Introduction

‘Wherever the art of medicine is loved, there is also a love for humanity’- Hippocrates

“Ethics is knowing the difference between what you have the right to do and what is right to do” – said Chief Justice of the US Supreme Court, Mr. Potter Stewart. When you extend this description of ethics on to the practice of medicine, the main objective that we all strive to achieve is to cause no harm to our patients, and try to offer as much benefit as we can. I feel it’s pertinent to understand here that causing no harm takes priority over everything else. When the aim is to look after the physical well-being of a patient, I believe most of us can vouch for ourselves that we’ve always made an attempt to take the best decisions for our patients in the light of given knowledge and circumstances. On the contrary, averting harm or distress to the patient can be multifold – there’s one where you decide your patient no longer can take an antidiabetic due to worsening renal function or the plan to change a drug that has caused the platelets to fall. Whereas, I’d like to bring your attention to the other aspect of preventing distress to the patients and certainly not causing it, knowingly or otherwise – Mental Health and Well Being, that perhaps surpasses the Physical health. As Donald Robertson has said “Remember that the fear of pain does more harm than pain itself”. How much time do we really spend looking after the happiness of our patient, which is possibly the highest form of health.

When you talk about the basic principles of medical ethics, it is based on four fundamental principles – Beneficence, Non-maleficence, Autonomy and Justice. I’ve briefly talked about the first two already but this specific debate is about the third principle – Autonomy, that gives the patient freedom to choose what he wants to do about all of his life as well as end of life decisions, where and whenever he is able to, but what happens when the patient doesn’t understand what is good for him/her. It may be because he hasn’t been relayed information accurately, or it may be because his mind fails to comprehend the complexities of the human body. What happens when the patient’s judgement is clouded by irrational beliefs in supernatural influences or strong premeditated cultural notions?

When the above ideologies are applied to a literate population, that results in practices where patient is all and he decides for his life and is allowed to give an advance directive ahead of time in case he no longer is able to do so. Literacy is defined as the competency or knowledge in a specified area as described by the Oxford Dictionary. The literacy rate in Pakistan is such that it is estimated that a population of 60 million is illiterate in the country. Which brings me to the real question being asked. Are the patients we treat in our hospitals on a day-to-day basis capable of understanding what has gone wrong with them? Are they able to cope with the news that we break to them on the bedside in a rather casual fashion? Are the patients given a real chance to decide for themselves?

Let me quote a few examples that will help you comprehend the point am trying to make.

I once during my training came across a diabetic patient who was in his 60s and had developed Acute on Chronic
Kidney Injury secondary to a nasty urinary tract infection. After a consultation with the nephrologist, it was decided that he needed an emergency hemodialysis. So, I went and explained to the family that this is what had to be done. The family asked for some time and came back with a refusal. They had decided hemodialysis was not a treatment option they wanted to consider for their patient. Unwillingly I had to put it down on their charts that dialysis was recommended but the family has refused and the family signed it. In the next 48 hours, the patient felt sicker and became critical where he was unable to maintain his hemodynamics. Being the bed doctor, I was by his side and managed him to the best of my ability and when things became even more serious, it was time to discuss with the family what next? What happens if he goes into an arrest? Does the family want him to be actively resuscitated and artificially ventilated? Patient needs to be in the Intensive Care Unit but we’ve already tried and no beds are available at the moment. This time the family decided that there was no permission for hemodialysis but a refusal to sign a DNR/DNV. I was quite baffled by this verdict as I couldn’t understand something that could be curative and could offer a chance at healing was being refused so bluntly, yet resuscitation was being allowed. It was important for me to try and grasp what the challenges of making such a decision were? Is it because we couldn’t break the stigma of an interventional procedure that killed the distant relative who got “their kidneys washed”? Was it the failure of the system to not arrange an ICU bed for him or were we just not able to communicate the importance of the therapeutic efforts that might have given him a chance to live?

Do we train our healthcare professionals to deal with social and mental challenges that come bundled with the physical complaints of a patient? Are we over-sympathetic and push our patient towards a personal ruling? Or do we stand at the other end of the spectrum and behave like robots and not connect at all? Do we truly hold our patients when they are asked to make a tough choice for their beloved ones because we are bound to abide by their wishes at the end of the day, how much ever contrary they are to our own personal choices. In a second instance, we were denied the permission to resuscitate a 24-year-old mother who had just given birth 2 days back and had developed a complication. In this case, the patient’s mother, along with about 10 relatives, all together, decided they didn’t want us to do anything. She seemed strong headed. Despite talking to her multiple times, her mind was made. It was inexplicable and paralyzing to stand by the patient and see her go. With the agitated family around, no one dared to do otherwise and well ethically as well, nothing could be done. So, everyone stood. As we become doctors and train, and work in hospitals, and interact with several sick patients daily, it almost becomes an instinct to try and save a life. To be honest, there wasn’t enough time to ask. She was the decision maker and no one could say anything to her. Was it the right choice? Did she understand what her daughter was going through, in terms of her perhaps reversible sickness? Did she think the team of doctors looking after her daughter could no longer help? Did she not trust us, in that moment, or was her judgement influenced by other unknown reasons? I began to question myself and the care that we were providing. As I finished my shift that evening and went home to a cozy meal, my mind wouldn’t give up the thought. The mother’s autonomous decision had left me confused and rattled. 10 years later, it’s been a learning curve for me where I’ve come to terms with respecting my patients’ choice regardless of my own verdict in a given situation.

And then there’s the breaking of bad news, we hesitate to talk to the patient truthfully and incline towards speaking to the immediate relatives first who are hammering us at the bedside for answers. Are we really going by the book when we are declaring a cancer diagnosis to the patient’s wife and not him directly? Does he want his kids to find out he’s got a year to live? How do we take it upon ourselves to decide this on the patient’s behalf? Why isn’t the patient’s autonomy everything? Through the few years of acquiring knowledge and being in this profession, I now try to put myself in their shoes when I talk to them. I make an effort, well mostly, to fathom the motive behind what my patient chooses. It takes some time for the patient to really open up and yet, at times they’re hard to crack and refuse to give in. I try to persuade the family I’d like to speak to the patient first. It’s not received well, I tell you. Am often responded with statements like “you can tell us, not him, he won’t be able to take it” “we don’t want him to know”. It’s not easy to influence an anxious, angry 30-year-old gentleman and convince him that his ailing father needs to be spoken with, while the son is present or not. But this is going to be his father’s decision to make at the end of the day and should be given his rightful authority.

I guess what am trying to say is that I feel in our overwhelming health system, autonomy is respected, for sure, but not enough time is spent to understand the reasons behind a decision.

As Thomas Frank once said, “I think there’s great potential for autonomy, but we have to remember that we live in a world where people may have free will but have not invented their circumstances”. Something to ponder upon.