

When a physician and a clinical ethicist collaborate for better patient care

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Abstract

Bioethics is a relatively new addition to bedside medical care in Arab world which is characterized by a special culture that often makes blind adaptation of western ethics codes and principles; a challenge that has to be faced. To date, the American University of Beirut Medical Center is the only hospital that offers bedside ethics consultations in the Arab Region aiming towards better patient-centered care. This article tackles the role of the bedside clinical ethics consultant as an active member of the medical team and the impact of such consultations on decision-making and patient-centered care. Using the case of a child with multiple medical problems and a futile medical condition, we describe how the collaboration of the medical team and the clinical ethics consultant took a comprehensive approach to accompany and lead the parents and the medical team in their decision-making process and how the consultations allowed several salient issues to be addressed. This approach proved to be effective in the Arab cultural setting and indeed did lead to better patient centered care.

KEYWORDS

bioethics, care, developing world bioethics, hospital, medical ethics, patient, rights

1 | INTRODUCTION

Bioethics is a newly emerging field in the Arab world. In our part of the world, a query beyond the medical or physiological aspect of care is seen as an intrusion, belonging to the realm of theology or philosophy. Although medicine has witnessed a shift in Western countries, in the Arab world it has been considered scientifically oriented with soft paternalism shaping the medical profession for quite some time. Paternalism is an analytical approach for treatment-based decision-making.¹ Paternalism comes from the Latin language meaning to act as a father to someone. According to Beauchamp and Childress, paternalism is deliberately bypassing someone's wishes with the justification that it is for the benefit of this person.² In this context, the voice of the patient (and/or his/her family) is often not heard and shared decision-making was not a preferred option by the medical team. Shared

decision-making was, and still is, often not considered as an option for patients due to multiple factors.

First, patients, in general, have a quasi-blind trust in the decisions their physicians take and rarely challenge or question them. Kraetschmer, Sharpe, Urowitz, and Deber conclude in their study that the desire for a passive role in decision-making is significantly associated with higher levels of trust in physicians.³ Studies have shown that older patients are more likely to trust their physicians and not question their diagnosis and decisions.⁴ Blindly trusting physicians refers back to the ideology that physicians have better knowledge of the patients' condition and are well trained to decide on behalf of patients.⁵ We are currently witnessing a shift in this phenomenon whereby younger generations prefer the collaborative process in the patient – physician

³Kraetschmer N, Sharpe N, Urowitz S, Deber RB. How does trust affect patient preferences for participation in decision-making?. *Health Expectations*. 2004;7(4):317-26.

⁴Meyer SB, Ward PR, Jiwa M. Does prognosis and socioeconomic status impact on trust in physicians? Interviews with patients with coronary disease in South Australia. *BMJ open*. 2012 Jan 1;2(5): e001389.

⁵Amalraj S, Starkweather C, Nguyen C. Health literacy, communication, and treatment decision-making in older cancer patients. *Oncology*. 2009 Apr 15; 23(4): 369.

¹Charles CA, Whelan T, Gafni A, Willan A, Farrell S. Shared treatment decision making: what does it mean to physicians?. *Journal of clinical oncology*. 2003 Mar 1;21(5):932-6.

²Beauchamp TL, Childress JF. *Principles of biomedical ethics*. Oxford University Press, USA; 2001.

relationship by requesting and practicing a more active role in decision-making.⁶

Second, patients resort to various sources of information before participating in shared decision-making. Our experience has shown that patients with severe illness or facing end-of-life illnesses generally have two main types of reactions: 1) fear of death while not ready to meet their Creator without having atoned for their sins. They are concerned about the Day of Judgement and hence want to make decisions in light of that (thus, for example, refusing a Do Not Resuscitate (DNR) or Do Not Intubate (DNI) order might seem to some like suicide which is not condoned by religion and which means damnation in the afterlife, and, 2) fearless acceptance of God's will and total surrender regardless of the nature and/or amount of suffering. However, there are always situations when patients are somewhere in between, usually depending on their social background or their philosophical ideas about life and death. Thus, one can argue that generally, after consulting physicians, patients as well as their families often resort to religion in case of severe illness and important decision-making. When it comes to making decisions about care for terminally ill patients, patients and/or surrogates who are fervently religious and who fall in the first category, tend to apply the recommendations of their religious authorities to the letter. Those who fall into the second category tend to accept their suffering and they embrace the idea of death with faith and acceptance without further reference. However, matters become a little bit more cumbersome when it comes to the opinions of religious authorities. Some request the application of the dictates of the scriptures or fatwas without negotiation and to the letter, and hence are unwilling to consider particulars or circumstances, while others make their recommendations based on their belief that pain and suffering are considered purgatory, a sign that God is remembering this person and cleansing his/her soul before he/she goes to the afterlife. In Lebanese culture, and one can argue the same applies in other Arab cultures, Christianity and Islam are the predominant religions which play an important role in the shaping of regulations to matters related to life, death and illness. The main premise is that life is sacred and only God has the right to take it away. Indeed, one of the most comforting statements patients accept and passively commit to is that *the doctor is nothing but a tool but the ultimate decision maker about healing, life and death is God Almighty*. Consequently, the general recommendation is that physicians should do all that they can to preserve life, regardless of the quality and shape of this life. Most importantly, when the medical team is faced with a situation of medical futility, a clash often occurs between the request not to pursue futile treatment and useless medicalization and the views of religious authorities who refuse to consider any argument that might counter their holy scriptures. Often, it is the patient/and or surrogate who pay the price and suffer from internal turmoil and agony. Very few religious authorities are willing to consider suffering (often multifaceted) as a reason to recommend the withholding of care in futile conditions, even with the availability of palliative care. Very rarely do we find religious authorities willing to revise their recommendations based on the contextual feature of the

case. However, after we (a clinical ethics consultant and a physician) requested to meet some religious authorities and spend time explaining the particulars of a patient's case, one can argue that this situation has started to change, albeit slowly, at least with some religious authorities. Thus, as in the case of Sami which we will discuss later, the religious ruling or fatwa took a different turn.

Third, family members are often part of the patient's care team (it is very rare indeed to see patients suffering from severe illnesses showing up alone at the office of the physician, the Emergency Department or the hospital). The involvement of family members often play an important role in patient treatment and decision-making. Families in this context are considered the primary support for individuals in general and patients in particular, including psychological, emotional and even financial support. This dependency on families goes back to the widely-held Eastern belief that living in groups/clans provides security and a sense of belonging to the individual. Families in turn consider themselves responsible for taking full care of all family members in cases of illness.⁷ In such cases, family members will often ask for information about the patients' health from the medical team or primary care provider.⁸ However, one can argue that this situation is changing slowly.

A fourth factor hindering shared decision-making in the Arab context is self-privacy. Individuals avoid disclosing private information to other parties unless they have established good relationships with them.⁹ Thus, sensitive information, in particular information having to do with the core values or beliefs of the patient is often not shared during the first medical encounter unless a real bond of trust was developed between patient and physician.

Fifth, in most Arab societies, a form of patriarchy still reigns where many women lack the freedom to make their own decisions in terms of their health and thus the decision is left to the father, brother, husband or son. This is enhanced even further in regulations that make the male partner, elder son or elder brother the main decision maker even if there are sisters or daughters willing to make the medical decisions or disagree with the decision of the legal surrogate decision maker. This is indeed the case with the Lebanese Code of Ethics, where, at times, what is legal might not be ethical and vice-versa; hence, in order to ensure real patient-centered care, there is a strong need for bedside ethics consultations with the patient. Finally, another particularity found in Arab cultures is that the male sense of masculinity and power prevents men from seeking out health care and deemed as showing weakness due to illness until the situation reaches its worst conditions.^{10,11} The same applies when men

⁷Lipson J, Meleis A. Issues in Health Care of Middle Eastern Patients. *The Western Journal of Medicine*. 1983; 139 (6): 854–861.

⁸EI – Kurd M. Cultural Diversity and Caring For Patients from the Middle East. PCQN Conference. 2013. Available at: https://www.pcqn.org/wp-content/uploads/2012/11/Sept-Call_Cultural-Diversity-and-Caring-For-Patients-From-Middle-East.pdf. [Accessed 17 Jan 2017].

⁹Lipson, Meleis. *op. cit.* Note 7.

¹⁰UNFPA. Men Engage boys and Men for Gender Equality. Men, Masculinities, and Changing Power: A Discussion Paper on Engaging Men in Gender Equality From Beijing 1995 to 2015. Available at: <https://www.unfpa.org/sites/default/files/resource-pdf/Men-Masculinities-and-Changing-Power-MenEngage-2014.pdf>. [Accessed 17 Jan 2017].

¹¹Aghacy S. Lebanese Masculinities. *Al-Raida Journal*, 2004; Volume XXI, Nos. 104-105, 2-3. Available at: <http://inhouse.lau.edu.lb/iwsaw/raida104-105/EN/p002-009.pdf>. [Accessed 17 Jan 2017].

⁶Berger RS. Including adolescents and young adults in decisions at the end-of-life. *Journal of Student Nursing Research*. 2013; 5(1): 3.

should voice their concerns to the medical team, risking the exposure of their weaknesses and other personal health issues, but opt not to because of an internal barrier waiting for its window to be pierced.

According to the Report of the American Society for Bioethics and Humanities, health care ethics consultations are “services provided by an individual or a group to help patients, families, surrogates, health care providers, or other involved parties to address uncertainty or conflict regarding value-laden issues that emerge in healthcare.”¹² The Stanford Center for Biomedical Ethics lists several ethical issues that might generate a request for ethical consultations. These include: end-of-life treatment, doctors refusing surgery for mentally challenged patients, disagreements between patient/family and the medical team, disagreements among the medical team, organ transplant, and Do Not Resuscitate (DNR) orders among others.¹³ Bedside ethics consultations have an added benefit that allows all of the stakeholders to contribute and participate in decision making including physicians, nurses, ethical consultants, patients, and their families.

In the West, patient’s rights movements have played an important role since the late 1970s in shedding light on the right of patient autonomy and participation in decision-making; however, this voice has hardly been heard in other areas of the world marked by medical paternalism. In the Lebanese context, the Lebanese Code of Medical Ethics (Law no. 240) stresses the right of the patient to participate in decision-making and to stop or refuse suggested medical treatments.¹⁴ Our experience of clinical ethics consultations ensured the importance of listening to the voice of the patient and/or his/her family and the underlined the usefulness of such consultations in guiding clinical care. These consultations proved to be a fundamental and crucial step to encourage and accommodate real patient-centered care and shared decision-making.

In the Middle East, Lebanon has the second highest ratio of hospital beds per population, as the most recent ministry report indicates a ratio of 3.37 hospital beds per 1000 people.¹⁵ Recently, the Lebanese Ministry of Health added the requirement of a research ethics committee (Decree # 1/141, Article 2) in each hospital, yet no clear directives were given about the need to have a hospital ethics committee. Still, several hospitals in Lebanon do have a hospital ethics committee educating staff, setting institutional policy, and conducting ethics consultations,¹⁶ however bedside ethics consultations are not typically offered. In 2012, The American University of Beirut Medical Center established the first bedside clinical ethics consultation service in the Arab World. Between 2011 and 2015, only five cases, all concerning end-of-life care were referred to the hospital ethics committee. These

cases were typically presented as flat cases (which were often conveyed as secondhand information from a physician or nurse), generally non-multidimensional since the views of the different stakeholders where not considered or assessed which meant that important particulars were not included in the deliberations. The establishment of a clinical bedside ethics consulting service in 2013 offered something new, namely that collaboration between the medical team, the ethics consultant, and the patient/family made for better patient-centered care, moving away from presenting flat cases of patients as mere cases to working with the patient him/herself for a mutually-desirable outcome. This was based on the belief that cases referred to the hospital ethics committee for discussion remain detached, unqualified, unskillful and theoretical. Using case vignettes for ethical discussions is not ideal since the particularities of each case are lost and hence decision-making is left wanting and the patient is betrayed.¹⁷ According to Fletcher¹⁸ the “central purpose [of an ethics consultation] is to improve the process and outcomes of patient care by helping to identify, analyze, and resolve ethical problems.” This is indeed what the bedside ethics consultation service aims to achieve at the American University of Beirut Medical Center with the collaboration of all the stakeholders. After the launch of this service, consultations increased remarkably and they included conundrums surrounding post-mortem sperm retrieval, severe depression, ambiguous genitalia, surrogacy, transplants, and neonatal surgery among others.

Since the philosophy, service, and discipline of bedside ethics consultations have not been introduced to the Middle East literature, to our knowledge, this article is the first to tackle bedside ethics consultations with patients for better patient-centered care in the Middle East and especially in Arab countries. In this article, we aim to highlight the importance and impact of cooperation between physicians and clinical ethics consultants in the care of patients to ensure patient-centered care in an Arabic society or with Arabs living in foreign countries. The experience we share describes how the clinical ethics consultant became an integral part of the medical team dealing with a difficult clinical situation. This article describes the journey of a family, as they travelled a tough road hand-in-hand with the medical team consisting of their physicians, psychologist, and clinical ethics consultant. This case among various other cases reveals the importance of teamwork and the significance of acknowledging the clinical ethics consultant as a central member in the medical team. We aim to emphasize the important role of bedside clinical ethics consultation and the impact of such consultation on patient care in general and pediatric care in particular in the Arab culture setting.

2 | CASE PRESENTATION

Sami (not his real name) was 5 ½ years old. Sami had multiple health issues that hindered his normal life activities since birth. He had an

¹²American Society for Bioethics and Humanities. Core Competencies for Healthcare Ethics Consultation 2011; 2nd ed.

¹³The Stanford Center for Biomedical Ethics. Bedside Consultations. Retrieved from: <https://med.stanford.edu/bioethics/service/bedside.html>. [Accessed 3 July 2017].

¹⁴Law no. 240. Code of Medical Ethics. 2012. Retrieved from: <https://www.aub.edu.lb/fm/shbpp/ethics/public/Documents/New-Code-of-Medical-Ethics-text-ENGLISH.pdf> [Accessed 6 July 2017].

¹⁵World Health Organization. Eastern Mediterranean Region Framework for health information systems and core indicators for monitoring health situation and health system performance. 2016; Retrieved from: http://applications.emro.who.int/dsaf/EMROPUB_2016_EN_19169.pdf?ua=1

¹⁶Kallab K, Daher M, Arawi T. Towards Implementing Medical Ethics and Bioethics Education in Lebanon. *Lebanese Medical Journal*. 2011 Jan; 59(1): 2-3.

¹⁷Arawi T. Using medical drama to teach biomedical ethics to medical students. *Medical Teacher*. 2010;32: 2205-e210.

¹⁸Fletcher JC. Quoting the consensus statement of the Consortium for Evaluation of Ethics Case Consultations. *Journal of Clinical Ethics* 1995; 7(2) 199.

undetermined syndrome that included brain atrophy, near blindness, some hearing loss, and ambiguous genitalia. He could only be fed via a gastrostomy tube, as he could not suck or swallow. He demonstrated some communication with his parents and caregivers by emitting sounds, smiling or even laughing out loud sometimes in reaction to the voices of his parents. Sami also suffered from seizures that were controlled with one anti-epileptic medication; he underwent fundoplication with a gastrostomy tube placement for severe reflux and the inability to feed orally. His recurrent episodes of wheezing led to multiple hospitalizations for pneumonia and respiratory failure; he also suffered from a neurogenic bladder with frequent hospitalization for pyelonephritis due to different drug-resistant bacteria. Sami's condition became further complicated by overweight, hypothyroidism and cardiomyopathy. He progressively deteriorated to such a degree that his hospitalizations and need for intubation became more frequent and more prolonged (from every 6 months, to every 3 months, then every 2 months). Two months prior to the clinical ethics consultation in question, Sami was brought to the emergency department (ED) ashy and hypotensive with upper gastrointestinal bleeding. After resuscitation and admission to the Pediatric Intensive Care Unit (PICU), discussions began regarding comfort care and a "Do Not Resuscitate (DNR)" order. Around this time, Sami had been admitted repeatedly to the PICU needing intubation for respiratory failure every two to three weeks. The family was approached about performing a tracheostomy. The parents were hesitant, and at this point, an ethics consultation was requested.

2.1 | Was it really about the tracheostomy?

Sami was admitted for respiratory failure. He had been intubated for more than a week and was not getting any better. Physicians were concerned about Sami's respiratory failure. Medically, a tracheostomy was indicated. His parents were emotionally distraught, particularly given the fact that Sami's father, a fervent practicing Muslim, had contacted a religious authority (Sheikh) who told him that everything that was medically possible should be done to keep Sami alive, even if it was for one day, regardless of Sami's suffering and regardless of what the parents were feeling or experiencing. This is based on the belief that life is sacred, is God-given, and as such, only God alone has the right to end the life of a living human being. The Qur'an, Islam's official religion reference, states that killing a soul is a kin to killing all souls and this is a crime that cannot be condoned.

However since Sami's condition was deemed futile, discussions were taking place periodically regarding comfort care. The parents were hesitant and ambivalent in their discourse. At one point, they requested their primary care physician make a decision on their behalf; then they reversed the decision after consulting a religious figure who was adamant that Sami should be kept alive regardless of the social and psychological constraints the parents experienced. At this point, an ethics consultation was requested. On the morning of the clinical ethics consultation, the attending pediatrician accompanied the clinical ethics consultant to the bedside and introduced her to the patient and the family and then briefed her on the medical situation. After reviewing Sami's medical chart and going about the steps of the clinical ethics consultation including but not limited to meeting with different stakeholders separately,

the consultant invited the family to a multidisciplinary meeting which included the attending resident fellow, the nurse and the social worker involved in Sami's care. During this first meeting, Sami's condition was discussed extensively; everyone including the parents shared their thoughts and concerns and a discussion about the pros and cons of a tracheostomy took place. This was followed by a series of meetings with the family, including meeting each parent separately and then jointly, almost on a daily basis, in addition to involving the psychologist for support for the parents. It became obvious that other crucial matters lurked underneath the surface. After multiple meetings, the cooperating team came to the conclusion that the parents were not solely concerned about the tracheostomy but had concerns about their conjugal life; their financial situation was disastrous; they were in debt and they felt abandoned by their respective families. Most importantly, the mother started having suicidal thoughts and in fact, attempted suicide more than once. After further probing, it was revealed that the sheikh Sami's parents had consulted had refused to listen to any background information including the medical facts of the case and upheld the religious dictum that "life is sacred and one should do anything to preserve it or else one is committing a sin". This troubled and confused Sami's parents and caused them a great deal of emotional suffering. Initially, Sami's parents voiced their wishes not to be involved in making medical decisions, stating that they "do not want that burden". However, after several long discussions with the medical team, the parents came to the realization that shared decision-making would be best for all concerned. This was the only way for all involved, including themselves, to have a clear conscience and peace of mind while attending to little Sami's needs. For the entire team, there was more than one patient to care for: there were three: Sami, his mother, and his father.

Having gathered all this information, which included a visit to the sheikh in question, and listening carefully to the fears and concerns of the family members, the primary care physician and the clinical ethics consultant agreed on a plan of action: the issue went beyond the tracheostomy. It was about a family struggling between their deep religious beliefs, the fear of falling short from what they ought to do in the best interest of their son, and the love of a son whom they saw suffering more and more every additional day of his life.

2.2 | What was done?

With the parents' agreement, the clinical ethics consultant discussed the case with a learned sheikh from the country's official religious authority, namely "Dar El Fatwa" (house of jurisprudence). The purpose was to discuss the parents' fears and concerns and to obtain a "fatwa" (religious ruling) from the highest level of religious authority possible regarding this *particular situation*. Prior to inviting the parents to the meeting, the clinical ethics consultant briefed the Sheikh about the case. Sami's parents and healthcare team members were grateful for the opportunity to discuss the case with the Sheikh. Indeed, the pediatrician along with the pediatric intensive care fellow, and the clinical ethics consultant joined the parents in their visit to "Dar El Fatwa. Although after initially hearing the question he gave the same verdict, namely that everything should be done to keep the child alive, he willingly agreed to give ample

time to the medical team who briefed him on the medical situation and the clinical ethics consultant who discussed the parents' moral, social and psychological situation. Matters started to take a different turn because this sheikh was willing to listen to the psycho-socio-economic and medical background of the case. The "fatwa" became different: "parents shall continue with their daily care, however, since the condition was medically futile and the parents' lives were affected in all dimensions, a DNR order was an option now". The parents were relieved, as were the members of the medical team. Yet, the parents never actually placed a DNR order; instead, they chose to care for Sami at home. They stopped seeking emergency medical care and continued comfort care for Sami at home with a new peace of mind.

Sami's case was discussed during one of the Medical Center Ethics Committee meetings as a "lesson learnt". As a result, a committee member affiliated with a non-governmental organization (NGO) volunteered to provide financial support to the family. The support consisted of covering the cost of Sami's numerous medications that were a burden on the parents and henceforth added another layer of care and comfort on the distraught family.

The family's initial request not to be involved in the medical decision making because of fear turned into a candid "Thank you for involving us. We feel much better and know that we are doing all what is needed". During the following weeks, Sami's parents continued to call the clinical ethics consultant and the pediatrician on their personal mobile numbers for advice or to ask questions. The psychologist also supported them answering all of their calls with patience and care. The mother who had a high school level of education became very skilled in nursing care; she performed the tracheostomy care, urinary catheterization, gastrostomy feeding and other nursing care without any difficulties. A few months later, the mother became pregnant. The parents asked the pediatrician and the clinical ethics consultant to accompany them during the delivery of their second baby, which was done without hesitation.

A couple of months after the birth of his sister, Sami succumbed to a severe case of influenza pneumonia; his parents had made the conscious decision not to bring him to the hospital for they did not want to see him attached to the respirator for the last moments of his life. He died at home while his parents were caring for him. He was seven years old.

2.3 | What was learned: The sine qua non of bedside ethics consultation?

Lessons learned from this case are many. Both the physician and the clinical ethics consultant (who are the authors of this article) reflected on matters that they thought needed to be constantly accounted for. Those are shared here with the hope they will make a difference at other hospitals and with other patients. It is important to note, however, that clinical ethics consultations are used by doctors who believe in shared decision-making. Doctors who did not use ethics consultation tended to think that it was their responsibility to resolve issues with patients and families and that they were already proficient in ethics.¹⁹

¹⁹Orlowski JP, Hein S, Christensen JA, Meinke R, Sincich T Why doctors use or do not use ethics consultation. *J Med Ethics*. 2006 Sep; 32(9): 499–503.

It is only natural to begin with three general yet essential statements: First, the clinical ethics consultant can do his/her work successfully if and only if the attending physician of the case and the patient (and/or his /her surrogate) trust him/her. Second, what is ethical is not always legal and vice versa. Third, two patients might have the same condition, the same prognosis, but they are not the same as there are usually particularities that can go unnoticed and should be probed; hence no two cases are ever alike. In their article, La Puma and Schiedermaier emphasize that clinical ethics consultations differ from one patient to another since each patient and accordingly each case is unique and can be approached differently.²⁰ These concepts typically play important roles in ensuring patient-centered care and are in line with our belief that medicine is a praxis aiming at caring for an individual patient with all the particulars of his/her case. To achieve this, listening and probing carefully is crucial to unravel what lurks in the minds and hearts of every patient and, often, family member(s). It is crucial to mention that to ensure the involvement of all stakeholders is essential. In the case presented, we made sure that the mother who is not the primary decision maker was involved in every step of shared decision-making although the Lebanese Law stipulates that the father is entitled to make all the decisions.

Perhaps the most important lesson is that close collaboration between the attending physician of the case and the clinical ethics consultant will only ensure that patients will get the care they need and deserve. After witnessing and being part of several bedside ethical consultations, we suggest the following recommendations for a fruitful and better collaboration between consultants, physicians, and patients: 1) Give ample time to listen to the patient/parents' concerns and fears. 2) Ensure that the ethics consultation begins at the bedside and that it includes careful study of the medical information. 3) Let the patient/parents feel that they have an undivided attention: therefore pagers/phones need to be turned off throughout the consultation. 4) Allow patients and their families to feel safe so that they can talk about sensitive issues that they do not usually disclose. 5) Talk to each member of the family separately as well as to each member of the medical team in charge of the care of the patient, including medical students, nurses, residents, to mention but a few. During the clinical ethics consultation session itself, which averages up to three hours in length of time, the clinical ethics consultant may hold further consultations. She/he will also do some reality testing by asking what will happen if the issue is not resolved, or how the other party is likely to respond. 6) Conduct another meeting with the family members together to make sure everyone hears everyone else's concerns followed by a multidisciplinary meeting with the medical team (which includes the clinical ethics consultant) and the family and/or patient. 7) Wait for the right moment to probe patients and encourage them to speak up and express their opinion in case their family members overpowered them. This was pointed out by Rodriguez-Osorio and Dominguez-Cherit who stated that in some instances, patients make a decision under the

²⁰La Puma J, Schiedermaier DL. The clinical ethicist at the bedside. *Theoretical medicine*. 1991 Jun 1; 12(2): 141–9.

influence of their families (familial pressure).²¹ For this reason, it is the duty of the consultant and the primary care physician to ensure listening to, and talking with, all people involved and make room for everyone to express their feelings and thoughts. 8) Pay attention to family dynamics since sometimes having a severely ill child triggers the resurgence of other hidden conflicts in the family. The clinical ethics consultant and the primary care physician need to be ready to recognize and face such an occurrence and not hesitate to involve the social worker and the psychologist if need be. 9) Play the role of a mediator when required by the situation. According to La Puma and Schiedermayer, ethics consultants are also considered facilitators that aid in finding the common ground between patients and the medical team and reach an outcome that is oriented towards the patient's best care.²² 10) Play the role of the psychologist by not only listening to the patient and the parents, but also keep in mind the unspoken words that can be depicted through facial expressions and bodily gestures. Such non-verbal expressions are the hidden but important thread in the tapestry. 11) Include a detailed consultation note in the chart whereby all information about patient/family's concerns, values, desires, and wishes are noted and opinions of all health care team members are documented. 12) Finally, help the patient/parents make their own decisions and avoid patronizing them. The role of the clinical ethics consultant and the physician lies in accompanying the patient and the parents through the process and helping them reach shared decision-making by listening and giving them all the information and the support they need.

We have discussed the presented case with the hospital ethics committee for further feedback and collective wisdom and to ensure that the case is not completely closed after the consultation. Follow-up is essential as it gives a sense of commitment and ownership. In order for good follow-up to happen, physicians need to understand the importance of proper case closure from the clinical ethics consultant's point of view. According to ethics consultants, closure does not occur directly after conducting the consultation; closure is achieved when the ethics consultant ensures that the proper action has been made and that the patient has reached the desired outcome. With this collaboration, patients appreciate that they matter and the consultant feels that he/she is always aware of any changes that may require a new intervention. This continues until closure. Finally, and perhaps initially, there are no rigid guidelines. The ethics consultant has to be flexible enough to know how to handle the situation and when to change direction, paying attention to a number of things at the same time, practicing a culturally-sensitive ethics consultation.

3 | CONCLUSION

When the medical team works in isolation, the process of resolution of an ethical issue does not really materialize. It is only when all voices are heard that the tunes fit together to create the needed harmony

²¹Rodriguez-Osorio CA, Dominguez-Cherit G. Medical decision making: paternalism versus patient-centered (autonomous) care. *Current opinion in critical care*. 2008 Dec 1;14(6):708-13.

²²ibid.

that will lead to better choices, better decisions and greater patient satisfaction. Most importantly, just like the conductor of the symphony and the musicians need to feel the music, the clinical ethics consultant needs to have empathy with the person on the other side of the stethoscope in an attempt at understanding him/her more. The physician and the clinical ethics consultant work in tandem; each has his/her role to play and his/her expertise to operate from yet each works with the other having the best interest of the patient/family in mind. Reflecting on his paintings, Monet once said: "it is the parts that give insight into the whole". The same can be said about our experience of bedside ethics consultations. The voice of the patient and/or his/her family along with that of the healthcare team are the fabric that constitutes the tapestry.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest regarding the publication of this paper.

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