Part II: The Practicum Component Prologue

Chapter 5

The Forgotten Text Vivian V. Altiery De Jesús



Ethics Committees and Ethics Consults

 $((\circ \circ))/$ I think that it is the closest keyboard-emoji that I can convey for the feelings during my first Committee sitting. My practicum mentor recommended to me a couple of books in order to understand clinical ethics in-depth and the committee dynamic $(\sim \bullet)/\sim$. There has been a couple of times where I have reached eudaimonia throughout my lifetime, and this was one of them. Here I was, as a fourth-year medical and first-year MBE student, sitting as a guest...Definitely this was one of the best birthday gifts, yeah, I know, geeky but proud $((\circ \circ))/$.

As a side note, besides common sense, I am committed to my oath as a physician in training to keep patient information confidential. Furthermore, I also accepted the confidentiality agreement of each Committee and IRB. In other words, the detailed experiences of the cases that I had the opportunity to learn, will remain in my mind alone. The same with my ward's cases, I owe patients respect and gratitude by allowing me to learn from them during my professional formation. Therefore, I will focus on the essence of the moral dilemma, as well as inflicting changes in the cases' facts, erasing any trace of identification. Moreover, the text will be revised by my mentors and faculty members.

I had the opportunity to observe Ethics Committee at two Johns Hopkins hospitals. Both committees had similar features, diverse composition of experts ranging

from physicians, lawyers, social worker, nurses, chaplains and patient representatives $({}_{\circ} \bullet {}_{\circ} \bullet {}_{\circ})$. The expertise to distinguish between a legal and ethical case, the synchronization for the next step in action, the insights of opposing opinions in the course of action...an astonishing experience for an MS4 an MBE student $({}_{\circ} \bullet {}_{\circ}) {}_{\circ} (I$ think for everyone) $(({}_{\circ} - {}_{\circ})) /$.

Although both committees had different cases and different patient populations, there were topics that were addressed: decision making capacity, end-of-life issues, refusal of golden treatment by patient, resource allocation, spirituality, and religious approach. Something interesting is that Ethics consults are requested by healthcare professionals, but also by the patient or patient's family. Another aspect is that "ethics" doesn't have a negative connotation. Before the MBE, I thought that "ethics" was something invoked when the physician was being dishonest (**•**_**•**); they were the police force of the medical license. Well yes and no, ethics actually goes beyond just policing professional behavior. Ethics serves as a prevention for errors or escalating issues. It is a tool that can provide benefits for the physician and the patient's health outcome. Ethics is more than judging healthcare professional behavior\(**°o°**)/.

Although different, I remember that our team had an ear-pulling situation (*and with reason*) (>>.<<) from an Administrative Committee, who was the gate keeper of the hospital beds under the distressful and disastrous situation of Hurricane María(\sim __).

Long story short, there was a point where we had hospital-admission-seeking behavior...as said by one of our patients "Here [at the hospital] I have food, air conditioner, water and electricity...I got nothing at home. My home was destroyed". This was a heartbreaking situation, especially in the pediatric population, where some patients suffered malingering by proxy^o. We understood the situation of our patient, but at the same time, we needed the resources (admission bed, power supply, water supply) for those that were in dire need of healthcare. It would be unjust to not provide the same opportunity of healthcare to the rest of the population.

Ethics for Lunch and BI Seminars

I remember orientation day at JHSPH. "We know that you guys can't properly function with an empty stomach..." (*_*) An ingenious idea, a cool way of maximizing our time $\Im(\widehat{\nabla})$. It caused massive laughter at Feinstone Hall, a majestic amphitheater. JHSPH had plenty of guest speakers and seminars running year long, most of them occurring during lunch or early in the morning. Hence maximizing the possibility of student participation. In exchange, they would feed us with either breakfast or lunch. Everyone cheered at the bargain $\langle (*O^*)/$. It felt like a Black Friday Deal (I must confess, I have never participated in a Black Friday, though $(\cdot \omega \cdot)/$). An astonishing idea, you had a lunch break, did not need to worry about cooking or

^o Malingering by proxy is when parents or caretaker make their offspring sick for profit¹⁸. Do not confuse with Munchausen syndrome by proxy where parents or caretaker makes their offspring sick in order to seek attention¹⁸.

fetching food, had a whole hour of innovating information, and your energy was renewed to continue with the rest of your classes ($\neg \blacksquare_{_}\blacksquare$).

The Berman Institute (BI) offered seminars, the topics ranged from clinical, food engineering and current hot ethical topics, such as CRISPR. Meanwhile, Ethics for Lunch was offered by each Hopkins Hospital, they had a clinical ethics focus. The modalities ranged from presentation to panel discussion, with ample opportunity to interact with the audience. These experiences also became part of my Practicum, they allowed me to gain more insight to the theory learned during course work.

Ethics Teaching

Ethics teaching ranged from medical students to residents from different specialties ($\bullet \bullet \bullet \bullet \bullet$). The topics were focused on ethical issues that may be encountered throughout the profession and tools on how to mitigate, avoid or solve them. Most of these sessions were done in small groups. Chapter 2: Professionalism was a glimpse of Ethics Teaching. In later chapters, more experience will be narrated along with the ethical analysis taught during my MBE. The sessions were highly focused and intense ($\circ \circ \circ$)/; sheer concentration from the audience. Most of the time (if not always) I had questions to ask afterward the lessons. Topics that were discussed included

informed consent, delivering bad news, VIP patients, professionalism, healthcare team conflicts, medicolegal among other high yield topics.

Participating in these sections was blissful, it is the equivalent of standing in two places in the same time $\langle (*o^*) \rangle$. And the last time I felt like that was when I was around 8 years old and my mother pulled over at the boundary between Carolina and Canóvanas, two counties at Puerto Rico. "There you go, if you stretch yourself you will be simultaneously at two places"- I don't know how much time I stood there splitting as much as I could, but I do remember the joy of the great achievement (^o^). It wasn't until years later that I stood simultaneously at three places. There is an exact location in the attraction "*Parque Nacional de la Cavernas del Río Camuy*" (*Camuy River Cave Park in Spanish*), where it has the boundary between three different counties. I am seeking to break the record soon (.o.).

Clinical Shadowing Experience

During my MBE, I also had the opportunity to shadow ethical cases in outpatient clinics and during Ethics consultations. This experience is compared to what I could imagine to be an archeological field trip. Literally, you are between two worlds: Ethics and Medicine. The dynamic is very different from a hypothetical case....I do not have enough words to describe this $\binom{n-n}{n}$ nor emoji faces.

Composite Experiences

The following statement may seem like a paradox, the BI-MBE is highly structured but at the same time, highly flexible. There are core unbending requirements, which allows a solid foundation for their students. Yet, the curriculum is flexible enough to draw on each student a set of skills, interests, and background. Throughout the year, the BI and JHSPH promoted a variety of activities that do not fall in the above classifications; hence, the "composite experience" section. My second interest is Research Ethics $(\bigcirc, \bigcirc \bigcirc)$.

I had a fair amount of banging my head (to the point of creating a unicorn horn) during my first IRB experience during the first summer at medical school "*How could offering one MISERABLE bonus point for Ethics class be undue influence? How was I going to increase participation from my classmates for the post-SWR survey?*" [Add the cricket sound] (=,=) Yeah, I know, I was almost too far gone $(i \land i)$. Of course, it was undue influence? $(^{j} \circ \square^{\circ})^{j}$ Even my justification spurts undue influence $(o_{-}o)$. This *is* research, not a marketplace -sheeeesh-... I banged my head a little bit more $(>_{<})$ when I made the retrospective research and also involved the Hospital Board + my school IRBs. Nonetheless, all of them were good empirical experiences that helped me enjoyed when I sat at different IRBs as a guest (""). The IRB's goal is not to make the investigator's life

miserable nor comfortable, the IRB's purpose is to ensure the safety and ethics of the investigation. We only need to glimpse back in time to see little bits of what lead to historical research atrocities, under what I want to believe were good intentions of investigators.

Another opportunity was to participate during Clinical Ethics Research in Progress (CERIP) sessions. The BI faculty takes turns to present to other faculty members their research. This session serves as a consult for advice and opinions regarding methodology, protocol development, data analysis, among others. It is interesting to listen how different minds converge and instantly create a product. The analogy that I can come with is a cake $\langle (\bullet \cup \bullet) \rangle$. I know that there are people out there that find cake confection fascinating. Water or milk, flour, egg, butter and desired flavor. Radically different ingredients to which their "uniqueness" is lost in the final product. Even depending on the ingredient ratio or the method used, different products could be made (e.g. pancakes). This is a trait I have stumbled upon throughout JHSPH, even at the Happy Hour Fraction (a school traditional Friday get- together) where different mind-entities join and have a good time (we tend to slip back into our lovely "geeky" talks) (~ ˘ ˘)~...It is a nice and unique group, we even auto-denominated that "Awkward Dancing" would prevail at the Spring Gala, and it did (XD) (another lovely school tradition).

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Lastly, activities such as the Henrietta Lacks Memorial Lecture, End of Life Project-Theater of War Production, and Conferences (e.g. APPE Conference) nourishes the ethical and personal experiences. These two activities in particular allowed me to appeal to suppressed material, concealed treasures for me. My major was in Cellular Molecular Biology, consequently this means lots of genetics exposure. I had the chance to meet one of the great icons in genetics, he was mentioned in almost every Cellular Biology course: Dr. Francis Collins, director of the NIH. It has been a long time since I had a Drosophila phenotype prediction using X², genetics (as in my bachelor's degree) is not used during medical school or clinics. Nonetheless, it is still a part of me, well five years of my life in the topic (^o)).

Meanwhile, the End of Life project used dramatic readings from Sophocles' *Philoctetes* and *Women of Trachis*. Definitely this is practically the equivalent of watching a *Disney* movie and going to *Disney on Ice* (\checkmark)... My high school had a very similar paradoxical structure to my MBE; structured but flexible^p. We were required one literature reading per semester, the choice was ours (\checkmark) \downarrow). This allowed me to explore my fascination with mythology, so I filled my quota for 9th-Grade with the *Iliad* and *Odyssey*(\clubsuit). Subsequent years I read the *Greek tragedies*, and they were re-read

^p Among the three [siblings] I have the most hybrid education. I was enrolled in the traditional system until the first trimester of 8th grade. The rest was under the Homeschool system.

during the Humanities Introductory course at college. The play allowed me to see another perspective for my thesis (which involved the ethics of assisting death).

Another powerful source are the national conferences. I had the opportunity to assists to a Teaching Workshop and a full day at the Association for Practical and Professional Ethics (APPE) annual conference. The only challenge that I found was that I couldn't not be at two places at the same time. (I truly wished I was 8 years old and that it could be solved by stretching between the boundaries) $\langle (\bullet \cup \bullet) \rangle$. Each session had 3-4 concurrent presentations with a wide range of topics from clinical to military, to business, to technological; a true ethical buffet.

All these activities constitute my Bioethics Practicum Experience ($\neg \blacksquare _ \blacksquare$). Along with my core requisites, the Practicum has been an essential experience for my educational formation. The time dedication goes beyond the required 48 hours for graduation. Nonetheless, every single second is irreplaceable and invaluable. Without further ado, I will proceed to the in-depth ethical analysis of selected experiences gathered throughout my Bioethics Practicum($\sim _^$).

References

18. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders* (*DSM-5*®). American Psychiatric Pub; 2013.