International Journal of Clinical Obstetrics and Gynaecology

ISSN (P): 2522-6614
ISSN (E): 2522-6622

www.gynaecologyjournal.com
2021; 5(2): 39-44
Received: 12-02-2021
Accepted: 18-04-2021

Dr. Kamalaveni Soundararajan
Specialty Registrar in Obstetrics and Gynaecology, Hull University Teaching Hospitals NHS Trust, Kingston Upon Hull, The United Kingdom

Dr. Vijaya Hebbar
Consultant Paediatrician, Diana Princess of Wales Hospital, Northern Lincolnshire and Goole NHS Foundation Trust, The United Kingdom

Mohammed Abdelaziz
Foundation Doctor, Diana Princess of Wales Hospital NHS Foundation Trust, The United Kingdom

Ibrahim I Bolaji
Consultant Obstetrician and Gynaecologist and Senior Clinical Lecturer, Hull York Medical School, Diana, Princess of Wales Hospital, NLG Foundation NHS Trust, Grimsby, The United Kingdom

Corresponding Author:
Dr. Kamalaveni Soundararajan
Specialty Registrar in Obstetrics and Gynaecology, Hull University Teaching Hospitals NHS Trust, Kingston Upon Hull, The United Kingdom

Medico-legal and ethical dilemmas in managing anencephalic pregnancy in a high risk pregnant woman - reflection on current practice in the United Kingdom

Dr. Kamalaveni Soundararajan, Dr. Vijaya Hebbar, Mohammed Abdelaziz and Ibrahim I Bolaji

DOI: https://doi.org/10.33545/gynae.2021.v5.i3a.902

Abstract
Antenatal care services are an umbrella term for the medical care carried out during pregnancy (Rooney CIF: WHO1992). It is an essential part of basic primary healthcare during pregnancy and it offers a mosaic of services that can prevent, detect and treat risk factors early on in pregnancy. It can also be used as a platform for additional interventions that can positively influence the maternal and fetal health status such as immunization, nutrition programs, smoking cessation and life styles management.
Although routine organ donation is controversial and may have ceased in anencephaly, opportunistic organ donation is underutilized and there is no consensus on the best practice option. In this paper we review the management of an anencephaly carried post term and discussed the missed opportunities of opportunistic organ transplantation in all its ramifications including ethical implication.

Keywords: Neural tube defects; Anencephaly, ethical, legal

1. Introduction
Congenital anomalies are the major cause of infant and neonatal deaths, second only to immaturity related conditions in the UK in 2016 [1]. Congenital anomalies caused 29% of neonatal, (age <28 days), 43.9% of post neonatal (age 28 days to 1 year) and 33.2% of infant deaths (age >1 year) [1].
Anencephaly is a defect in the development of the brain via a neural tube defect. The bones of the skull are improperly formed, resulting in severe damage to the developing baby's brain. It occurs very early in the pregnancy in the first 24 days after the egg is fertilized by the sperm [2], corresponding roughly to 38 days from the first day of the last menstrual period (LMP). Whilst there are associations such as lack of dietary folate, the exact cause is often unknown. However, there is an increased recurrence rate of 2% as compared to background incidence of 0.06% [2]; hence making genetic factors a likely association.
The UK's antenatal timetable was established to ensure that expectant mothers are screened and supported from early pregnancy to well into the post-natal period. How then are health's professionals to act when a patient fails to follow this journey, when the baby is at risk and patient presents just before delivery?
This paper aims at navigating through the medical, ethical and legal dilemmas at managing a parturient with a lethal congenital abnormality and who refuses to engage with healthcare professionals. It also examines the issue of opportunistic organs donation in anencephaly.

2. Case Report
Ms L, a 37 year-old single, unemployed multiparous (G4P3) woman attended antenatal clinic for booking. In her first pregnancy in 2004, she booked at 14+2 weeks gestation and she was seen only once antenatally at 31 weeks. She declined to have any prenatal diagnosis as she would not consider TOP if abnormal. She was admitted with spontaneous rupture of membranes at Term+3. The male infant was delivered weighing 3.45kg with APGARS of 9 at 1 and 5 minutes and was noted to have a 'pungent smell'. Swabs showed light growths of candidiasis.
The second pregnancy was a Born before Arrival (BBA) at home following a concealed pregnancy in 2006. BBA refers to when a baby is born at home prior to the arrival of any midwifery or medical support.

Due to post-partum bleeding, she was transferred via ambulance to the hospital where a retained placenta was delivered complete on arrival. The male infant weighed 3.84 kg with an APGAR of 9 at 1 & 5 minutes.

In her third pregnancy in 2013, she booked late at 34+4 weeks. She then had a spontaneous vaginal delivery of a male infant within 7 minutes of arrival at hospital with an APGAR of 9 at 1 and 5 minutes.

All the three children were fortunately born healthy without complication. Historically, she regularly failed to attend most antenatal appointments in hospital and she was often inaccessible to community midwives. All her previous children were under the care of social services and none of them live with the patient.

The patient was of low socioeconomic background, with minimal social support. Two of her previous pregnancies were concealed pregnancies delivered physiologically assumed to be at term. "Concealed pregnancy" refers to the situation of a woman knowing herself to be pregnant, however failing to inform any healthcare professional, thereby missing opportunities for antenatal care.

In the current pregnancy, she had a BMI of 31Kg/m^2 and a venous thromboembolism (VTE) score of 4 based on age, weight, parity, and smoking and she was offered thrombo-prophylaxis. She was a heavy smoker and she was referred to smoking cessation. She was chronically anaemic, likely secondary to poor diet, with hemoglobin of 88 g/l. She had very poor compliance with oral iron supplementation and parenteral iron infusion was discussed.

She was unaware of her gestational date, however her booking scan revealed a single fetus at 34 weeks with features of anencephaly. The images were verified by two senior sonographers, and the confirmed diagnosis was noted as incompatible with life.

Upon discovering the diagnosis of anencephaly, the consultant discussed the ultrasound scan result and he explained the condition as severe brain defect unlikely to survive pregnancy or birth. The patient was offered termination of pregnancy at booking. She was informed of the lack of resuscitation support to be offered, potential complications in delivery including malpresentation as well as dystocia, and the need for high dose folic acid postnatally. She was uncertain on what to do and wished to reflect on the discussion. She was provided a leaflet on anencephaly. She later expressed a desire to continue with the pregnancy with good understanding that the baby was unlikely to survive to infancy. Her wishes were respected, and she was offered support with neonatal review as well as bereavement midwife support. The patient did not engage with these services. She additionally failed to attend for intravenous iron infusions on account of her chronic anemia. The risks of anemia in pregnancy were discussed, as well as her increased risk of venous thrombosis. She received the low molecular weight heparin for prophylactic daily administration at home by the community midwife. She was to have midwifery appointments for follow up, along with open access to the hospital in case she changed her mind.

She next presented at 41 weeks gestation in the antenatal clinic and reported good fetal movements. She was again offered induction of labour, which she declined in favor of a 'more natural course of delivery'. However, by week 42 weeks gestation, she agreed to induction of labour with intravaginal prostaglandin for cervical ripening and the neonatal team was informed of admission. She subsequently had a normal and uncomplicated vaginal delivery of an anencephalic infant two hours following amniorrhexis and syntocinon infusion.

The neonatal registrar was present during delivery and the baby had an APGAR of 0 at 1 min, and 8 at 5 minutes. The neonate was warmed, dried, wrapped and given to the mother, with supportive care to keep mother and baby comfortable being offered. Further care was discussed with the mother by the neonatal consultant and an advanced care plan was completed in line with Royal College of Paediatrics and Child Health (RCPCH) guidelines. As per her wish, a place was arranged in the paediatric hospice for further supportive care. The Chaplain additionally attended in the hospital as per the mother's wish and baby was blessed and named in the hospital. Memory keepsakes including photographs, foot and hand prints were created for the mother while in hospital. The baby was transferred to the hospice with palliative/comfort nasogastric feeding as mum felt the baby would be hungry. The hospice staff felt unequipped to deal with a baby who lived for about 48 hours, and at one stage wanted transfer back to the hospital whereas the mum preferred to stay in the hospice. As expected, the baby unfortunately died two days later. The mother was offered a consultant appointment for follow up at six weeks, which she did not attend.

The poor engagement made it difficult to discuss foeticide and organ donation in the event of delivery and an advance care plan to be put in place prior to delivery. Poor engagement also prevented discussions, education of staff and forward planning with the hospice and its staff.

3. Discussion

Diagnosis of anencephaly is straightforward and is usually noted by the booking/dating scan carried out after 11 weeks gestation. It can be later confirmed by the Fetal anomaly scan done between gestational weeks 18 and 21 [2]. Signs include a small head (Coronal views show Fetal head to be distinctly smaller than the torso); 'The Frog Eye' sign; Mickey Mouse sign (Two abnormal hemispheres- the ears noted without an associated cranial vault) and the Elvis Presley Profile (Longitudinal view of the fetus showing the cerebral hemisphere jutting forward, giving the illusion of Elvis Presley's hair) [3].

3.1 Maternal Risk factors

Women with deprived socio-economic backgrounds, advanced maternal age and receiving subtotal antenatal care, are persistently over represented each year in UK maternal death statistics. In the recent Confidential enquiries [4], the rate of maternal mortality was double amongst older women age >35 compared to <35 (14/100,000 vs. 7/100,000), as well as those living in the most deprived areas. Twenty-eight percent of women who died belong to the most deprived socio-economic settings, with one in five women being in unemployed households (both partner and women). Eighty percent were known to social services. Thirty percent of women did not attend the required antenatal appointments.

In our case, our patients also exhibited a late booking at 34 weeks and had previously concealed prior pregnancy. She failed to attend antenatal appointments and post-natal follow-ups. She arose from a poor socio-economic background with poor social and financial support.

Pulmonary embolism has remained a leading direct cause of maternal death in the UK since 2009 [4]. More than 75% of patients who have pulmonary embolism in pregnancy have identifiable risk factors. In our index case, identified risk included age greater than 35 years, obesity, parity of three and smoking. According to RCOG recommendations of formal VTE

risk assessment, her total VTE score of 4 would require her to have antenatal thrombo-prophylaxis from the first trimester until six weeks postnatally [5]. In women who died during pregnancy or during the puerperium, improvements in care may have made a difference to the 69% of outcomes [5].

Our patient exhibited both a raised BMI and was an ongoing smoker, placing her at high risk with her pregnancy status. Due to non-engagement with the services and late presentation in this case, thromboprophylaxis had not been started till 34 weeks which could easily be "too little!, too late!" - a recurring theme in the MBBRACE report. In the MBBRACE report in Dec 2018, 66% women who died antenatally by embolism were less than 28 weeks gestation.

Postpartum hemorrhage is the second leading direct cause of maternal death in the UK [4]. Polyhydramnios is more common in anencephalic pregnancies. Most anencephalic pregnancies go to full term or about 10% post term [6]. Some of the maternal risks of polyhydramnios include maternal dyspnea, preterm rupture of membranes leading to chorioamnionitis, abnormal fetal presentation and postpartum hemorrhage secondary to uterine atony by hyper distension.

Our index patient was at a higher risk of post-partum hemorrhage due to her antenatal anemia [7], polyhydramnios and high parity.

3.2 Practical, legal and ethical aspects of termination of pregnancy

No treatment is available for anencephaly, and the condition is incompatible with life. Prevention in the future is through high dose folic acid 5 mg OD taken at least three months preconception and up to the end of first trimester [8]. A Cochrane review of five studies involving 7391 pregnancies showed a protective effect of folic acid supplementation in daily doses of 360 micrograms to 4 mg in preventing recurrence of neural tube defects [9]. The results of the comparison of five studies with 6708 births, high quality evidence showed a protective effect of daily folic acid supplementation in preventing NTDs (RR 0.31, 95% CI 0.17 to 0.58) [9]. The result of comparison of four studies involving 1846 births, showed folic acid had a significant protective effect for recurrence (RR 0.34, 95% CI 0.18 to 0.64) [9].

There are many different methods of terminating a pregnancy depending on various factors including medical and surgical termination of pregnancies. In advanced pregnancies, feticide is essential to avoid a life birth and the possible neonatal resuscitation refusal that may follow. Feticide was not agreed here due to lack of engagement.

Practically, feticide is done using local anesthetic under continuous ultrasound guidance; a concentrated solution of potassium chloride is injected through the maternal abdomen and amniotic cavity, directly into fetal heart to achieve fetal asystole. Cardiac activity is observed for at least two minutes to confirm permanent asystole, with a repeat scan done after a few minutes to confirm and this takes about 15 minutes. Rh negative patients will require Anti-D prophylaxis with a Kleihaur test within the next 72 hours as per routine practice [10]. The procedure is exclusively performed in the Fetal Medicine units. The process is usually followed with Mifepristone / Misoprostol to initiate uterine contractions to expel the products of conception as per RCOG guidelines.

The act of feticide is only recommended when offering termination of pregnancy after 21+6 weeks gestation, as it is deemed unnecessary prior to this due to the unlikely probability of a live birth [11]. If a baby with major congenital abnormalities of greater than 21+6 weeks is born without feticide, and exhibits signs of life following termination, then the child may potentially end up receiving neonatal support and intensive care if it is in the best interest of the child [11]. This risk should clearly be explained to mothers who might be against the idea of feticide.

When a pregnancy incompatible with life is diagnosed at birth, it is usual practice to offer termination of pregnancy. Current practice in the UK is governed by the Abortion Act of 1967 [12]. Section 1(d) of the Act states that termination of pregnancy by two medical practitioners is not a chargable offence if of the opinion in good faith that "there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped" [12]. Only 2% of total terminations performed in the UK are for major fetal abnormalities[2]. The rest of the provisions for legal abortion are also contained in the act and include amongst others:

- Termination necessary to necessary to protect mental and physical health of the pregnant woman, Section 1(b)
- Continuance of pregnancy would pose greater risk to life of the mother than if pregnancy were to be continued Section 1(c)

There is no gestational age limit for approving this type of termination of pregnancy, unlike terminations for other reasons which have a cut off limit of 23 weeks and 6 days [12]. Interestingly "substantial risk" or "serious handicap" does not have any strict legal definitions and is prone to subjective interpretation [11]. Additionally, modern medicine has made it such that termination is in the vast majority of cases safer than continuing with the pregnancy, thereby fulfilling the above criterion (Section 1(c)).

Ethical discussion ranges from the mother's right to exercise control over her own body, to the sanctity of life, especially in vulnerable individuals. Here however the focus is on the general ethical conundrums in aborting or continuing with the pregnancy of a fetus that is confirmed not to be compatible with life.

As well as reducing the risks to the mother, feticide is performed to spare the baby the stresses of labor and ensures that the mother and healthcare professionals are not in the situation of making the difficult decisions of resuscitation and neonatal intensive care support [11].

If the child is unlikely to survive, neonatal resuscitation is seen as simply postponing the inevitable demise as well as placing the baby under undue distress; comparable to adults with non-curable terminal illness with significant debilitating symptoms. To make such a decision is understandably cruel and difficult for the mother who has to choose between actively causing the death of the fetus who is alive, or facilitating a delivery that will result in complex post-natal intervention and fetal stress. There is no right or wrong answer, however choosing feticide may often streamline the post-natal period for both the mother and healthcare professionals. There is a perceived mercy and kindness with feticide to the woman, as well as towards the baby unlikely to survive. This is compounded by the idea that extremely preterm infants may feel pain from 23-26 weeks gestation [10].

3.3 Offering Compulsory Termination of Pregnancy

Termination can place live in danger, but this risk increases as the pregnancy continues to term. Risks include: VTE, Malpresentation, operative intervention with associated risks.

The question then arises for a treating obstetrician providing care for this pregnant woman as to whether to actively

encourage her to terminate her non-viable pregnancy in the balance of the high risks with minimal benefits. Why should she be supported to put her life at risk for no fruitful outcome? Who would be accountable if the women died via embolism? Is it ethical to allow pregnancy to progress knowing that it can harm her?

"*Primum non nocere*" – "First do no harm" is the age-old ethical principle governing the practice of medicine. In this case, the fetus is non-viable and the physician is unable to help it, however s/he can intervene and prevent the mother having complications because of pregnancy. Does this mean that doing no harm requires actively assisting in termination?

GMC good medical practice dictates that to "make the care of your patient your first concern" - and "Take prompt action if you think that patient safety, dignity or comfort is being compromised"[13]. Hence the Obstetrician caring for this mother faces the dilemma of supporting her through the pregnancy as per her wishes in spite of the risks highlighted earlier. At the same time, the paternalistic patronizing approach towards patient care is heavily discouraged and counterproductive, with greater emphasis on partnerships with patients and coming to a joint informed decision [13].

3.4 Legal Rights of the mother and the fetus

The cohort of women with multiple risk factors as per earlier that still continue to become pregnant are posing a great harm for themselves, as per our index case. Should they be offered and encouraged to have sterilization as a means of promoting their health and safety? Is it not an obstetrician's obligation to promote woman's health and wellbeing? Will such measure infringe upon a mother's human rights? What about the human rights of unborn children that will eventually end up in social care?

As per European and UK law, the fetus, whilst in utero, is regarded as not being included within Article 2 of the European Convention on Human rights. As such the fetus has no rights to life and the rights of the mother take precedence. Furthermore the mother can refuse to consent for any course of action to save the life of the baby prior to the birth[14]. For instance, intervention can be declined in the instance of fetal bradycardia and impending fetal death or irreversible fetal brain damage. Laboring woman can also refuse to have a caesarean section and/or operative vaginal delivery. This situation forms the basis of legal claims in instances of cerebral palsy resulting from birth injury, allowed up to three years after the child reaches adulthood (i.e.: up to the age of 21).

3.5 Organ Donation in Anencephalic babies – Technical & Practical Issues

Organs are often harvested with consent from patients with diagnosed brain deaths or death by circulatory failure. In 2018, a total of 4039 organs were donated by deceased donors and total of 1064 by living donors [15]. A deceased organ donor can donate their kidneys, heart, liver, lungs, pancreas, small bowel, corneas and tissue. A living organ donor can understandably only donate a kidney or part of their liver. At present there are total of 5946 patients awaiting organ transplant in the UK; of this 184 are children below the age of 18 years [15].

For a successful transplantation to occur from an anencephalic newborn, a few criteria must be met. Firstly, the newborn must be born live, so that the organs are in a condition that can be retrievable with minimal ischemic injury [16]. Secondly, as 65% of anencephalic newborns die within the first 24 hours [17], there is a need for pre-arrangement of the retrieval process. This includes either a retrieval team on hand, or arrangements for ventilatory support to extend the newborn's life. NHS Organ Donation and Transplantation (NHS ODT) have advised that heart valves may only be retrieved if the baby weighs more than 2.5kg (>37 weeks gestation). As such, there is usually little opportunity for early delivery for the purposes of organ donation.

Furthermore, for hepatocytes to be donated from a neonatal liver, there should be a planned elective caesarean section, making a vaginal birth not ideal for specific donation options[15]. Heart valve donation is not limited by mode of deliver[15] and is even possible after fetal demise [18].

There are many steps to organ donation, including identification of potential donors, referral to retrieval teams, consenting for donation, the preparation of the retrieval process, and contacting potential recipient centers to accept the organs[19]. Each of these stages adds to delay in the process and minimizes the possibility of a successful donation. Anencephalic newborns however create a unique scenario as their condition is usually diagnosed antenatally in-utero. As such, with the combination of planned Caesarean-section deliveries, the process can be anticipated and arranged beforehand, with a surgical retrieval team available on hand. Ventilating the newborn to prolong the window for retrieval is a technical possibility but brings about many ethical issues as mentioned later. Furthermore, when ventilation is withdrawn, there is no guarantee of rapid demise, with time to asystole being prolonged. Such delays can prolong the anxiety and trauma for mothers. It is evident that the requisites for successful organ donation cannot be guaranteed in all the cases, especially if the mother has to endure a long labor which an anencephalic baby cannot withstand, or if the delivery cannot be postponed due to maternal reasons (resulting in a smaller than expected baby with organs not viable for donation).

These should be discussed with the mother in detail and with the support of the organ donation specialist nurse.

If donation is abandoned, emphasis becomes shifted to the palliative support of the neonate. RCPCH has published extensive guidance on palliative care support on neonatal units, with inclusion of anencephalic newborns. Emphasis is placed upon robust pain relief and symptom control, including the provision of feeding support for the goal of comfort and not nutrition. Nutrition can be provided either orally or artificially, depending on whichever reduces distress from hunger/thirst adequately. Invasive ventilation is generally discouraged as it is regarded as life-sustaining treatment. Opiate analgesia was seen as more effective at alleviating hypoxic distress compared to supplemental invasive oxygen. There is particular emphasis on adequate emotional and psychological support, with religious/pastoral support to be offered as necessary [20].

3.6 Organ Donation in Anencephalic babies - Legal Issues

Death is defined as the irreversible loss of the capacity for consciousness and irreversible loss of the capacity to breathe [16]. Hence death is diagnosed by either circulatory (Donation after circulatory death [DCD]) or neurological failure (Donation after Brain Death [DBD]). The donation of organs from anencephalic baby is by DCD, confirmed by circulatory criteria. DBD can't be used as some degree of brain stem function (midbrain & pons) is often be present, allowing for some degree of spontaneous ventilation, and standard tests cannot be meaningfully interpreted.

In the UK, donating organs from the anencephalic babies by the consent of the mother is legal[16]. The death in this case is assessed by the circulatory criteria and donation is under the

category of Donation after Circulatory Death (DCD)[16]. This can be further supported if the mother expresses a wish for this without being actively prompted.

Regarding withdrawal of intubation and supportive measures mentioned above to prolong neonatal survival for organ retrieval, the Royal College of Paediatrics and Child Health (RCPCH) have published guidance reiterating circumstances in which treatment can be ethically and legally withdrawn if not in the child's best interests [21]. This includes the withdrawal of treatment in cases where treatment would not be medically appropriate and would not be able to "achieve its intended purpose of preserving life or restoring health". Additionally, treatment can be withdrawn if not in the best interests of the child. Both of these recommendations are fulfilled in the case on anencephaly.

Importantly this differs from Assisted Suicide (illegal under Suicide Act 1961) or Euthanasia, which can be charged as manslaughter or murder. Both assisted suicide and euthanasia intend to actively hasten death, as opposed to supporting the natural course of one's demise [22].

3.7 Organ Donation in Anencephalic babies - Ethical Issues

Transplanting from an encephalic baby has opened up a plethora of ethical and legal issues for physicians. Kantian ethics places moral law as the upmost imperative, irrespective of the consequences. As such, the act of hastening the demise of an individual for any reason could be seen as troublesome. In contrast the utilitarian approach should see no issues with such a situation as the idea of allowing the already inevitable demise of one baby would be seen as a moral imperative in order to save the life of potentially four to five others.

It is not incomprehensible that for a proportion of women with anencephalic pregnancies, organ donation is often seen as a consolation. They embrace the opportunity to save a life and prolong the legacy of the unborn baby, however this is not without conflicts.

Regarding the process of retrieval, we previously mentioned the possibility of having to physiologically support the newborn until such a time that retrieval is possible. Such a decision may include intubation, venepuncture, vascular access and other potentially distressing interventions. To what degree is the distress of the newborn in the best interest of the anencephalic baby. Much of this can be avoided with sedation and analgesia, yet the balance of risks and benefits must be weighed up.

As anencephaly is usually diagnosed during pregnancy, the quandary then arises for the mother if she is to carry the fetus to term. Carrying on with the pregnancy will undoubtedly prolong her grief as she is continually reminded of the impending demise of the baby ahead. To then proceed with the delivery of a larger fetus with increased risk of complications endangers the mother more than necessary. Regarding the anencephalic fetus, to what extend is continuing the pregnancy in the interests of the fetus. It should not be regarded a mere container of organs being incubated, but rather be treated as an individual with dignity. As such, any intervention taken should look to minimize any perceived pain for the baby whilst offering any interventions. Definitive advice can be obtained from the UK Donation Ethics Committee, especially in cases of uncertainty [16].

4. Conclusion

Medical and ethical dilemmas are an integral part of obstetric practice and they are only increasing with advancing medical care access to radiological investigations, cutting edge medical technologies and the widening use of organs to save another life. This case gave us an opportunity to revisit current UK practice and reflect on management.

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