

The pivotal role of clinical ethics consults in critical clinical decision making in the Neonatal Intensive Care Unit within an Arab culture

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Abstract

Medical Ethics is a relatively new field in developing countries and, to date, Lebanon is the only Arab country that offers bedside ethics consults; however, this is limited to a single medical center, the American University of Beirut Medical Center (AUBMC). The clinical ethicist running the bedside clinical ethics service was trained in the United States and the United Kingdom. However, once she began practicing in Lebanon, she realized that much of what she learned in terms of theory and practice as well as navigating ethical issues did not apply to the local context. Rather, much needed to be sifted and adapted to a different culture, social decorum, and mentality. This is more evident when working with patients in the Neonatal Intensive Care Unit (NICU), where parents coming from various areas in the region bring in their unique values and beliefs.

The admission of a premature newborn to the NICU is often a strenuous experience for parents and a challenge for healthcare providers. Ethical conundrums often arise when there is a potential partial success with a plan of treatment(s). For example, from an ethical point of view resuscitation is less problematic than surviving severe illness with brain damage, and thus controversial issues linked to quality of life surface as living in a vegetative or incapacitated state can be deemed worse than death. In this article, we present our own experience as neonatologists and clinical ethics consultant (CEC) teaming up at the AUBMC's NICU in an attempt at navigating the muddy waters of decision-making and ethical controversies within an Arab culture characterized with specificities that are often neglected and thus might negatively impact the decision regarding the right plan of treatment. The aim is trying to come up with a recommendation that is in the best interest of the infant and his/her parents and in an attempt to ensure that parents understand

the importance of them being part of the decision-making process.

Keywords

NICU, neonatologist, conflict, clinical ethics consultant, patient care, ethical controversies, Arab world.

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Introduction

Medical Ethics is a relatively new field in developing countries and, to date, Lebanon is the only Arab country that offers bedside ethics consults; however, this is limited to a single medical center, the American University of Beirut Medical Center (AUBMC). The clinical ethicist running the bedside clinical ethics service was trained in the United States and the United Kingdom. However, once she began practicing in Lebanon, she realized that much of what she learned in terms of theory and practice as well as navigating ethical issues did not apply to the local context. Rather, much needed to be sifted and adapted to a different culture, social decorum, and mentality. This is more evident when working with patients in the Neonatal Intensive Care Unit (NICU), where parents coming from various areas in the region bring in their unique values and beliefs.

The NICU is an arduous unit, boisterous and overpowering to parents as well as to the healthcare team. Yet, before the development of such units, critically ill newborns including premature infants would die and, with their death, something is shattered in the spirit of their parents as well and often in the hearts of their physicians. The admission of a premature newborn to the NICU is, more often than not, a strenuous experience for parents and a challenge for healthcare providers.

Ethical conundrums often arise when there is a potential partial success with a plan of treatment(s). For example, from an ethical point of view resuscitation is less problematic than surviving severe illness with brain damage, and thus controversial issues linked to quality of life surface as living in a vegetative or incapacitated state can be deemed worse than death. Babies, although considered legally as “persons”, are not individuals with decision-making capacities capable of having and sharing what they view as their rational plan of life and thus to partake in decision making [1]. Rather, parents and the healthcare team witness their development over time, often elusively. Thus, when it comes to neonates, decisions are often being made by proxy. We start from the premise that parents have the best interest of their child in mind and thus are the legal guardians or proxy for their children (with the exception of rare situations in which the guardianship can be legally removed when it becomes clear the parents are not acting in the best interest of the baby). Yet, in the context of our Arab culture, oftentimes the physicians are expected to play the role of proxy and to come up with clear recommendations and decisions. Parents, as well as the healthcare team in the NICU, have moral and professional obligations to promote the best interest of the newborn in compliance with the principle of beneficence, which requires avoiding harm and maximizing benefits. The difficulty lies in determining what constitutes the best interest of acutely ill neonates and on which premises these determinations are based on. Naturally, in such an encumbered, delicate and demanding atmosphere, ethical issues are bound to arise, as would disagreements about plan of care, thus leading to moral uncertainty and moral distress. This becomes a little more cumbersome in an Arab culture which has traditionally viewed the physician as the sole decision maker, where both patients and members of the healthcare team view the case as one that requires scientific scrutiny, the realm of ethics being an intruder to the field of medicine. In addition, religiosity is still a defining element in Arab society, as is adherence to patriarchal traditions, two vital elements that complicate the decision-making process of the stakeholders and the clinical team. Religious figures and elder male members of the extended family dominate the narrative in some cases where the family of the young patient are religious and/or traditional. Sadly, these satellite figures are not usually emotionally invested in the young

patient, and their exercise of authority is mainly a display of power. Parents who seek religious advice from their respective religious figures, especially when it concerns a terminally ill child, are always met with the religious dictum that they are bound to uphold the sanctity of life and to do whatever is in their power and to demand every medical procedure to prolong the life of the child, irrespective of the suffering of the patient or the futility of the efforts. One of the roles of the clinical ethics consultant (CEC) in the Arab world is to try to communicate with the religious figure consulted and try to get them to understand the individual medical cases presented to them along with the moral dilemma and the psycho-social aspect of care/illness and the financial toll of care to mention but a few. As mentioned earlier, the Arab culture is characterized by patriarchal ideology, where males are valued more than females, which sometimes leads to double standards in decision making based on the sex of the neonate [2]. As noted by Attum and Shamoan, “when providing care to Muslim patients, it is important to understand the impact the Islamic faith has on the provision of healthcare. Healthcare professionals need to be aware of privacy and touch issues, dietary practices, and unacceptable medicines” [3]. Yet, one of the general errors made about Arab countries is that they are exclusively Muslim countries. This is a common misconception, and Lebanon exemplifies this in its religious diversity much like many other Arab countries. While many patients indeed possess an Islamic background, others possess a variety of different religious practices and beliefs, such as Christians from different denominations, Jehovah’s witnesses, and atheists. Thus being attuned to this religious pluralism is vital in a region where studies in interfaith are not at all common. Thus, while ensuring that the crucial principles of ethics in patient care are respected, taking into consideration possible *prima facie* obligations and contextual features, we are always reminded that principles are never suspended in space, rather are related to context and other accidental characteristics. As noted by Beauchamp and Childress, “specification must be used to reduce the abstractness of the principles, to provide them with action-guiding content [4]. This process of specification is context-related and may also be influenced by one’s particular cultural or religious background i.e. by one’s morality in the community-specific sense” [5]. Thus arises the need to provide a culturally sensitive healthcare

and clinical ethics consultation [6]. The frequently asked question of whether it is morally defensible to limit potentially lifesaving care for neonates and if so, who is to decide, particularly when parents are incapable of making decisions and acquiesce to any recommendation suggested by the healthcare team, even if contradictory, is further complicated by the above culture specific intrusions.

Modern technology has played a major role in improving the treatment and survival rates of seriously sick infants. Yet, whether to allow technological advances and/or invasive procedures such as connecting the baby to the mechanical ventilator, parenteral nutrition simulating *in-utero* nutrition, and preserving temperature in a warm humid incubator to protect them from environmental exposure (light, sound, cold), to be part of a potential treatment or not is rarely a “black-and-white” decision. The viewpoints on ethical issues in the NICU differ and, as noted by Sundean and McGrath, “conflicts arise from the differences in ethical perspectives of the decision-makers, whether they are physicians, nurses, parents, alone or in combination” [7]. Often, there is no agreement on an unswerving approach to settling these conflicts [8]. In two recent cases received at our institution, we had two babies in the NICU in incubators that were facing each other. Both babies had the same illness, the same diagnosis, and the same prognosis. The parents were distressed and terribly confused as to what decision needed to be made for their respective infant, an infant they could see, smell, touch, and above all, love. The mothers of both babies used to accidentally meet in the NICU and talk to each other. Yet, each mother took a different decision when it came to what she and her husband would want for their baby. They were each operating from a different set of values and premises. More often than not, such deliberations take into consideration the effect of decision making on the family as a whole, factoring in emotional fears, family views regarding the value of life in case of disability and/or cognitive deficiency, financial or social long-term burdens on the family as well as religious trepidations. A significant number of concerns and relevant considerations have to be deciphered and addressed before a final decision is made, particularly when it comes to a critical case that is taxing on all stakeholders. Therefore, working in silos is not the optimal way of handling such matters. A safe and placid collaboration between the neonatology team and the clinical ethics

team confirmed the value of such partnership in patient centered care. Developing a framework to deal with ethically controversial or laden patient cases is a first step, albeit not a conclusive one. Particularly when it comes to illness, every case is unique and characterized by a number of particulars and salient issues that need to be probed and highlighted before a recommendation is made for that particular patient.

Nowadays, and with the clinical ethicist acknowledged as part of the medical team in different parts of the Western world, decision making and navigating through the different stages of deliberations are made with a greater sense of appreciation to the voice, values, fears and concerns of the patient/family and that of the healthcare team. This appreciation for the role of the clinical ethicist is slowly gaining ground in other parts of the world. The challenges for the societal acceptance of the role of the clinical ethicist as part of the medical team in the Arab world, where they are invariably seen as intruders, are many. In a society that is very partial to status and where a physician is regarded as holding a high status, the clinical ethicists often find themselves in a position where they have to indulge the public's taste. One example is the wearing of the traditional white coat of doctors, not in an attempt to deceive but doing so has proved to increase the trust of patients. An additional hurdle is the gender of the clinical ethicist. The more traditional of Arab men finds it hard to accept recommendations from a female professional, though at the same time a female practitioner would have better access to female patients and mothers of neonates due to gender segregation rules in some Arab societies. Generally speaking, Arab mentality keeps a collective unconscious which leads to a distrust of women as authority figures as women do better staying at home [9]. However, irrespective of culture, most parents view their baby as a member of their family even when still a fetus, although decision may vary based on culture. A nearby Arab country once requested from us a consult about a pregnant woman scheduled for natural delivery who needed an emergency C-section. The physician in that country could not perform it without the consent of the husband. The latter refused for aesthetic reasons and, sadly, his request was honored. Thus, in most Arab countries, gender still plays a role in healthcare. According to Said-Foqahaa and Maziad, "gender-based dual deprivation is defined, analyzed and

diagnosed as vicious and multi-layered circles surrounding women's abilities to make decisions concerning their own lives on the one hand, and restricting their capacity to delve into established institutional mechanism of decision making, on the other hand" [10]. This necessitates that the physician and CEC use their *phronesis* and moral courage to navigate through this gently, delicately and properly to ensure patient best interest. Only then can they remain faithful to their profession. In another case from yet another neighboring Arab country, a genetic test revealed false paternity and the physician felt he was morally obligated to chastise the wife and to breach confidentiality. When the case was discussed with one of us, the plan of action and recommendation was totally different. Thus, while Lebanon is in general a country where religion plays an important role, the role of the physician and consultant are far from being ruled by religious dictates and gender-based law expectations. For example, while the law might command the male to be the main decision maker, as a medical team, we always make sure to respect the law while at the same time ensuring the ethical dimension of the right to make decisions by including all stakeholders, in this case the mother, in the decision-making process. But irrespective of culture most parents view their baby as a member of their family even when still a fetus and this is becoming more so with the availability of ultrasounds parents look forward to as well as the reaction they have the first time they see their little one on the screen. It is akin to a virtual birth welcoming the baby to real life. Strong bonds have already developed and if parents seem passive, at a loss as to what is the best interest of their baby, then more needs to be palpated.

In what follows, we present our own experience as neonatologists and CEC teaming up at the AUBMC's NICU in an attempt at navigating the muddy waters of decision making and ethical controversies. The aim is trying to come up with a recommendation that is in the best interest of the infant and his/her parents and in an attempt to ensure that parents understand the importance of them being part of the decision-making process. We will share one case and elaborate on the impact of team work and how it affected the care of the baby, the psychology of her parents, that of the members of the healthcare team and the NICU atmosphere at large. While generally most discussions of similar cases revolve around the principles of bioethics as elaborated by Beauchamp and

Childress, summarized in the provision of benefits in minimally harmful ways while respecting the person concerned and ensuring fairness in the distribution of scarce resources [11], we will look at this case from a different perspective. Patients and their families are complex beings with psychosocial, spiritual dimensions (among others) and this has a fundamental impact on almost everything in their lives. Henceforth, complex situations cannot be solved by resorting to a tablet of guidelines or algorithms since each patient and family is unique as much as each member of the healthcare team. Even beneficence can be viewed, albeit discretely and carefully, from subjective points of view: what parents might consider beneficial to their child might not be what other parents consider beneficial, even if both are in the same situation as in the case presented earlier on. They all carry within them concerns that often need to be addressed (or brushed aside) when deciding what the best for the newborn is. A study by Placencia et al. noted that ethicists tend to advocate the interpretation of the best interest as one that also includes the effects on the family, neonatologists refuse the idea that the family's interests can act as an external restriction on their obligation towards the child [12]. Critical appraisal of the best interest standard is needed in neonatal ethics [13]. However, our setting was a little different, perhaps due to the nature of the culture, which views parents (and at times extended family members) as an essential part of the medical decision process. As noted by Da Costa et al., "asking parents alone to be explicitly involved or take full responsibility for decisions involving life and death is not culturally or socially acceptable in this community. Presence of extended family, and indirectly sounding out and taking into account their wishes, is more appropriate after assessing the resources and support services available" [14]. Thus, as a NICU team, we believe that we have the patient in the incubator and the "patients" outside the incubator: the parents, and this constitutes a continuum. Any plan of action should also factor in how the entire team, including parents, view the best interest of the child and discussion is always open as to the effect of that plan of action on the parents as well as on the baby. The best interest standard has its roots in secular Western judiciary systems, where it has been a guiding principle on which stakeholders and courts base their decisions regarding children's welfare. A recent example would be the case of Charlie Gard at Great Ormond Street Hospital in London as the 11-month-old

baby spent his entire short life in a hospital bed. It also highlights the involvement of the courts which allowed doctors overrule parents. This is a matter that very rarely happens in Arab countries particularly because it is strongly believed that parents (capacitated and well meaning) always have the best interest of their child in mind and hence the role of the medical team (including the CEC) is to help them understand the options particularly when reasonable disagreement is prevailing. Just in the case of Charlie, one of the most worrisome situations that parents face is the feeling that they have no control over the life (or death) of their own son. And of course, the challenge that neonatologists face is "in defining what constitutes a sufficient level or chance of harm to justify overruling parents" [15]. Generally speaking, in an Arab culture, the law is an intrusion into clinical matters and an interference in their personal life when it comes to the health of their child [16]. Note too that the courts are not very well versed in clinical ethics matters which often impacts the judge's decisions. The same issues can be raised in connection to the case of 23-month-old Alfie Evans [17].

Most Arab countries have laws that are based on Arab traditions and religion, these countries identify as being Muslim. Lebanon is peculiar in the region in that it has 18 legally recognized sects and each religious sect follows a distinct set of personal status laws, laws that govern marriage, inheritance, child custody and guardianship, etc. Different citizens are governed by different personal status laws, each according to their sect. All agree on one thing though, discrimination against women in the sense that it is often men who get to make the decisions. Thus, in the case of baby Nadine that we are going to present in the next pages, it was her father making all decisions and the mother simply nodding in passive acquiescence. All this makes it hard to borrow the current format of the best interest standard from the literature and experience of the Western world and implement it in Lebanon, therefore the CEC is forced to tailor a new form(s) of the standard for use in the region. Add to that the potential for moral distress when parents seek religious advice which turns out to contradict their inner most personal values. In such a case, the parents will be left with guilt whatever they decide. What should parents do? Should the medical team interfere, and if yes, to what extent, since they do not have the right or legal status to come up with religious dictates that are in line with

the values of the parents [18]. There are even cases when resorting to religious figures to get advice, parents get contradictory recommendations. Who should decide which to follow and based on what?

Case presentation

Zeina, a 32-year-old lady from rural Akkar in the north of Lebanon, was during her third pregnancy when she went to visit her obstetrician during the third trimester (32 weeks). She had two older children from a previous marriage; this one was the first from her current marriage. An awaited new member whom she hoped would complete the family. Her obstetrician noticed an abnormally low heart rate with unusual cardiac morphology. Given his limited resources and experience in such complex cases, Zeina's obstetrician discussed the condition with the parents, and then with the pediatric cardiologist there who in turn communicated with the neonatology and cardiology team at the AUBMC to transfer the baby after she was born for further medical care.

Zeina and her husband espoused the Muslim faith. Consequently, and given their cultural and religious background, abortion was not an option, since the Islamic law (Shari'a) stipulates that termination of a pregnancy after the first trimester is strictly limited to the presence of a medical condition that endangers the mother's health and has a "life-threatening" complications. According to Islam, ensoulment takes place at 120 days of pregnancy, the cutting point where the biological entity turns human, and thus abortion is considered an act of murder. Some schools of Muslim law allow abortion during the first 16 weeks of pregnancy, while others only allow it in the first 7 weeks. Nadine was bound to come to this world.

Nadine was born at 34 weeks via an urgent C-section. The prenatal diagnosis was confirmed. After stabilizing her, the medical team in the north of Lebanon discussed the options of management with the parents, and they all settled on transferring her to the NICU at the AUBMC for further management. The NICU at the AUBMC is a level 4 intensive care unit, a referral center that cares for severely ill newborns including those with complex congenital heart diseases, starting from proper diagnosis, preoperative stabilization and postoperative management until home discharge. Accompanied by her father and the Red Cross, Nadine arrived, and was found to have bradycardia with a heart rate below 60, third

degree atrioventricular (AV) block, and complex congenital heart disease including left atrial isomerism, large patent ductus arteriosus (PDA), incomplete AV canal, and sub-aortic membrane causing left ventricular outflow tract. Given her age and weight, placing epicardial pacing wires was the only option until she became eligible for an internal pacemaker. Nadine underwent the surgical procedure on the same day; however, her post-op recovery did not go as expected. She did not tolerate extubation, which was attempted several times, and she underwent another open-heart surgery for PDA ligation and repairing of an aortic coarctation with relocation of left subclavian artery.

At that point in time, the family members involved with Nadine's case were mainly her mother and grandfather. The father had to be physically away most of the days given his work as a soldier serving in Akkar, which was quite far away from the capital Beirut, where the AUBMC is located. However, both mother and grandfather found themselves having to refer back to him for any decision since this was the general culture in rural Akkar, which also happens to be in line with the Lebanese law and which stipulates that the father was the final decision maker. After the second operation, the family was invited to a multidisciplinary meeting with the cardiology and the neonatology teams to be updated about the complexity of the situation, the need for multiple surgeries to correct the anomalies, the high mortality risk with each surgery, and the poor overall prognosis. The family, in agreement with the father that was not physically present, elected to keep escalating the medical and surgical care no matter how futile it seemed.

During their recurrent visits, the mother and father did not seem in full realization of the critical state of their daughter's condition. This was exacerbated by their weak educational background, which made options and consequences not readily understandable. Nadine's mother had an elementary school education and the father did not make it to high school. This led to the more or less repetitive assertion that "all is the product of God's will" as averred by the family members with sorrow and hollowness in the eyes. This was later noted by the clinical ethicist when contradictory options were presented to them, to which they automatically agreed without hesitation, deliberation or questioning. It was clear that they were mentally prepared and anxious to make a final decision.

The only thing they kept saying was to give their daughter everything possible that will allow her to survive.

Almost two weeks later, Nadine started having biliary secretions and elevated liver function tests with rising direct hyperbilirubinemia were found. Upon further investigations including abdominal ultrasound and HIDA scan, she was diagnosed with congenital biliary atresia, an obstruction due to the hepatic biliary tree which can only be temporarily relieved by surgical bypass (Kasai procedure) until liver transplantation is feasible. The neonatal intensivists opted to continue dealing with Nadine's tribulations trying as much as possible to save her life, an option which was not favored by the pediatric surgeon who had joined the team as the situation called for it. The pediatric surgeon was adamant: it was a very high-risk intervention with high cost for a medically futile case. For the pediatric surgeon, a Kasai procedure hepato-porto-enterostomy is usually performed as treatment of biliary atresia. In the case of Nadine, her anatomy was not the usual one. She had a situs inversus, her liver was to the left and she had multiple small spleens on the right, in addition to the presence of a large pleural internal pacemaker which would make it a very high-risk procedure, especially in the light of her critical cardiac condition and cholestatic liver injury and coagulopathy, all of which are subject to further injury due to anesthesia. All this would provide temporary relief, as 75% of such cases will need a liver transplant eventually in best-case scenarios, at 3-4 years of age. Consequently, this was a very high-risk temporary procedure for a medically futile case. The pediatric surgeon saw no reason for intervention.

As for the cardiologist and the cardiac surgeon, it was an even more complex situation. Nadine definitely needed an internal pacemaker, since the inserted epicardial wires were being fibrosed and were not properly detecting the electrical activity from the heart and thus losing control over her heart rhythm. However, the problem with the surgical pacemaker insertion was that it was unavailable in Lebanon at that time; not to mention that the size of the generator was large compared to her weight, so it would occupy the pleural cavity, but the upgrade of the pacemaker was not unavoidable. After dealing with Nadine's heart rhythm, her structural heart disease would need a staged serial operation at 6 months, and later at 2 years of age, and might even need a heart transplant after that. During this period, she would need to be strictly maintained

on medical therapy and very well protected from viral infections, and would require optimal care at home.

Dealing with Nadine's family in the intensive care setting was not easy for a team whose conscience was turning into a whirlwind of questions and concerns and at times conflict of opinions. At this point, with different recommendations from the pediatric surgeon and the neonatologist, along with parents who were docile and passive and unable to favor any of the recommendations, the neonatologist in charge of the case felt agonized by the responsibility of coming up with a recommendation he could live with. When a feeling of impasse was reached, and with the previous experiences of what a thorough, honest and good-natured discussion, involving the parents, the physicians and the clinical ethicist would lead to, he requested an ethics consult. Based on the assumption that the voices of the parents need to be patiently heard and that if parents are silent, more needs to be done, the CEC emphasized the importance of understanding and acknowledging the relationships that exist between them on the one hand and between them and the medical team on the other. Thus, the CEC began by visiting Nadine and talking to the healthcare team after which she went through the medical chart. Then came the crucial step, which was meeting with members of the family alone. She discussed with them their understanding of Nadine's medical situation, their values, beliefs and concerns. It is during these personal safe spaces that much of what is hidden is unraveled. It was equally important to see if the parents actually had the needed financial and intellectual resources that would, one way or another, consciously or pre-consciously, shape their decisions. Towards the end of an honest discussion, which was meaningful precisely because the neonatologist and the pediatric surgeon were willing to dedicate as much time as needed for this case to be discussed, a number of questions were raised: Are we speaking of a medically futile case? And if so, is it better to stop intervening and transfer the neonate to a nearby hospital next to her parents and thus minimize the financial burdens on the family? Will this be the right choice that would allow another baby to be saved by using the resources of the NICU? How appropriate is it to continue medical support, knowing the multiple organ damage that Nadine had (which included the eventual need of a heart transplant), after multiple corrective surgeries, and

a liver transplant after Kasai procedure to survive? To follow the wishes of the parents and do all what is needed to keep their baby alive would mean that the little baby should have a tracheostomy placed as she had been ventilator-dependent for more than one month and might need it soon. Parents had a crucial concern: Should Nadine survive, would she be able to lead normal life like her siblings, could she get married and have kids? Their concern was validated and addressed. Towards the end of the meeting, the neonatologist and the clinical ethicist presented three options to the parents:

1. Not to do anything and to allow nature to take its course, and thus follow an “allow natural death” (AND) directive,
2. To allow Nadine to go to a nearby hospital to continue basic care, so her parents can spend more time next to her,
3. To insert an internal pacemaker (though the surgeon was a bit uncomfortable with that).

The parents opted to take Nadine home. Sensing their protective feelings towards their baby girl, the clinical ethicist noted that while this was an option, it carried the very possible risk of getting attached to her and seeing her slip away with guilt feelings for not having allowed her a second chance. Accordingly, she asked the surgeon whether there was another way to have the pacemaker inserted. At that point, the surgeon considered inserting the pacemaker in the pleura, albeit a complicated surgery, but a feasible one. This would allow Nadine the chance to seek other necessary treatments or surgeries later. Everyone was content with that decision. Two days later, the procedure was carried out successfully, and then Nadine was transferred to a hospital in the North of Lebanon. Unfortunately, after 1 week, she suffered a severe infection and passed away.

Discussion

The presence of the clinical ethicist as part of the medical team in the NICU is no longer a sporadic occurrence at the AUBMC, the first and only medical center in the Arab region to date to offer such services. Indeed, attending physicians at the AUBMC have come to appreciate that, unlike what Ingelfinger stated during the pre-Baby Doe era, namely that physicians and ethicists kept each other at arm’s length, today the approach to neonatal ethics is multidisciplinary. It eventually became clear that the precepts of the clinical ethicist, unlike that of the philosopher who ponders

issues from her office, is certainly not a product of “armchair exercise” [19].

In the NICU, perhaps more than in many other units, medical and ethical issues often intertwine and require some form of merging of both to be able to come up with the best course of action for that particular patient. Often, physicians from different specialties need to collaborate together and, at times, with different recommendations as each views the best interest of the patient from a different perspective (for example, surgeon and neonatologist). Decision making in this setting is generally recognized to be quite complex due to a variety of reasons including, but not limited to, the fact that the baby cannot yet exercise her autonomy and thus give (or not) consent to one course of action or another. Consequently, several stakeholders are involved in decision making. These primarily include her parents (most importantly) and the healthcare team (which include residents, fellows, nurses, medical students, neonatologist, clinical ethicist, cardiologist and surgeon). Several relevant considerations need to be factored in, religion and finances being only two of them with the former exerting a moral pull as is customary in an Arab culture. The parents’ level of education plays a critical part in the success of the collaboration. Parents who have a modest educational background tend to relegate decision-making responsibility to physicians, feeling inundated by all the medical data and terminology that they are required to process and make decisions about. One indication of the passive role parents assume is the often noticed situation where they seem to agree with every option the physician advances, even when the two options are contradictory in nature. This is one situation where the valuable role the CEC plays is highlighted. One role of the CEC is their ability to explain the options to the parents in layman terms, ensuring that the parents are giving informed consent once they finally reach a decision. Evidently, once a decision has been made, stakeholders face the haunting uncertainty of outcomes for the baby that the NICU team often experiences and labors with. The baby reacts in ways that are not always expected, and often potential trauma lurks in the horizon. This makes decision making even harder and heavier on the heart and mind of the decision makers who repeatedly find themselves mitigating consequences and repercussions. Usually, the stay in a NICU is quite long with consequences on the life of the baby as well as the psychological and

financial status of the parents. As noted by Liu et al., infants in the NICU “face very complex and prominent ethical problems: (1) these infants must undergo various invasive, painful, and even meaningless examinations and treatments; (2) in many cases, the purpose of the treatment is only to temporarily prolong life, although death is ultimately inevitable; (3) the interventions may cause more serious iatrogenic damage, with even more disastrous consequences for the individual or family; and (4) when facing the situation of brain death and organ donation, infants’ parents have no idea to express any personal willingness” [13].

In the case of Nadine, the first three were valid concerns. While parents are the closest to their children, it is often a double-edged sword in that they fear making decisions that might lead to the death of their child. Therefore, frequently, in such uncertain situations that the NICU often offers, parents in this part of the world defer to the treating physician to make the decision on their behalf in a form of defense mechanism that will save them from pangs of conscience, guilt or regret. However, in the long run, parents start blaming themselves for being aloof and for not making the right decision, a matter that we try hard to avoid. In Nadine’s case, the CEC discussed with the parents the importance of partnership in care and in decision making that needs to be based on clear and transparent deliberations. Their religious beliefs were pressing, and the religious decrees were discussed with them after thorough discussion of these matters with the religious authority pertaining to this case. The clinical ethicist still appealed them that if it were their genuine wish not to make a decision, this would be honored and respected and that physicians would update them on any developments that ensue. After listening to the family and in an effort to reach a consensus on what they thought was in the best interest for their daughter, a multidisciplinary meeting with the clinical ethicist involving the cardiologist, the neonatologist, the cardiac surgeon, the pediatric surgeon and others was held to think through the different possible options available that can serve the best interest of the neonate. Different, at times even opposing views needed to be listened to, validated and discussed. The best interest standard has been the main guiding principle of neonatal ethics years after the famous Baby Doe case. To the vitalists (vitalism being a philosophy that is primarily disease-oriented), the goal of medicine is to sustain life, which became more possible with

the advancement in medical technology. Parents began by holding this stance. As honoring of life as this philosophy might seem, vitalists seem to forget that often it is the quality of life that matters more than its longevity and that keeping alive by every means possible a baby whose treatment is medically futile can be dehumanizing to the baby and agonizing for the parents and the medical team. It also meant that physicians were the final decision makers and the choice to keep the baby alive regardless was not discussed with the parents to being with. At the other end of the spectrum is the belief that there are situations much worse than death, which in many ways opened the door for some form of euthanasia or another. That was clearly discussed with the parents as well. Yet, one major obstacle faced by the team was that the parents were willing to agree to any decision or recommendation even if they were contradictory. The decision-making process itself, as far as parents are concerned, can often be riddled with tension and internal conflicts. Indeed, very few studies have been done as to how parents make decisions for extremely premature infants and no such study is available in connection to the Arab culture [20].

Recommendations

This case clearly illustrates the importance of a clinical ethics consult and the valuable role it plays for the clinical team in the NICU caring for sick babies in different circumstances and situations including: conflict arising within the clinical team caring for a critical patient, conflict with the family or conflict within the family of the patient, and obstacles due to certain religious beliefs or concerns.

From the several experiences we, the CEC and the healthcare team, had while collaborating together in the NICU, it became clear to us that the following recommendations allow for smoother and less distressing atmosphere and care for everyone involved in the care of the neonate patient:

1. Hold staff debriefing sessions and multidisciplinary meetings: these were of paramount importance to ensure all stakeholders were involved in the decision-making process and aware of developments.
2. Update parents on the go: parents need to be constantly updated on any development and often invited to attend the multidisciplinary

meetings. Often lack of decision making on behalf of parents is linked to either not having sufficient information or not understanding the information well enough.

3. Appreciate the importance of culturally-sensitive and appropriate care and deliberations. At times, parents can come from a background which might be a little different from what the healthcare team believes, but is in no way harmful. This needs to be respected and considered to make the parents more at ease in their decision making.
4. Appreciate the difference between patients: although we might have patients of similar age and similar prognosis, yet, there are other factors that make the decision-making process and recommendations different. No two patients nor families are exactly alike. We hope to address this in another article.
5. Develop a channel of communication with members of the clergy which will allow the healthcare team (with clinical ethicist) to shed lights on matters pertaining to the medical case of the patient before coming up with a strict uninformed and uneducated edict that might not be in the best interest of the patient and might lead to devastating moral residue.
6. Most importantly, we believe that stakeholders who have to make decision about a neonate, be they parents, members of the medical team, court judges or others should engage in ‘reflective equilibrium’, a term coined by John Rawls. As noted by Wilkinson and Savulescu “judges, or doctors, are not necessarily or exclusively ethical experts” [15]. In his *Outline of a Decision Procedure for Ethics*, Rawls notes that people engaged with reflective equilibrium must have “sympathetic knowledge ... of those human interests which, by conflicting in particular cases, give rise to the need to make a moral decision” [21].

Conclusion

Regardless of cultural diversity, working with newborns who are vulnerable and sick, resuscitating, stabilizing, and helping them grow, is a very challenging task. Given the complexity of these cases, multiple disciplines and consultants are involved with different points of view and decisions. When the need arises, the CEC might request the involvement of risk management, psychiatry, or social services. The dilemmas we face each day while trying to serve these patients make us raise

a lot of questions: Are we doing the best thing for this baby? Are we doing any harm by continuing his life support? At what point should we stop? Who decides what is in the best interest of the baby when his family is in a denial of how sick he is? Each family and each baby are different from others by all means. All these issues are compounded when the role of the CEC is new to a society such as that in the Arab world. The few CECs who are practicing in the Arab world are true pioneers in every sense of the word, and on their shoulders lies the responsibility of attaining the trust of the society they serve so that bioethics attains the pivotal role it has attained in the West. They also have the burden of proof of remaining faithful to the role of the CEC while navigating the muddy waters of a culture that is both developed and traditional.

Neonatal intensive care has greatly improved and what was not possible in the care of neonates a few years back is now possible. The future holds even brighter prospects. Yet all this brings forth new ethical concerns and controversies, and often the interpretation of the best interest of the newborn varies among the different stakeholders. Thus, what one can do is not necessarily what one should do. Herein comes the importance of the collaboration between the neonatology team and the CEC who work together with the parents to understand and decide on plans of actions that are in the best interest of the newborn (which can be interpreted in different ways by different stakeholders). Technology and science are constantly developing, yet, sometimes these can stand in the way of decision making as the neonatologists feels torn between the ability to “play God” (albeit to some extent) or to think this through with compassion, care and *phronesis*. The neonatologist is a steersman who traverses a turbulent sea. The clinical ethicist and the neonatologist work together to make sure the team, which includes them, set their eyes on a number of things: the temperature of the water, the setting of the sun, the direction of the wind etc. to ensure they sail with a clear conscience.

Declaration of interest

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