter of one’s death, is perfect.

The overriding truth that God is sovereign drives us to the conclusion that euthanasia and assisted suicide are wrong. We know that physical death is inevitable for us mortals (Psalm 89:48; Hebrews 9:27). However, God alone is sovereign over when and how a person’s death occurs. Job testifies in Job 30:23, “I know you will bring me down to death, to the place appointed for all the living.” Ecclesiastes 8:8 declares, “No man has power over the wind to contain it; so no one has power over the day of his death.” God has the final say over death (see 1 Corinthians 15:26, 54–56).

Euthanasia and assisted suicide are man’s attempts to usurp that authority from God. The best answer probably lies somewhere between the two views. Given these considerations, a clear and present danger of “playing God” exists at both extremes: eliminating suffering at all costs, and utilizing every possible therapy at all costs. Rather than play God, we should let God be God. Scripture tells us to depend on God for wisdom (James 1:5) and to weigh what is meaningful while life remains (Ecclesiastes 12). In those moments when you know this, when you accept this, there is nothing more comforting. There is no more "enemy", when there is no more "fight".

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A Request

Ms. Sheeba Verghese

I have never ever thought or dreamt in my worst dreams that I would be handling my father's last moments at the hospital. My father always lived a very happy and full life. He never bothered about his health much and except for some cold and cough, constipation and a bit of a hemorrhoids issue did not have any urgent medial issues that needed serious attention. Yes, he had a bypass surgery in 2003 and was taking medication for the same. He lived a very healthy and fruitful life. He was a very people friendly, happy and contended man. Hundreds of lives were blessed through his direct intervention for various issues in people's lives. His motto was sincerity and integrity.

He turned 84 on the 19th of February 2016. He told my mother that his life on this earth will be numbered from now on. My mother did not take that seriously saying that it is God who plans and the purposes of God gets fulfilled in a person's life in God's appointed time and the conversation ended there.

In the month of April from the first week itself my father looked tired and wanted to lie down a lot, ate little saying that he had no taste. He was taken to the cardiologist in the 3rd week of April and everything seemed to be fine. He had a cough and cold and was given antibiotics by a physician, but he was not improving. So I decided to do a series of blood tests and his LFT reports were cause of concern to me as the parameters were not good at all. I decided to take him to one of the big hospitals in Faridabad.

A few weeks prior to these happenings, in one of the conversations with us the family, he had voiced that he should not be put on a ventilator should anything serious happens to him. He insisted that he be allowed to die at home with dignity.

Alas, that was not to be. I took him to the hospital on the 26th of April through the emergency for immediate investigation. My father never expected that he will be admitted there that night. He insisted on returning home but that was not to be. That night he was in a room but the next day when the duty doctor arrived, seeing his new blood reports, ECG and others, he insisted on immediate intervention and he was moved to the IMCU. A few hours in there, I was called to say that due to the condition of his heart which was only functional 58%, he needs to be moved to the ICU for intubating and also put on a vent. It was the most difficult moments of my life as I stood there and signed all those papers.

My father insisted that he be left alone and that his time is up and needs to go and requested me to the tell the doctors not to bother him with injections and medicines. He was coughing and breathless and his heart beat was anywhere between 180 and 190. After being wheeled into the ICU, we his family had no control over our father's life. I was only called in to sign papers after papers and what I saw was a silent man who was heavily sedated, tubes going down his throat. My father loved to talk and here he was lying motionless. I could imagine what I was seeing. All kinds of machines blinking everyone, pipes and tubes all over.

I thought that I had punished my father and gone against his wishes. The thought that he would never speak to me again tortured me from then on. I was asked to sign for the jugular vein insertion, arterial vein intervention and so and the doctors always had a reason for these intervention. We as his dear ones wanted the best to happen to him. Then came the dialysis. We gave permission for the 1st one but even before completing twelve hours and without our permission they were doing the second dialysis which we found out when we insisted on seeing him in the ICU. It went on and on…….
We were not allowed to be near him and he was not allowed to be discharged.

After consulting with several family members and as advised by friends and other doctors we decided to tell the doctor in charge to stop all active intervention/treatment and to continue with only passive treatment. This upset the senior doctors and they walked away angrily, even without responding properly. It was at this point that they told us that they had to intervene this way because he had a heart attack after he was admitted which was not told to us earlier. The ICU doctor in-charge understood us and agreed to do as we desired. I was made to sign several papers again. My father breathed his last on the ventilator 9 hours later.

My request to doctors is to tell the truth – tell the diagnosis in understandable terms. Tell clearly what the real problem is, whether it is curable or not. Explain what interventions are possible and the pros & cons of the said interventions. Allow the patient or his/her surrogate decision-maker to decide what should be done. Just because a patient is admitted, do not assume that there is blanket consent for whatever the physician wants to do. My father wanted to die with dignity, at home. He wanted to be discharged. But all these could not be fulfilled as the doctors continued one intervention after the other until there was no more room to extract money from a patient who did not have any health insurance.

Ms. Sheeba Verghese
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Hope in the midst of dying

Ms. Sarah Victor

We recently visited a close family who is caring for their elderly father at home. Uncle is suffering from terminal cancer and is in the last stage of his life. We had gone to them with the hope of offering encouragement but came back feeling encouraged and blessed.

What struck us most was the calmness and peace that each member of the family demonstrated as they cared for uncle in various ways, and also carried on with their daily living. There was a quietness and a normalcy in the home which you would usually not expect during such a grave time. Though each member was grieving inwardly, they carried out their responsibilities with grace - whether seeing patients on rounds and responding to calls on a Sunday morning, cooking meals and treats for the family and for the many visitors, leading people in praising and worshiping God during the Sunday fellowship at home, or spending time with people who were visiting, among many other things.

There was a pervading sense of togetherness as the family took turns to sit with uncle and interact with him- whenever he wanted to. The family also graciously facilitated the extended family and friends to meet him and pray with him. Uncle was taking morphine for pain relief, and was drowsy most of the time, but there were few moments of alertness when he would recognize and speak with whoever was sitting with him. In those moments you could see uncle's inner person peeping out of the frail body - inquiring about the ones visiting him, praying with them, graciously receiving their care, and even being witty (yes even that!).

Saying goodbye to a loved one is always difficult - much more when it is a goodbye forever. We were touched to hear how Uncle thanked each family member for who they were to him, and the response each one gave in the same vein. Our hearts were comforted through this display of love. When it was our turn to say goodbye to him we did it not with a heavy heart. For Uncle did not allow us to feel that he was going to depart forever. His hand grip was strong and the twinkle in his eye conveyed that we would meet soon – maybe not in this world, but definitely in a much better world to come where we would all be together with our dear Lord Jesus. This is the hope that sustains him and the family as they live each day – in the midst of dying.

Ms. Sarah Victor MBA
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LAMA and Finances: Ethical issues

Dr Ashu Sara Thomas

R was a 26 year old boy with mental retardation and developmental delay since birth. He suffered from periodic episodes of continuous seizures which required frequent hospitalisations. He was admitted to our hospital with one such episode two years ago. However, this time, the seizure had gone on for a long time and had resulted in him choking and aspirating some of his stomach contents. He was shifted to the intensive care unit for artificial ventilatory support. He was initially bewildered, very upset with all that was being done to him, clinging to his brother for support. However, as he slowly improved, he became more cooperative and communicative. Though by 4 days, his seizures had stopped, his lungs still showed signs of disease and he continued to need ventilatory support. He was a tenacious fighter, this young lad, and despite his breathing difficulties, he would be often smiling, always cooperative, and gesturing to make everybody understand his needs. However, the ICU care was expensive for the family. They had already spent a lot of resources on the boy since his childhood, and this admission was draining their dwindling resources. Finally on the 6th day of admission, with no speedy recovery in sight, the family decided to take the boy home with the breathing tube still in his mouth. He was smiling as he was disconnected from the ventilator, waving goodbye to all the staff there, so happy to be going 'home'……..but as he was being wheeled out of the hospital, we could hear the monitors alarming ominously in the distance.

Patients admitted to an ICU present with complex needs: they may have one or more organ failure, old age, an irreversible or a terminal illness. They may require complex life sustaining interventions, and have physical, emotional and spiritual needs that they often cannot communicate.

Potential areas of ethical dilemmas in such scenarios include decisions regarding admissions in the ICU, multidisciplinary team conflicts, decision making on incompetent patients, surrogate decision makers and their nomination, informed consent issues regarding procedural interventions in intensive care, withdrawal or with holding supportive care issues in critically ill patients, communication issues, advance directive of critically ill patients and finally end of life Issues. Research, payers' interests, dual obligations, patients' wishes and family interests also contribute to these conflicts.

In our case study, two ethical issues stand out: Patient autonomy (surrogate decision making), and end of life decisions (withdrawal of care leading to death) based on financial constraints. We shall discuss the latter briefly.

The Indian health care system is a complex integration of the national public health system, private hospitals, and alternative medicine practitioners [1,2]. Approximately 70-80% of health spending nationwide is from individual out-of-pocket payments [3, 4]. The public health care system is free for people below the poverty line, yet despite the demands on this system, it lacks resources and accountability [1]. India's public health system constitutes only 1% of its total gross domestic product, placing it below most low-income countries and in the bottom 20% of all countries [4]. Because the public health system is perceived to be poorly equipped to provide quality care, the majority of Indians (more than 80%) seek health care in the private system and pay out-of-pocket [1, 3]. It is well accepted that one episode of hospitalization is enough to account for 58% of per capita expenditure pushing 2.2% below the poverty line.[5] Even more disconcerting is the fact that more than 40% of those admitted to an ICU had to borrow money or sell assets.[5] Understanding these issues create ethical dilemma for the clinician, particularly when the clinical status of the patient suggests a poor outcome. And so, with prolonged admission in the ICU, the predominant factor that impacts decision-making in ICUs is the unbearable financial burden that it entails, and relatives are finally left with little option other than simply 'taking their loved one home'. As a consequence the family goes through complex emotional upheaval. The doctor is often a witness to the feelings of guilt, fatalism and denial that the families experience.

Leaving against medical advice (LAMA) is a situation peculiar to this part of the world and is regarded as withdrawal of treatment unilaterally by the patient's family. A preliminary study [6] from a hospital in New Delhi reports that of the 298 patients who had died in their hospital during the study period, 48 patients (22%) had life limiting management, 4 patients had written 'Do not Resuscitate' (DNR) orders, and none of their patients had withdrawal of life-support. In contrast, 38 patients left against medical advice (LAMA) - all due to financial constraints. In another study in the emergency department of a leading private hospital in India, 46 out of the 55 patients (84%) leaving against medical advice made the decision solely based on financial reasons. Sadly, the study revealed that women were more likely to leave AMA than men, and were themselves were never involved in that decision making process.[7]

LAMA is associated with numerous ethical and legal implications. In a developing country like India, these most important ethical issues relate to patient autonomy and unjust use of healthcare resources. Patients are usually brought to the hospital and financed by family members, who have their best interests at heart. A demand for LAMA does not mean these good intentions have changed. In the case of chronic disease with poor prognosis, hospitalisation will not achieve much except in cases of medical emergencies. In fact, it increases the risks of hospital-acquired infections, spirals healthcare costs and causes a potential breakdown in the family and social structure. On the other hand when the family of a patient with acute, potentially reversible illnesses demands a LAMA, it is often a tragic consequence of the enormous financial and emotional burdens that the family has to endure in the context of critical illness. In a review of end-of-life care in India, Firth stated; "In India, the patient can be taken home, which implicitly discloses to the patient that death is imminent.[8]

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My mother's treatment & dilemmas

Dr. Manoj Jacob

My mother was a diabetic and also suffered from Coronary Artery Disease. In spite of having two sons who were doctors, one of her desires in life was never to step into a hospital. She was somehow very afraid to get admitted to a hospital.

When she had a Myocardial Infarction, she collapsed and hence we managed to take her to hospital as she was resisting all along before that. Subsequently, after a few years she had a sub-endocardial infarction and we had to manage her at home.

From late 2014, she started having episodes of pain abdomen, fever and jaundice. Clinically, with a diagnosis of cholangitis and high leukocytosis, she was treated with I.V antibiotics at home, as she refused to go to hospital. A second similar episode occurred a few weeks later which again was treated at home as she adamantly refused any tests or hospitalisation.

With a 3rd similar episode and severe pain she agreed to get an ultrasound done which revealed multiple stones in her gall bladder.

With much reluctance and after much persuasion, she agreed to go for consultation with a gastroenterologist. He suggested an ERCP which was done and subsequently a stent was inserted into her Common Bile duct.

A few days later she again had high fever and pain abdomen and did not want to go to hospital. Finally she agreed to go because of excruciating and intolerable pain. Her last question before leaving home was “Will I come back alive?”

Blood tests revealed septicaemia and a CT scan done showed that her gall bladder had a small perforation. The treating doctor decided to do an emergency ERCP to remove any blocks that he thought might control the infection. During the procedure, she had a cardiac arrest from which she was revived and shifted to the ICU, which was the last place she would ever want to be taken! In the ICU after 24 hours she had another cardiac arrest and again she was revived and put on a ventilator. After a few hours she had a third cardiac arrest for which no resuscitation was done due to her poor condition and considering the overall situation, after discussion with us.

I had requested the treating intensivist to inform us when her condition deteriorates which he promptly did. As I knew the doctor and the hospital, I could get permission to take all the immediate family members (children, their spouses and her grandchildren) into the ICU to be with her during her last moments. All of us stood around her and prayed and slowly her life ebbed away in about 30 minutes. It was a good closure for the family as all of us could be with her till the end.

A few questions troubled me after my mother's home call:

1. Should we have forced her to be investigated earlier which would have prevented this situation?
2. Should we have compelled her to go to hospital early against her wishes?
3. Should we have agreed for the stent when few other specialists were not in favour of this?
4. Should we have brought her home when her condition was deteriorating, so that she could have her end at home peacefully, without all the tubes and machines?

There are no easy answers to these questions and I suppose I will have to live with these.
I took her to the hospital keeping her best interest in mind. Knowing that cholangitis and septicemia is a treatable and reversible condition, we hoped she would respond to antibiotics and get over the crisis. It was not easy to decide when to stop active intervention in this situation. Being a doctor myself, and few doctors whom I consulted felt that it is not wise to insert a stent. But the doctor treating her felt very strongly that a stent will help and we had no choice but to agree, as her condition did not permit transporting her out of the town she was in.

Usually when a patient is very sick, the relatives are not allowed to get into the ICU. The patient has to go through the trying situation alone in the absence of his family. The anxiously waiting loved ones get the information that the patient has become critical or has died. Closure is very important for the family. In a country like ours, where family ties are strong, we should think of a better way for the patient and his/her loved ones say the final good bye. Could we have a separate section /room beside the ICU where the dying could spend the parting moments with one's family and friends without disturbing the other patients? A good coordination between palliative care physicians and intensivists is important.

Dr. Manoj Jacob MD
General Secretary EMFI

Quality of Life and Death
Supported by Palliative Care
Dr. Stanley Macaden

The night was long, but strangely bereft of anxiety and hopelessness. My sisters and I sat around my mother's bed. After her second stroke we had watched a steady and progressive deterioration in her condition and now she was slipping away. There was a difference, however: Amma was at home with us, her pain was controlled and she was kept as comfortable as possible by following instructions of the palliative care team. Above all she was at peace with herself and her Maker. We had also shared a few beautiful moments and heartfelt sentiments with her. The dawn ushered in the first few rays of the sun through the window. We held her hand as she breathed her last…

- A family's experience

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

This is further explained as -

- It provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy

WHO definition 2002

Death is an inevitable reality for all. The only certain event after birth is death. We do our best to make birth a safe and good event. However, there is much to be desired in the way we die. According to medical ethics doctors have a dual responsibility: to preserve life and to relieve suffering. As a person approaches the end of life, relief of suffering is the more important of the two, especially as it becomes increasingly impossible to preserve life. The four cardinal principles of medical ethics are: patient autonomy (or respect for the patient as a person), beneficence (doing good), non-maleficence (minimising harm) and justice (including the fair use of available resources). These must be applied against the background of respect for life, on the one hand, and acceptance of the ultimate inevitability of death, on the other.

Doctors should certainly strive to preserve life but, when such attempts turn biologically futile, it is equally important for them to provide comfort during the dying process. Overlooking this balance can result in untold suffering for both the person who is dying and for that person's family. As Dame Cicely Saunders, pioneer of the modern hospice and palliative care movement, said, "How people die remains in the memory of those who live on." A bad death complicates the grieving of those left behind. Palliative care emphasises quality of life, which includes quality of death.

The debate on euthanasia intensifies now and then and the collective wisdom over the ages has rightly kept this at bay. With only a handful of countries allowing euthanasia, it is illegal everywhere else.

Dignity in death can be provided by good palliative care, which aims to restore the shattered comfort and dignity of people affected by a terminal illness by alleviating their suffering. When such people are supported by holistic palliative care they invariably want to live. This adds life to days and not necessarily days to life.
Sometimes palliative sedation is needed to manage and control intractable symptoms like severe pain, breathlessness, agitation or severe bleed.
This is distinct from euthanasia and is part of good palliative care, explained on the ethical principle of 'double effect'.

The principles of a good death — as outlined by the authors of The future of health and care of older people: the best is yet to come [London: Age Concern, 1999] and published in the British Medical Journal in January 2000 - includes the following:

- To know when death is coming and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and mitigation of other symptoms
- To have choice and control over where death occurs (at home or elsewhere)
- To have access to information and expertise of whatever kind is necessary
- To have access to spiritual or emotional support, as required
- To have access to hospice care in any location - not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives which ensure last wishes are respected
- To have time to say goodbye

These principles must, of course, be applied in the context of regional and cultural backgrounds.

We must all do our part to make death a good experience. As individuals facing death we can express our wish that we do not want our life to be prolonged by inappropriate interventions - and even leave clear instructions to this effect as advance directives. As health professionals we should, through joint multi-professional consultation, respond to the complex decision that death is imminent and change focus to provide comfort in dying. This is possible by applying existing, evidence-based guidelines, such as the Integrated Care Plans for the dying. As a community and a society we must accept the inevitability of death and let nature take its course.

It is said that ‘Man lives on Hope’. The question then is can we die with hope? In spite of the hopeless situation hope is obtained by honest explanation and assurance of support to cope with and accept the reality of death. Hope is then maintained by making small realistic goals and achieving them. Each person will have to find that inner strength to cope with the reality of death. Understanding of family and their explicit support lifts up such a person. A common fear of a dying person is of dying alone. Family support, involvement and care strengthens the all-important sense of belonging and assures you that you are not alone.

A peaceful and dignified death with hope and surrounded by loved ones can be a reality if we all work towards this. In the words of Rabindranath Tagore, “Death is not extinguishing the light. It is putting out the lamp because dawn has come”. We can all find meaning in making death a good experience.

The Spiritual dimension is all encompassing and must be guided to accept the inevitable and to surrender oneself totally into the hands of the Almighty. In my Christian faith, which is based on a personal relationship with Jesus, I am assured that God is with me in my suffering and that He will never leave me or forsake me. I am also assured of an abundant life in spite of the ravages of a terminal illness and I am assured eternal life with God. This is the ultimate desire of every soul – every Athma to join with the Paramathma. This allows me to die with HOPE!

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Caregivers Burden

Dr. Ann Thyle

Introduction

An essential principle of good palliative care is the importance of support of caregivers, mainly family members and palliative care healthcare workers. Families provide practical care and journey with the patient. The burden and economic impact on caregivers is poorly understood . They usually feel ill-equipped from lack of specific knowledge, skills and understanding of how to provide best care. Recognition of the serious impact of the illness on caregivers' emotional and physical health has led them to be branded as 'hidden patients'.

Defining Caregivers

No definition encompasses all. Illness is a threat to the family system. Caregivers provide a wide range of voluntary care to dependent children, spouses, parents, siblings, other relatives, and sometimes friends. They are closest to the patient in understanding and affection. Supportive palliative care to caregivers begins with open consideration of all those involved in caring as defined by family members.

What is Burden?

This is defined as the extent to which caregivers perceive their emotional and physical health, social life and financial status being affected from caring for their relative. It is divided into:

1. Objective burden: quantifiable challenges faced by family members in everyday life such as financial costs, loss of free time and altered social relationships.
2. Subjective burden refers to abstract or emotional costs faced by the family resulting from the patient's illness.

Mrs A is the sole caregiver for her husband who can no longer work due to advanced oral cancer. She also runs the home and cares for 5 children, 3 of them born blind. The family is in deep debt from largely futile medical treatment. Living in a small village she has little access to information and her burdens defy description. With no assets, they face starvation.

Characteristics of Caregivers

Caregivers are those who regularly give the most assistance with one or more:

1. Practical assistance: basic activities of daily living (housekeeping, meals, feeding)
2. Personal care (monitoring medication, bathing, toileting)
3. Physical help (assist movement, supervision, medical care, provide transport)
4. Emotional and social support (keeping company, talking about emotions)
5. Finding and accessing services (medical centres, Government subsidies and benefits)
6. Behavioral support (communicating, managing challenging behaviour)
7. Financial help (financial support, managing finances)

They could be providing care for majority of their time or in small bits. Some feel forced; others feel incapable.

Impact of Being a Caregiver

There are many sources of stress. In developing countries there is a general lack of knowledge about caregiving and uncertainty about treatment because of inadequate information sharing by the medical fraternity. Physical restrictions add to the burden such as lack of freedom, lack of sleep and inability to care for oneself.

The emotional toll includes isolation, resentment and disruptions to daily routine that results in a lack of control over every normal activity. Somatic problems add to the emotional turmoil as many caregivers have to lift, support or carry the patient several times a day. This leaves them exhausted, isolated, lonely, angry, grieving, guilty, frustrated and burdened by responsibilities
Carers of children live in a high conflict, low support situation with social isolation, marriage disruption and physical or emotional distancing from their other children. However, children who are caregivers are forced to stay out of school, lose their peer friendships, and are expected to assume responsibilities that are far beyond their age.

A variety of expenses borne by the patient and family leads to economic burden. Generally out of pocket medical expenses result in most or all family savings being depleted or the family is in crippling debt from loans. Often multiple consultations are sought before a diagnosis. Expenses incurred from incorrect or futile treatment and the faith that people place in traditional healers adds to the burden. Non-medical issues such as income or time loss due to caregiving activities, neglected personal medical problems and/or depression, or children's' inability to attend school heightens the burden. Healthcare professionals should recognize that economic distress can be a major consequence of terminal illnesses.

Caregiver Needs

Five main areas have been identified to address and offer support to lessen caregiver's burdens.

1. Patient comfort that includes symptom management, hygiene, financial help, how to find resources, and responding to the dying process.
2. Information needs
3. Practical care needs
4. Emotional support
5. Economic support

Patient Comfort:

The capacity of the family to respond to patient distress is a central component of care. Caregivers suffer along with the patient when regularly exposed to poorly managed symptoms. They feel inadequately equipped to respond. In particular, pain management is their leading concern. Pain may produce fears about disease progression causing emotional and physical exhaustion for both patient and family members . Palliative care teams therefore need to ensure that family caregivers have adequate information when providing symptom relief to the patient.

Mrs M was the main caregiver for her husband, dying from oral cancer that ate away half of his face. She was anguished and helpless at his pain-wracked screams. Her home and 4 young children were neglected. Her brothers-in-law awaited his death so they could inherit the house that was rightfully hers. Morphine administered by a palliative home care team provided full pain relief. They also provided legal advice about inheritance laws. Her husband died pain-free a few days later. Mrs M's immense gratitude was a touching reminder of the huge burden she had carried for so long.

Information Needs

Family members constantly report difficulties in accessing information. Often health professionals cite busy schedules and lack of opportunities for discussion. They may hurriedly give information in medical terms and wrongly assume that the family understands. Some may avoid information sharing due of discomfort at communicating difficult news and dealing with distressing emotions.

One of most effective ways of supporting families is providing them with substantial amounts of simple, well-timed information that addresses care challenges. They need to know how to provide comfort care, how to communicate with the patient and each other, how to pace their own energy and who to call on for help. Home care nurses are a valuable source of information and are often the most accessible and specific in providing knowledge about care and support. A family conference can be used to clarify questions. Practical information to help families anticipate the next steps of the patient's illness is beneficial before deterioration takes place especially as they fear how to manage care at the time of death. They appreciate knowing common signs that indicate death might be approaching, allowing time to call family members who may wish to be present.

Practical Care Needs

Families' practical needs are underestimated because caregivers are seen as assets rather than recipients of care. Families may stretch beyond their usual limits out of a sense of duty. If the caregiver is an older person with personal health issues, the demands are even more taxing. This type of over-functioning results in caregiver fatigue. Respite services can be helpful to sustain energy. Goals of care by the multi-disciplinary team should enumerate practical support advice so that the ability to provide good quality patient care remains most advantageous.

Emotional Needs for Family Functioning Issues

A family's ability to support a patient emotionally depends largely on the amount and quality of social and health professional support they receive. Families who have limited communication skills are less able to manage stressful situations. Information shielding can also occur when family members attempt to shelter the patient from unsettling news. Relationship strains may occur resulting in conflict and anxiety. Early exploration about family member communication problems can alert health professionals to help families talk through how they are going to share information.

Economic Needs

Affordable home care, appropriate use of medicines and respite care that makes it possible for the patient/relative to work can relieve economic burden. A social worker in the multi-disciplinary team can assess the family's economic status and provide information about Government or NGO benefits or support. Health professionals can advise against futile treatment.

Professional Burden

Working with patients with incurable diseases and dying exposes professionals to their suffering and family member grief. Other sources of stress for professionals are organizational (e.g. overload, management, resources) and conflicting work relationships. Burnout is described as emotional exhaustion, impersonal response towards people and reduced personal accomplishment. Sickness rates among nurses are two to three times higher than those among doctors. Nevertheless, overall, palliative care professionals tend to experience lower job stress and higher job satisfaction mainly from meaningful relationships and high levels of autonomy and job variety. Reducing work overload, good training, clinical supervision on the job and adequate training in communication skills and management greatly helps to reduce professional burden.

Conclusion

Comprehensive care requires that caregiver concerns are understood and addressed. When confronted with a terminal illness the family has responsibility for providing care and coping with grief throughout the illness and dying process. They have to adjust to loss and restore family balance. So, the patient and family/caregiver becomes the all-important "unit of care".

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End of Life Care

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My mother celebrated her 87th birthday as lively as ever. She had been a diabetic for over 50 years, but apart from that, she was fine. However, the next day she wouldn't want to get up from her bed. Thinking that she was feeling a bit unwell, she was taken care of at home. The following day she was taken to her brother's hospital, where she remained, for over 100 days in the ICU and on rare occasions, in the ward.

At the hospital is was found that she had complete heart block. A temporary pace-maker was hooked on to her and a 48 hours' time was set. As the clock ticked the loved ones at her side became nervous, afraid (that she would die in the set time) and were worried. At the set time the pace-maker was discontinued. As her heart was unable to function normally, the temporary one continued to function and a permanent pace-maker was suggested by the cardiologist. During her stay at the hospital she developed bilateral pneumonia and a mild stroke, after which she could not speak.

Initially when she became sick, she was glad to be taken to the hospital. But when weeks and months passed bye, she was not too keen on staying at the hospital. On a few occasions she expressed her desire to go home. However, she was encouraged to stay on. Neither she nor we were clear of what to expect. Arrangements were made for the permanent pace maker. When I asked the cardiologist, “Is this really going to help her?” he said, “we will try this” and other family members agreed. So she had the pace maker, but her general condition did not improve. She was also getting tired of the interventions, nasogastric tube, catheter and the like. But she was retained in the hospital by her family who wanted to do “all that was possible”. The days rolled on to weeks and the weeks to months.

What did we achieve? We tried to prolong her life, but in fact we prolonged her death.

Recently the draft bill on the Medical Treatment of the Terminally Ill Patients (Protection of the patients and Medical practitioners) bill was put up for comments, by the Ministry of Health and Family Welfare. This bill could be called ‘The End of Life Care Act’.

Terminally ill patients can still be capable of making decisions. A person who is able to understand and has the capacity to make informed decisions pertaining to one's own treatment, voluntarily, should be allowed to do so. The best Interest of the patient - that which is good for the patient's quality of life, in the context of his/her condition important. The 'informed decision' is the decision regarding continuance or withholding or withdrawing medical treatment taken by a patient who is competent or by his close relative/guardian. This should be documented and witnessed.

Provision should be made to carry out do not resuscitate (DNR) request made by a competent terminally ill patient or by his/her relatives, if the patient is incompetent. The refusal should be in writing and has to be a witnessed by one from family and one from the healthcare team. Refusal of medical treatment by a terminally ill competent patient should be binding on medical practitioners. Similarly Living will and durable power of attorney registered before the competent authority should be honored, as it upholds one’s autonomy. The medical professional when acting on an informed decision taken by the relatives to withdraw or withhold treatment for an incompetent patient should be protected. Similarly protection of the relative or person taking the required decision should be provided for in this bill.

In order to discuss difficult cases, an (ethics) case consultation could be done by clinical ethics committee, which consists of clinicians, nurses, spiritual leader, a relative or lay person representing the patient and advocate or retired judge. This should be witnessed by a relative and a healthcare professional.

If a patient or family insist on continuing inappropriate treatment in a totally futile situation then this should not be binding on the doctor. Even though medical treatment has been withheld or withdrawn by the medical practitioner in the case of competent patients or incompetent patients in accordance with the foregoing provisions, such medical practitioner must arrange for or continue to provide Palliative Care until death takes over.
Advance medical directives:

Facing the death of a loved one is inevitable when it happens. While every effort should be made to uphold the autonomy of a patient, the best interest of the patient and quality of life of the patient have to be considered. The advance directives given by the patient should be honored. Death is a natural, normal event. Trying to prolong life with advanced technologies could be a way of prolonging death. Discerning the difference and allowing one to die peacefully in the company of one’s loved ones will be a welcome step forward.

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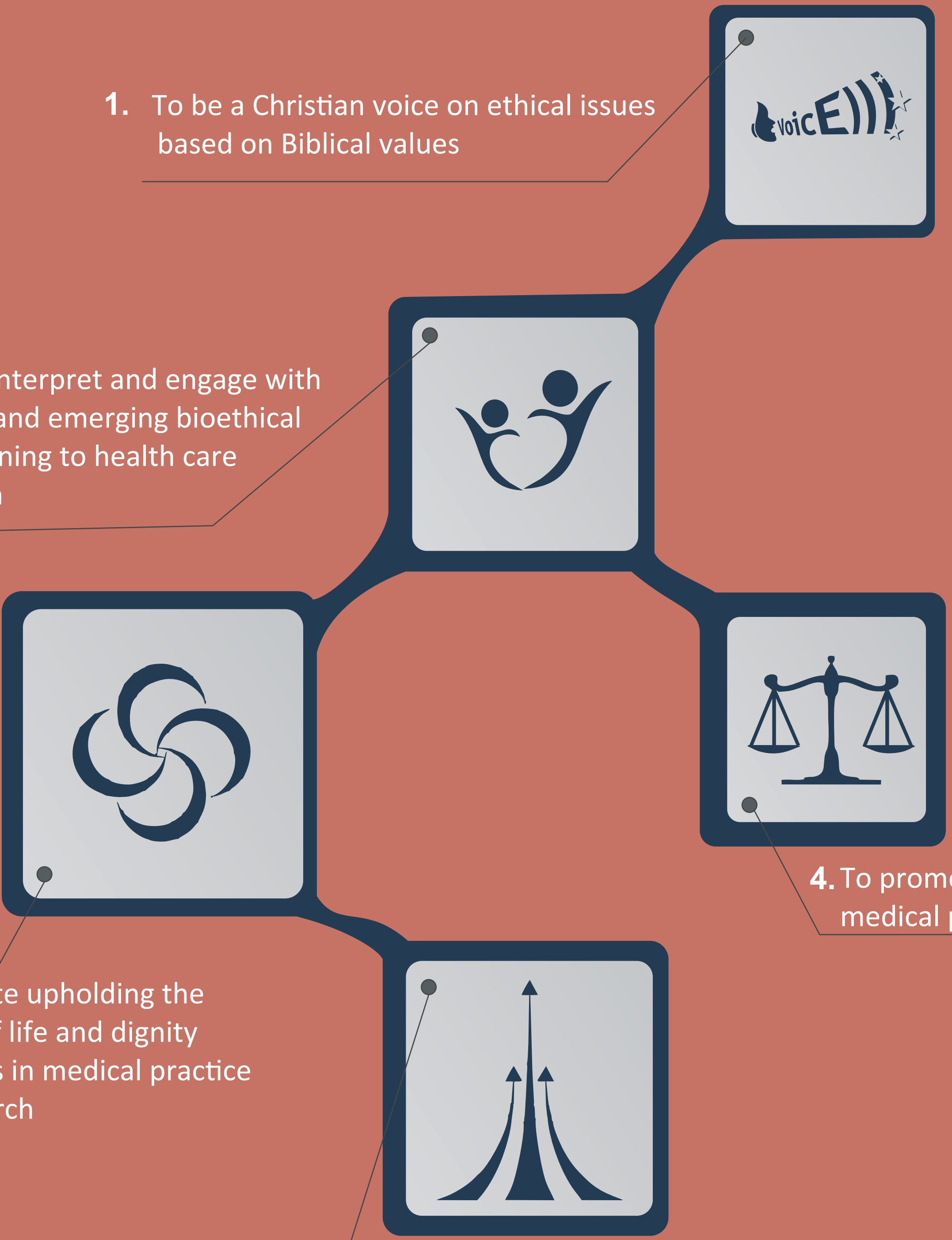
Aims & Objectives of TCB



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.

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