

Compassionate and standard operating procedure-based counseling and practice are essential in high-risk infantile anesthesia and managing death in eye surgery

Sushma Jayanna^{1,5,6,#}, Subhadra Jalali^{1,5,6,#}, Tapas R. Padhi^{2,5,6}, Komal Agarwal^{1,5,6}, Mahima Jhingan¹, Bhavik Panchal^{3,5,6}, Sameera Nayak^{4,5,6}

Physicians have to play the role of a team leader and counselor and take written informed consent for high-risk surgeries in many cases. This is the first step toward initiating a mutually trustworthy relationship with the patient and family. The situation is more sensitive when vulnerable patients like small premature babies or the elderly are under consideration. In the event of a death, leadership and processes in place become extremely critical. We share our experience and practice pattern during this process, especially suited to India, but the broad principles would apply to most human situations. Hopefully, some of these can be incorporated into the existing training curriculum for team building and the art of effective physician-patient communication that should be intricately woven into the curriculum for the Science of Ophthalmic care.

Key words: Counseling and managing death during eye surgeries, Death in ROP, SOP during infant death in eye surgery, Team building,

Many infants in tertiary care undergo urgent eye surgeries under high-risk anesthesia. Conditions include retinopathy of prematurity (ROP), corneal exposure/perforations/impending perforations, endophthalmitis, acute lacrimal sac problems, ocular trauma, etc., Other conditions that need early treatment include retinoblastoma, ocular inflammation, large eyelid/orbital hemangiomas, vitreous hemorrhage, retinal detachments, and congenital problems including cataract, glaucoma, or corneal opacities. The intervention might be required as early as the first day of life. Many could be preterm or have systemic co-morbidities. The vulnerable patients might appear stable only to succumb to a seemingly trivial situation perioperatively. Counseling for these patients for unavoidable eye surgery, preparedness to tackle any systemic casualty, and post-event management in case of a loss to life or permanent systemic disability warrant a standard operating process and team effort.

The typical responses while evaluating these vulnerable patients are “postpone case” or “not fit for anesthesia.”

¹Srimati Kanuri Santhamma Center for Vitreoretinal Diseases, Kallam Anji Reddy Campus, LV Prasad Eye Institute, Hyderabad, Telangana, ²Department of Retina and Vitreous, Mithu Tulasi Chanrai Campus, LV Prasad Eye Institute, Bhubaneswar, Odisha, ³Department of Retina and Vitreous, GMR Varalakshmi Campus, LV Prasad Eye Institute, Visakhapatnam, Andhra Pradesh, ⁴Department of Retina and Vitreous, Kode Vekankatadri Chowdhary Campus, LV Prasad Eye Institute, Vijaywada, Andhra Pradesh, ⁵Newborn Eye Health Alliance (NEHA), Child Sight Institute, L V Prasad Eye Institute Network, India, ⁶Child Sight Institute, L V Prasad Eye Institute Network, India #Both first authors have equal contribution.

Correspondence to: Dr. Subhadra Jalali, Director Retina Institute, Quality, and NEHA, LV Prasad Eye Institute Network, Kallam Anji Reddy Campus, Hyderabad - 500 034, Telangana, India. E-mail: subhadra@lvpei.org

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Lack of coordination and clear delineation of roles among the surgical team can lead to delays and doubts in parents' minds to decide taking the risk of anesthesia and surgery. We can achieve a lot more if we get our act together and improve our communication and team building.^[1,2] Effective Physician-patient communications significantly correlate to health outcomes, including emotional, functional, pain relief, and physiological parameters.^[1,2] Neither our medical training nor our mainstream ophthalmology literature addresses this issue. For more than a decade, we have tried to understand and devise ways to build our team and improve effective communication and processes. It has been a continuous learning and refining process, and this communication is to share our experience.

The Team

The team includes the Surgeon (team leader), counselor, physician (neonatologist, pediatrician, or other specialists for systemic issues), anesthetist, operating room administrator, fellow/resident doctor, nurses (surgical assistance and postoperative care), parents, and extended family especially in countries where multigenerational joint families decide together.

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Roles

Each person in the team has to form a safe, effective, and efficient net around the patient with the blinding eye condition and risk to the patient's life at the center of focus. Communication, protocols, and procedures are to be well defined and standardized so that everyone is on the same page. The professionals and equipment essential for such surgeries are a greater challenge to put these in place in an exclusive eye hospital,^[3] but are not part of communication here. This paper specifically addresses the communication and counseling to bring parents into our medical-surgical team as partners in the challenge.^[1,2]

Invariably the surgeon is the first point of contact with the baby and family and hence must take complete ownership. It is hence mandatory that the operating ophthalmic surgeon is familiar with the medical conditions common in this age group and address them when required with the attending pediatrician.

Prehospital visit communication

Parents or referring doctor may contact the surgeon with previous medical information over email or teleconsultation. Proper communication, if required with a video call, regarding the urgency of the hospital visit, should be done. The parents should be instructed to carry all past records, including birth and post-birth systemic and eye examination reports as few parents fail to get these as were not considered to be important by referring doctors. Probable need for general anesthesia, and appropriate systemic investigations and specialty consultations when needed to avoid undue delay during eye hospital visit have to be informed. If hemoglobin is less than 10.0 gm%, appropriate transfusion with their local doctor is suggested. Almost 80% of acute ROP surgical cases needed transfusion before surgery (our unpublished data). This reduces their stay and running around in a new city and makes the baby receive a transfusion at least 24–48 h before surgery. If the baby has hydrocephalus/epilepsy/respiratory or cardiac problems, which are not uncommon, then appropriate parenteral/oral antibiotics and other treatments including nebulization/chest physiotherapy/anti-epileptics/cardiology or neurology consultation including appropriate imaging (2D echo/Neurosonogram/MRI brain) should be considered before traveling. This requires a good talk with the referring doctor. Patients coming from smaller towns may be able to get some of this at least done, if not all of them. This again saves time during preanesthesia evaluation. While general realistic expectations can be informed, it is important not to promise prognosis prematurely before an actual physical consult. This prevents any ill feelings and is also important to avoid medico-legal litigations. Logistics of travel, appointments, stay, cost, and duration of treatment are to be handled and informed actively by the counselor.

Hospital Visit (outpatient)

A Relaxed, detailed, and unhurried conversation with artful history taking helps make decisions.^[4] The parents should be encouraged to talk, and patient listening on our part would put them at ease. All the pregnancy, delivery, and post-natal documents should be uploaded into the medical records, and this again saves time down the line. The process and duration of evaluation in the outpatient should be informed. After completing the evaluation and ocular investigations, all concerned family members are invited to the next step.

Preanesthesia, counseling, and written informed consent

This is the most important step in establishing trust, a good rapport, and making the family a part of the surgical team, especially if the diagnosis dictates the urgency of the situation.

Counseling the condition to family sitting in a quiet room is essential. Studies have shown that an unhurried discussion and good body language help build confidence in the family.^[5] If the doctor sits down and talks, the perception is more reassuring and seems to have devoted a long enough time, than if doctor was standing, even if same things were spoken for same duration!^[5] It helps if we hold patients' hand or keep our hand on the babies' head (the cultural practice of blessing a child) and look into parents/mothers' eyes with reassurance but with a relatively serious expression so that gravity of the situation and doctors' focus and compassion are simultaneously conveyed to the family. This "touching baby" would need modification to noncontact body language during COVID-19-epidemic-like situations or different cultural sensitivities.

No other team member except the surgeon should counsel so that no contradictory information is given. The condition should be explained with the help of diagrams/brochures/images in simple terms. The urgency of the situation and ocular risks should be explained. The risk of anesthesia and the need for possible ventilation/transfer to intensive care and probable additional costs should be informed. The use of appropriate language is very critical. Negative words/sentences do not help the cause. (Example, "damage/failure" can be spoken as "may not be as good as we want to achieve" or "we may not succeed in our attempt, but we will do our best"). Guarantees and promises should be discouraged and avoided. After giving a clear picture of the risk of a lifetime of blindness if surgery is not done versus the chances of a life-threatening event with data, the parents can be encouraged to take a decision (more details in supplementary content).

The entire approach to counseling and the written informed consent should not be arrogant and defensive. It should not appear that the process is in place only to avoid litigations or responsibility. Such counseling scares the parents and does not make them part of our team or harness the required confidence in us. This is especially true in countries with many alternate systems of unproven therapy, diverse cultures, family/community health practices, low levels of literacy, and socioeconomic hardships.

It is important to address the anesthetic and surgical risk clearly and state it as a "challenge" that your team would be willing to take for the welfare of their patient. A standardized fast-track system has to be built with counselor/neonatologist-pediatrician and anesthetist speeding up all the gaps so that time is not lost. Every member needs to know what essentials are to be in place as a checklist, and try to complete it usually within 24 hours or lesser.

After counseling, it is time for the family to ask queries and to come to terms with the information. Calmness in this whole endeavor and not having an over-powering "doctor-like-hurried" attitude is important. Generally, they have 1-2 small queries, but our attitude tells them we empathize. With teleconsultations becoming acceptable among doctors and patients, this technology can be used very efficiently and effectively to carry on the conversation if needed.

The day of the surgery

It is important to maintain the fasting time and timing of surgery as much realistic as possible, especially where ambulatory surgery is envisaged. This improves confidence in the team. Delays invariably happen; regular communication between the operating room and waiting/preoperative areas either through closed-caption television systems or verbally through staff members keeps anxiety levels of parents in check.

Very often, we have seen surgeons not being around to provide support to the anesthetists, and it seems the anesthetists are at one end of the patient and the surgeon at another during preanesthetic counseling. For all critical conversations, we should stand along with the anesthetist. This makes the team of parent-surgeon-anesthetist into a strongly linked chain rather than compartmentalized entities.

Breaking Unpleasant News

A most critical role is when something goes wrong such as a death or need to transfer the baby to children specialty hospital/unit. At that time, it is very critical for the “Team leader Surgeon” to be closely working and provide all support to the shocked and worried parents and especially to the anesthetists and internists, who are often sweating-worried and doing their best. The documentation of all informed consents, conversations, events in writing is of utmost importance. Proper Standard Operating Procedures (SOP), handling public relations, training in compassionate and careful grief counseling, breaking bad news,^[5] keeping up good communication with all concerned,^[2,5-7] regular role-play and mock drills including Code Blue and security drills go a long way in building up the team for preventing such situations from going out of hand. Fortunately, such moments are rare. More common are happy and relieved moments when the baby wakes up and gives a cry—the professional satisfaction and the great “Win” of the Team are in the eyes of every member who made this possible. Sharing the joy of the baby and the parents a few months after a successful surgery with the anesthetist and thanking them for giving anesthesia while ensuring systemic safety motivates them greater for the next case. In fact, the credit of the sight restoration should be shared by the initial team equally; a group photo can at times be a boost for the team to handle a more challenging baby next time.

An illustrative case of challenging situations, from personal experience of the team, is of a 7-month-old baby operated for ROP who succumbed on the table. After the surgery, the baby developed cardio-respiratory failure and did not show any signs of improvement after cardiopulmonary resuscitation (CPR). The father was called in first during CPR. The surgeon explained to the father the serious condition, and this was re-explained by the anesthetist, ensuring that there was absolutely no discrepancy between the two versions. The father was allowed to witness the doctors’ efforts at revival. Once death was declared, the mother was called in. The surgeon, as the team leader, held her hand with compassion and relayed the tragic news of the loss. Anesthetists then explained about cardiac arrest and respiratory failure. Parents were given appropriate time to cry/express grief-anger/ask questions. The family was then moved to a quieter place outside the OR for further conversation and communication. One senior staff nurse was always with them to console, with all sensitivity for the immense loss, provide help, getting them connected to other family on the phone, offer drinking water, and comfortable seating to cry their heart out. Meanwhile, the doctors completed the case notes meticulously with event timelines, death certificates, and billing. The administrators made arrangements for an ambulance/vehicle to transfer the dead body and the family, with all dignity and sensitivity. A similar case example has been described step by step in supplement 1.

It took a lot of mental strength for the individual team members to keep calm, with sensitivity and compassion during this extremely difficult situation. All these were part of the SOP on grief counseling^[6] and carried out by trained staff who had undergone “mock drills” earlier. It was overwhelming in this

case to see the father understanding and accepting the situation and actually counseling the mother to accept the unfortunate situation! He did not blame the team involved and acknowledged the efforts made by the team in the surgery and efforts to revive the baby. With deep regret from our whole team, we bid them. The experience reaffirmed the huge importance of continued compassionate communication and strong team-building with parental incorporation into the team right from day one. Deaths in eye hospitals are very rare. Eye hospitals, especially in middle or low-income countries, may not have such systems in place—it is strongly recommended to set them up.

Conclusion

Human life is precious and takes precedence over any sight-threatening pathology. On the other hand, life without sight is a challenge, and tertiary care centers have to provide surgical care to mitigate possible blindness. There is no shortcut for eye surgical suits to having a robust team-building strategy that can ensure the utmost care for systemic casualty even if it is rare. Hospital accreditation through National Accreditation Board for Hospitals and Healthcare providers (NABH) plays a big role in refining the systems and processes. These include SOP with regular drills of code blue, violence against doctors, case notes, written informed consents, appropriate intraoperative monitoring, and presence of skilled Internists/anesthetists support for patients with systemic co morbidities. The leadership of the person who takes control of the precarious situations, facilitates the family to reconcile with a very sad situation, supports all the hospital team members by taking up the challenge, provides a single version of events, and communicates well with grave calmness, compassion, cultural and human sensitivity to the family, without losing cool or getting into an argument, cannot be overemphasized.

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Conflicts of interest

There are no conflicts of interest.

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Supplement 1

Case-based, stepwise, real-life example of managing Death in an Eye Hospital

A 69-year-old diabetic patient underwent ambulatory vitreoretinal surgery by ophthalmologist in training under local anesthesia after appropriate evaluation by an internist and anesthesiologist. After surgery that ended at 7.30 pm, the patient and surgeon walked from the OR to the recovery room. The surgeon went to complete the notes and discharge summary. The patient went to the toilet in the OT complex and, on coming out, complained of breathlessness. He was immediately put into a wheelchair, and "code blue" was announced. The anesthesiologist leading the OR Code Blue team rushed to attend to him. In no time patient lost consciousness and had a cardiac arrest. Due to all infrastructure and trained personnel in place, no time was lost in starting cardiopulmonary resuscitation (CPR). However, the patient was not responding. The accompanying son (approximately 26 years old) was called in. One senior surgeon was finishing cases for the day and leaving for home when the situation evolved. It was noted that the anesthesiologist and the Operating surgeon were busy with resuscitation. Some members of the staff (nurses/technicians/administrators) had collected around the patient. Few persons started to talk to the son and give him information about what happened. One person said, "your father is diabetic, he has a heart problem, he is old and such things can happen!" The son expressed in disbelief that this was totally unacceptable as he had lunch with his father only 4 hours ago, his father had no cardiac problem, and there was some serious mistake by the surgeon and hospital. Another person started to say, "actually, your father vomited the food he had and has aspirated" to which the son angrily replied, "but your counselor only told us that as he is diabetic, he should eat something before surgery." In a few minutes, the situation could get out of hand with claims and counterclaims. Violence against doctors and vandalism of hospitals by patients' relatives are not uncommon in our country. The Senior Surgeon immediately took a leadership position, and the following actions were taken:

1. Moved out all personnel who were not needed for the resuscitation efforts.
2. Put a "gag order" on everyone: ONLY one "responsible, trained person would talk to the son."
3. Arranged a chair for the son to sit next to the fathers' bed and watch the resuscitation efforts. Allowed the son to make phone calls to his family.
4. Called in the Hospital Head of Security to the OT complex. The Security Officer called in the local Police personnel (He had good and periodical communication with the local police station team).
5. Meanwhile, the patient was placed on a ventilator by the anesthesiologist, and the senior anesthesia technician with recovery room staff nurse did the monitoring
6. Calmed down the doctor surgeon who was very unnerved by the unprecedented and unpredicted turn of events after a wonderful surgery.
7. The senior surgeon held an immediate meeting in another room with the anesthesiologist and the operating surgeon. A quick review and written documentation were done of all details of systemic history and presurgical investigations. An exact chronology of events was noted with proper timings. Once all the three agreed that the written version was accurate with no discrepancies, it was finalized as the only version that would be conveyed to the family, mentioned in the death summary and other mandatory case notes/incident/sentinel event reports, etc., It was deemed that patient had a sudden cardiac arrest, not uncommon in long-standing moderately controlled diabetics, and was not related to any surgical, drug therapy, or associated procedural lapse. Death was declared by the anesthesiologist as per protocol.
8. Meanwhile, the OR administrator prepared one room in the pre-op area to receive and seat comfortably all the family members who by now had collected and been obviously quite agitated on hearing that their loved one had died in hospital after eye surgery.
9. A meeting in grave mood took place at about 10.00 pm with family (eight members including two women) seated on one side of the room (our security officer and the policeman sitting in their midst) and three doctors (senior Surgeon, the operating surgeon, and the anesthesiologist) seated facing them. Obviously, the family had a lot of questions, simmering anger, and a threatening attitude.
10. The single version of events (that had been finalized earlier in writing) was conveyed verbally by the Team Leader. The anesthesiologist and operating surgeon also narrated briefly the parts where they were involved in the care. Our regret at losing our patient was conveyed in the most compassionate and sensitive way. Enough time was given to the family to absorb the information and ask questions. Points highlighted were: (a) Cardiac arrest can happen at any age and especially in diabetics, and this could have happened without any warning or "mistake." (b) All precautions of necessary tests, systemic clearances, and intraoperative monitoring had been taken. (c) The surgeon reaffirmed that the surgery went well; in fact, the patient thanked the doctor, and both had walked effortlessly to the waiting area, and the patient then walked to the toilet himself. (d) The patient was not administered any "dangerous drugs" during the procedure. (e) Since the cardiac event happened inside the OR complex, all resuscitation measures were started without any delay by a trained Code Blue team under a competent anesthesiologist. This "Heart attack" could have happened anywhere at home or outside, and any small chance of resuscitation would not have been there. (f) Subtle examples were given about "natural" cardiac arrest deaths at home or in workplaces including of well-known personalities, which one would have witnessed.
11. Our security officer informed that the CCTV footage from the OR area could be retrieved and viewed for further corroboration if the family or police so desired.
12. The Policeman acted neutral. He informed the family that *Prima facie* he did not suspect anything as this was only an eye surgery with no general anesthesia, and possibly could not have caused death due to any negligence. However, if the family had any doubt whatsoever, he was ready to file a case, secure the dead body for post mortem, and arrange it to be sent to the nearest government mortuary. He repeatedly offered this to the family, explaining that to arrive at a conclusive proof of negligence, a post mortem to know the exact cause of death was the only way.

13. The family went into a huddle with a security officer and policeman standing guard while the doctors moved out for some time. They returned back after 15 minutes or so to answer any further queries/doubts. The family elders decided that (1) it seems quite plausible that death could have happened due to unforeseen natural cardiac arrest. (2) At his age (69 years, which was beyond normal average life expectancy in India and also especially for diabetics), they could consider our version and logical explanation of events and our sincere efforts to revive (which had been watched by the son). (3) They were not very keen on a postmortem (cultural practice). (4) They wanted to see the CCTV footage. The policeman was willing to help them out; transparency of communication and overall calm and compassionate professional environment possibly helped.
14. All protocols and procedures related to death were completed, dignified transportation of the dead body was organized, and we bid the family regretfully, with a solemn promise of sharing CCTV footage the next day (as it was late night by then and the video retrieval was not possible).
15. The next day the son with two family elders viewed the unedited CCTV footage, which corroborated all events, especially the elderly patient thanking the young surgeon while walking out of the operating room (camera inside the OR); and walking into and out of the washroom comfortably (camera in the corridor next to the washroom). The video recording also revealed how he suddenly complained of discomfort to the nurse at hand, who immediately put him into the wheelchair and wheeled him into the next room for resuscitation, without any delay. The situation hence closed amicably.