Is Perinatal Palliative Care an option for Termination of Pregnancy in the Case of Incompatible to live fetus??

As a doctor dealing with pregnancy, childbirth and all the other issues and decisions that go with it, what happens when it is not the kind of perfect baby that one was expecting? I can not only imagine the images of the preterm neonate lying in the corner in a NICU, isolated, with its tiny chest moving on high-frequency mechanical ventilation, delicate features overwhelmed by different lines and tubes, miniature wrinkled fingers sometimes not even touched or stroked by parents or caretakers with there huge hands, as in their minds is eternally a feeling and thought process going on which says “Oh God can’t this be the one on which you show your miracles, if not can’t you just take it off the misery”. Then we start questioning, especially if we are from low or limited resource setting, asking *What kind of suffering is this baby experiencing? What kind of quality of life will he or she have?* Is it resonale to ask a mother who might be a laborour or even middle class parents, who are not supported by any sort of insurance to invest in it even when we are not sure if it will be a failure or a success.

As trainers or a trainees in a medical school have we ever discussed how to even handle such situations? Have we even in our wildest dreams thought about the idea of end-of-life care even before independent life has even begun? In medical practice, healing is couned to be successful and death has no place. But then, letting someone die with dignity- is it really a failure or a big huge success. It's a change of perspective but one worth thinking off.

A regular day in the clinic, running from one patient to another, I tell a patient of mine who’s 2- year old son also has been delivered by me, who is walking around the entire clinic with his car in one hand and his little milk bottle in the other. It was the day when I had called her mother for the anomaly scan and like all other days she comes, huffing and puffing into my room saying “please do mine a bit early, my son is throwing tantrums today”. I look at her and say “*well it's the detailed scan today so will take time, can’t be rushed in so fast. “Please. Please, Please”*- I oblige and take her to the ultrasound room which is filled with her son’s vocabulary which both of us are giggling to as I put the warm jelly onto her abdomen to do the scan, A while later as the my giggles kind of subside, she asks me if she found something wrong with the fetus— I reluctantly tell her that I was seeing a problem. She panicks and says “*but I took all the required medications this time even before I conceived”.* We had discussed it after her last pregnancy that because of a mild diabetic issue she always has a chance that the baby might have some problems- but nothing happened the last time when she did not even plan or realize she was pregnant and this time she had planned it all, taken her prenatal vitamins, controlled her sugars all and yet I told her there was some problem with the baby. I ask her to get a second opinion scan from another center and get back to me with the reports. She comes back after 2 days and with our conversations that narrowed in quickly on prognosis. For the baby, there were not many possibilities. The essential facts were that it did not have both the kidneys. Because of the lower gestational age, it was a near certainty that its lung development would be seriously compromised. It was possible that it would be stillborn, meaning that he would die in utero at some point during the pregnancy or during labor or delivery. It was possible that she could go into preterm labor or that the pregnancy would go all the way to term. There were all kinds of possibilities which are usually there in all the other patients I handle usually too but in this case the anxiety level was much higher than expected as the child that was to come out would be either not there already or come into this world and die in some time- a time which none of can actually predict. So then if I opt to keep this child as not many of my pro-choice friends would advice, what happen then? At birth, this child could have breathed spontaneously or not at all. And if it did it would probably need some assistance with breathing, and given the severity of the damage, it most likely would require mechanical ventilation, if that route is chosen. At birth as its kidneys are absent so does this kid stand a chance for a kidney transplant? What does it mean to have an infant on a transplant list? On dialysis or mechanical ventilation? Is that even a thought process that can be inculcated or are these just lines in some research book. In todays world which is running to towards consumer rights, even in a place like India where so many essential medical facilities are in a big questionable form when it comes to situations like these all such questions pop up and when there aren't any relevant answers given they go into jurisdictions of verdict where these kind of issues are fought on a day to day basis by giving one reason or the other and proving the fact that its all for good and aborting this child as soon as it was diagnosed is such a valid justice. Making a decision like this we are taking care of both the mother and the child.

So, then are we actually taking care of the mother and the child? Undoubtedly for the time being yes by washing our hands to face the real situation and covering it up, but does that actually solve the situation is a question we need to dig deep into.

Choosing an end-of-life care plan for this child- is that something even heard of? In the west may be, but in India I don't think we are even wanting to hear about it. And because my patient and her husband like most of the other individuals in India nowadays believed more in evidence than in miracles, they wanted to know the appropriate plan of action. The evidence of each of these entities comes with the search on Google which starts the sentence in such kind of cases as “*incompatible with life*”. They explicitly consider the potentially tremendous cost of pursuing aggressive treatment and the psychological impact on there family of continuing a pregnancy with what would end up being, one way or another, a dying child, but in retrospect those who are concerned it would be our decision-making.

This is a true story of a couple who has a life threating condition, what about the numerous ones whom we diagnose everyday of having chances of any kind of anomaly even if they are in particular not seen but a certain test has detected that there is a 1:500 chance of the child to have it. Not necessary that the child would have this anomaly but there is a chance and so we don’t take any chances of abnormalities or disabilities in life and hence we chose to end this life – as it would end up as a burden or a liability. Is this the same life we are talking about which is at other times claimed to be so precious.

A pro-choice woman is someone who decides to have an abortion she feels she has the right to cope with her experiences and her emotions on her own. A pro-life woman on the other hand is an individual who choses that it's the child’s life and emotions at stake too and so it is not right of me to decide to end a life just because I feel its not worth a living. Just like any experience of loss, the emotions after an abortion will differ from person to person.  There is no normal, Abortion choices create a situation of disenfranchised grief in women’s lives.  Disenfranchised grief is grief experienced by an individual that is not openly acknowledged, socially validated or publically observed[[1]](#footnote-1).  The loss experienced is real, but survivors are not accorded the “right to grieve” by anyone around them. Most of the times it is thought that the most common belief is the feeling of relief from a problem. Unfortunately, this sense of relief is not always permanent.  Every circumstance surrounding an abortion experience is as unique as the woman who chooses the procedure.

Sometimes a deep feeling of sadness will set in *immediately*.  Because abortion is a final decision that can’t be taken back, I believe most women, are forced to go into a period of stuffing down the sadness and getting on with life.

Here comes the concoction.  Combine the emotions of relief and deep sadness and the kind of emotional cocktail do we get?  Confusion!  The days, weeks, months and years following the decision can result in a lot of confusing emotional distresses.  On one end of the spectrum is an overwhelming relief to be out of the crisis, and on the other end there is an amazing depth of sadness that resonates to the core of one’s being.

In our cultures the legalities of abortion are confused with the actual process of resolving the natural loss that follows, there is an implied message that the abortion is the closure. This is where the truth gets dispersed. Anyone who is undergoing a loss needs a place which is comfortable for them to be in. Having a child who may not cope with life is a realty and giving it the dignity to die is peace and a loving environment is also something we as humans need to understand. The reason for this statement being that when we loose a loved one, age no bar we are usually surrounded by our friends and family who stand along with us telling us the goods and the bad’s, the fun time and the laughter, anything that would make us just comfortable. But, when we talk about abortion, usually it is not exactly how it is. The person is either alone when it’s done due to the reason called “unwanted pregnancy” and if it is else wise that is when the reason is the growing fetus is “not up to the mark” there is fear, confusion, anger, blame, conflict, guilt, shame, isolation, and anxiety which often undermined with the fact “good ridden’s”.

There are many complex emotions which women are left to cope as soon as a woman learns (or even suspects) she is pregnant.  There is a different kind of emotion of feeling one faces when one realizes that there is another human being growing inside one self and then somewhere down the lane she is told that this human being whom she is expecting going to be somewhat like her or her partner. Then when you are told that this person is not perfectly made, the first thought that passes one’s mind is that, “*what did I not do right”*

It has been my experience that it takes a lot of effort and counseling at a personal level till one can really admit a past abortion. And when asked if they would do anything differently, most of the patients I came in contact with broke down saying *no one ever gave them an option or choice to think elsewise”.*

A competent patient must always be involved in the decision-making process regarding offered medical treatment. Competence is a global concept and may fluctuate from day to day, and a patient may be competent to make some decisions but not others[[2]](#footnote-2). Decision making capacity is more of a clinical concept, and it acknowledges that capacity is task-specific and may fluctuate[[3]](#footnote-3). If women could share their stories openly without fear of being judged by society.  Abortion is such a hot topic and there are many people shouting loudly on both sides of the argument.  Sadly, the one voice you never hear, and perhaps the voice that is most important, is the woman who has had an abortion.” It is therefore necessary to assess the decisional capacity as it is an essential part of the informed consent process[[4]](#footnote-4).

The medical decisions then must be based on either what the patient would have wanted under those circumstances or what is best for the patient[[5]](#footnote-5). There is also no “objectively correct” standard delineating what a patient must decide; patient may make choice that the majority of people may not chose, but that does not necessarily mean that the patient does not have capacity[[6]](#footnote-6). What I learned from my personal experience and what I see with the women I work with is that in order to survive the dialectical thoughts of “I’m so relieved and I’m so sad,” a woman has to go into a shut down mode emotionally.  Imagine dealing with thoughts like “what made me so relieved also made me sadder than I’ve ever been and what made me sadder than I’ve ever been actually gave me relief.”  This thought pattern has no positive return for the person stuck in it.

Guilt is an important and valid feeling that follows many types of loss for many reasons.  In the case of abortion there may be unique feelings of guilt, as abortion is a decision deeply intertwined with our spiritual, ethical and political belief systems.

 Even when a woman feels confident in the decisions she made, there still can be sadness about the loss of a future as a mother, with that child. It is important to feel and acknowledge sadness, and accept that it is okay to feel this emotion despite the abortion being a choice.  Sadness can be confusing when it comes simultaneously with emotions like relief and happiness, but this is the reality and complexity of grief. If one choses to continue the pregnancy for purely selfish reasons. and not abort, this child’s birth would be noted, his death would be marked, and our deep and long-lasting grief would be been acknowledged and validated. Instead, we chose to give this baby what we feel is the most humane, comfortable, and loving end-of-life experience “*for the mother, not the baby*”.

Because of the choice we make to end its life, this child will never get the chance to gaze up at his parents, to see who it was that had been talking and singing to it all along. It never got the chance to fall asleep in its parents arms, bundled and cozy. Rather, what it got was to get suffocated to death at its abortion, his small body gasping to fill his woefully hypo plastic lungs. He did feel all kinds of pain shooting throughout its body as the medicines tired to cut its blood supply. We to prevent it form being a burden, chose instead, a painful death at our own choice and time.

We think that the right to life includes the right to live with human dignity and all that goes along with it, viz. the bare necessities of life such as adequate nutrition, clothing and shelter over the head and facilities for reading, writing and expressing oneself in diverse forms, freely moving about and mixing and mingling with fellow human beings[[7]](#footnote-7). Community in terms of the individual or the collective assigns equal worth to all, without any distinction of color, race, caste, gender, ethnicity, ability/disability, or language. It is intrinsically valuable and is hence non-negotiable. The vulnerability refers to people’s propensity to fall, or stay, below a pre-determined minimum security of basic needs of life[[8]](#footnote-8). As the Council for International Organizations of Medical Sciences (CIOMS) it argues that vulnerability is best conceived as inability to protect one’s own interest, it’s the function of people’s exposure to risks and of their resilience to these[[9]](#footnote-9). Basically the Dignity and vulnerability are two sides of the same coin. Vulnerability is neither necessary nor sufficient for determining whether exploitation has occurred[[10]](#footnote-10).

Human rights, as the term is most commonly used, are the rights that every human being is entitled to enjoy and to have protected. The contemporary international statement of those rights is the Universal Declaration of Human Rights [[11]](#footnote-11). Backed by a framework of rights, dignity creates a sense of self-respect, which can be reflected in demeanor and body language[[12]](#footnote-12). Of course, the magnitude and the content of the components of this right would depend upon the extent of the economic development of the country, but it must in any view of the matter, include right to the basic necessities of life and also the right to carry on such functions, and activities as constitute the bare minimum expression of the human self.

What has recently come to be recognized, however, is that women have long been undeserved in the context of modern medicine as well [[13]](#footnote-13). People who are viewed in terms of dignity, sacredness, equality, and unity grounded in their identity as being in God’s image will be treated in certain ways [[14]](#footnote-14). People will treat them with respect, by treating those created in the image of God in a particular way; one treats the creator in the same way[[15]](#footnote-15). As Christians we believe that God loves all of humanity and does not show favoritism, but accepts men from every nation who fear Him and do what is right” (Acts 10)[[16]](#footnote-16). The ethics of care values the ties we have with particular people and the actual relationships constitute our identity[[17]](#footnote-17). Emotional response to right and wrong, good or bad, is the only measure of the good. In other words, people make ethical decisions on the basis of their personal preference, attitudes, and feelings. And one person’s preference may not be another person’s choice.

And so we are left with moral disputes and no objective mean to resolve them[[18]](#footnote-18). To commit an offence against another human being is also to commit an offence against God[[19]](#footnote-19). Christian ethics would be the principles derived from the Christian faith by which we act. Love is God’s ultimate intention for relationships of people with one another and with the natural world a well[[20]](#footnote-20). Nearly all of us have benefited from another’s care and recognize that care as having fundamental value[[21]](#footnote-21). While God’s Word may not cover every situation we face throughout our lives, its principles give us the standards by which we must conduct ourselves in those situations where there are no explicit instructions. A happy life is one with a clear preponderance of pleasures over pains but, to treat happiness as a distinct state; one involving a feeling of satisfaction with one’s life as a whole, in past, present and future equates suffering or despair with dissatisfaction with one’s life as a whole[[22]](#footnote-22).

Human relationships are not between equally informed and equally powerful persons but between unequal and interdependent persons. The greatest thing we can offer to each other through an ethic of care, the presence of God in us, full of faith, love and hope for the others and a presence that inspires and guides. The shift in moral perspective is manifest by a change in the moral question from "what is just?" to "how to respond?"[[23]](#footnote-23). Because issues can be complex, some of our decisions may involve choosing the wise course of action rather than the absolute moral good[[24]](#footnote-24).

So, instead of running to wards options to, terminate each and every “*unwanted”, “undeserved”, “underdeveloped*” individual, why not change our perspective and give them a chance to live a life which might be just a few seconds or minutes or hours or days or a few months or years. When we don’t know when to stop the line then, are we rightful in saying its ok to stop the line. For only He knows the time which has been numbered for each of us and then how can we even think of stopping someone else’s. Prenatal palliative cares should be an option given to such individuals where they are fully aware of the situation they are in, the prognosis of the child, the growing fetus, the not so wanted – as it would be a liability individual and yet they decide to be with this child till nature takes its natural course of death and make those moments worthwhile for proper grief and love to be established between the parents and the unborn or the new born child, leading to a more meaningful and less regretful decision for one’s life ahead. After all aren’t we to follow the principle “*as to what ever you do to the least of my breathern you do it for me*”[[25]](#footnote-25). May be even in the form of Karma, let me not get in return the hatred I showed to my dearly so loved one but the immense love that I showed to them just by excepting them the way they are, unformed, broken yet fully in the image of the maker and sustainer.

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