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Antenatal and intrapartum care of pregnancy complicated by lethal fetal anomaly

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Key content

- Congenital anomalies are the number one cause of infant mortality in the developed world. Antenatal diagnosis of lethal fetal abnormality is likely to have a profound psychological impact.
- The multidisciplinary team should aim to meet the medical, emotional and spiritual needs of the family, through appropriate referral in the latter aspect.

Learning objectives

- To consider the psychological impact of an antenatal diagnosis of lethal fetal abnormality.
- To review the principles of informing parents about the diagnosis.

- To provide a framework for the management of a pregnancy involving a lethal fetal anomaly.
- To increase the awareness of the emotional and spiritual needs of the family.

Ethical issues

- The dilemma of psychological impact of carrying a pregnancy with a lethal fetal anomaly for a mother and a family.
- The issues around care including feeding the liveborn baby with an anomaly.

Keywords: anomaly / lethal / multidisciplinary care / perinatal hospice / individualised care

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Introduction

Congenital anomalies are the number one cause of infant mortality in the developed world, accounting for 20% of infant deaths.¹ Lethal fetal anomalies encompass a wide range of conditions, which, mainly as a result of advances in ultrasonography, are now routinely detected in the antenatal period. These conditions include brain anomalies such as anencephaly, skeletal anomalies, genetic disorders including triploidy and trisomies 13, 15 and 18, and bilateral renal tract anomalies such as renal agenesis, multicystic or dysplastic kidneys and polycystic kidney disease.

The diagnosis of lethal fetal anomaly poses significant challenges for obstetricians, paediatricians, and the bereavement and loss team, as parents struggle to come to terms with the reality of the diagnosis. Currently, there is a paucity of literature addressing the management of these pregnancies, and clinicians in training realise little experience

in this area. A handful of authors have studied outcomes in pregnancies complicated by lethal fetal anomaly,^{2,3} while even fewer have proposed a strategy on how to care best for these babies and their parents.¹ The first published report on the maternal grief reaction in stillbirth was published in 1968 and the first report on parental grief following neonatal death was published in 1970.^{4,5} Before these publications, the implications of perinatal deaths were often ignored, with clinicians underestimating the significant impact on parental morbidity in terms of post-traumatic stress disorder, relationship difficulties, anxiety, depression and suicidal ideation.^{6,7} There is now also much evidence on the concomitant morbidity in both the existing children and subsequent siblings in terms of attachment disorders, behavioural difficulties and depression.^{8,9}

In a study based in the United Kingdom (UK) in 2007 Breeze et al. reported that only 40% of women faced with a diagnosis of lethal fetal anomaly chose to continue with their

pregnancies,² with the other 60% electively terminating the pregnancy. The authors, who are based at a large tertiary-referral university teaching hospital in the Republic of Ireland (ROI), report their experience. Termination of pregnancy is not legalised in Ireland, which contributes to clinicians having more experience in managing ongoing pregnancies affected by lethal anomalies. The legal right to life of the fetus is enshrined within the Irish Constitution, with an equal right to life being accorded to both fetus and mother. There is no universal policy of prenatal screening for fetal anomaly and while screening for aneuploidy is privately available, a minority of pregnant women access this service. While parents can travel abroad in order to obtain a termination of pregnancy the dominant parental choice is to continue with these pregnancies.¹⁰ The experience gained by clinicians in the ROI, provides learning for other clinicians and teams where continuation of the pregnancy is less common.

The antepartum and intrapartum care of pregnancies complicated by lethal fetal anomaly is unique and requires an individualised management plan to meet the significant obstetric and psychosocial needs. A multidisciplinary team approach is the ideal, involving obstetricians, neonatologists, sonographers, bereavement and loss midwives, social support services and pastoral care support. The parents need to be assisted and supported from the time of initial diagnosis through stages of shock, denial, anger and grief to a level of adaptation whereby they can begin to cope with their loss and even engage with the positive aspects of their experience.

Significant time and emotional support is needed around the time of antenatal diagnosis and in preparing the parents for delivery and the postnatal period. Frank, open and informed discussions need to be held with the parents regarding the difficulty predicting the time of fetal or neonatal death, the complications that may arise in the antenatal period, as well as timing of delivery and management of labour.

Perinatal hospice and multidisciplinary approach

The most striking difference between 'normal' pregnancies and pregnancies complicated by lethal fetal anomaly is the profound psychological effect these pregnancies can leave on affected families. The cornerstone of caring for these families should not just involve monitoring for the physical side effects of pregnancy but also focus on psychological needs. In 2001, Hoeldtke et al.¹¹ introduced the concept of perinatal hospice. In this paper the authors proposed that families who were carrying pregnancies complicated by lethal fetal anomalies be likened to those of a terminally ill child. They proposed extending the traditional hospice model to care for families anticipating a perinatal loss.

Core to this approach is the multidisciplinary team who together aim to meet the medical, emotional and spiritual needs of the family, and who continue to liaise with them after the death of the baby.¹² Bereavement and loss midwives develop an ongoing relationship providing support throughout pregnancy, delivery, the postnatal period and where possible, into a subsequent pregnancy. The primary obstetrician leads and directs the care providing a sense of continuity and security. Input from neonatologists prioritises the identity of the fetus as an individual. Ethnicity, culture and religious beliefs also have a profound effect on the grief reaction to perinatal loss. Lathrop et al.¹³ describe recent developments in bereavement theory focusing particularly on a way to restore the parents' sense of meaning and self-purpose in life. In considering this process it is clear that chaplaincy or spiritual support has a valuable role to play in addition to traditional religious ministry. It is vital that parents take control and exercise as much choice as possible in areas such as birth planning, creating memories and burial arrangements.

Antenatal management

Diagnosis and breaking news

Informing parents of the diagnosis of lethal fetal anomaly is perhaps the most difficult interaction in the early relationship between the clinician and parents. If the diagnosis is suspected but not confirmed it is best to be honest and advise the parents there is a concern and you will organise a specialist opinion as soon as possible. To avoid the woman returning alone for the scan and diagnosis, she should be advised to bring her partner or support person. Similarly, the diagnosis may not be confirmed until after results are available from invasive testing. Once confirmed, parents need to hear the information regarding the pregnancy in simple, non-medical language and usually, more than once. The information is delivered in an appropriately private space with both partners present if possible. The clinician needs to take cues from the parents and proceed gently, checking on existing knowledge and concerns. Some parents will require a lot of information while more than the minimum facts would overwhelm others. Parents value both visual images and written information to enhance their understanding at this time.¹⁴ The introduction of other team members (specialist midwifery, counselling, pastoral care) at this stage may be helpful in initiating a relationship that will provide ongoing support. Communication with the GP and community midwife is very important as they will be involved with the care and be a resource for the parents. Regular updates to these healthcare professionals, ensures appropriate care responses to new symptoms.

Parent support networks and/or advocacy groups (such as UK Stillbirth and Neonatal Death or Antenatal Results and

Choices) may be of benefit depending on the parent's individual needs. Providing written information may also be appropriate in aiding parents with their decision of whether to terminate the pregnancy or continue on to term. It is appropriate, even in countries where termination is not readily available, that both options be discussed and presented to the parents using a non-biased and non-judgmental approach. It is recognised that termination of pregnancy at this stage is associated with significant parental grief reactions¹⁵ and support following termination should be continued for as long as necessary.

Antenatal care

If the parents choose continuation of pregnancy then a well-documented plan of care for the pregnancy should be agreed on. This should be an individualised plan based on the diagnosis, certainty of the diagnosis and likely prognosis. Consideration should be given to the fact that not all patients will want a comprehensive holistic package and an appropriate plan with selected components should be developed to meet their needs also.

The importance and appreciation of continuity of care is stressed. It is important to manage this period as sensitively as possible, as it may be the only opportunity that the parents will have to bond with the baby and create memories while he or she is still living. It may also be worthwhile for example if the parents wish to establish the gender or use the baby's given name. Flexibility when seeing these families for antenatal care is hugely important. Some women will request to be seen outside of the usual antenatal clinic times, when there are fewer pregnant women in the clinical areas, and this request should be accommodated wherever possible. Women will often need to be seen for more frequent visits than the usual antenatal care schedule. This is both for ongoing reassurance that the fetus is alive, and for early diagnosis of any developing pregnancy complications.

A meeting with a senior neonatologist is important in the antenatal care schedule. It is key that the parents are fully aware of the supportive nature of care that will be given to the neonate should he/she be born alive and that they understand that resuscitation is not appropriate should the baby be born alive. Analgesia requirements, neonatal unit facilities and visits prior to delivery should also be discussed. The outcome of this meeting needs to be clearly documented in the antenatal notes and an outline of the care to be given to the neonate recorded as part of the intrapartum care plan. Ideally, both parents should be involved at this meeting, as this helps to lessen parental anxiety in the postnatal period.

Pregnancy complications

Monitoring for the appearance of pregnancy complications is another vital facet in the management of these pregnancies. Although repeated ultrasonography may impact on the

emotional wellbeing of some mothers, for others it may be necessary to diagnose complications in a timely manner. As well as the more common pregnancy complications (pre-eclampsia, gestational diabetes, maternal anaemia), certain anomalies are associated with increased rates of specific complications. In their report on anencephaly, Obeidi et al.³ found that 27% of pregnancies developed polyhydramnios. Polyhydramnios has also been associated with the lethal skeletal dysplasias.¹⁶ Certain trisomies (such as trisomy 13) and triploidy can lead to hydrops and there is a specific association of fetal hydrops with polyhydramnios¹⁷ and severe early onset maternal pre-eclampsia. The Ballantyne Syndrome, also known as the maternal hydrops syndrome or mirror syndrome, can affect women pregnant with a hydropic fetus. This syndrome is characterised by maternal 'mirroring' of the hydropic state – hypertension, severe oedema, and can progress to maternal eclampsia. The exact pathophysiological basis for this disorder is unknown but the maternal condition dramatically improves upon delivery.

Polyhydramnios can cause significant problems both antenatally and during labour and induction. Maternal discomfort can be severe with tense polyhydramnios, and this may itself be an indication for amnioreduction. Polyhydramnios also increases the risk of placental abruption, unstable fetal lie, ineffective uterine activity during labour and postpartum haemorrhage. Amnioreduction may be needed several times during the pregnancy and although it relieves maternal discomfort, is not without complications. It has been associated with a 1.2–3%^{18,19} procedure-related complication rate, which can include prolonged pre-labour rupture of the membranes (PPROM), chorioamnionitis, placental abruption and maternal visceral injury. While providing comfort, amnioreduction may delay labour onset and thus not be in the best interest of the patient.

The substantial risk of intrauterine fetal death (IUFD) is another complication that needs to be discussed with parents. This risk has been reported at 15–35% in the literature, depending on the type of anomaly.^{3,20} Obeidi et al. reported a 23% IUFD rate in their anencephaly population³ and for trisomy 21 it is estimated that 40% of affected fetuses die in utero.²¹

Intrapartum care

How and when to deliver, both ongoing pregnancies with lethal anomalies and those already complicated by IUFD needs to be addressed in detail with the parents. Ideally, vaginal delivery with minimal intervention should be encouraged. If induction of labour is necessary (IUFD, no spontaneous onset), the majority of clinical protocols now rely on initial mifepristone and later misoprostol. This is primarily based on a study by Wagarachachi et al.,²¹

published in 2002. This study found that the combined use of mifepristone and misoprostol was not only safe but also had an average time to delivery interval less than any of the other induction regimens in use at the time of publication.

There is little consensus on the appropriate timing of induction of labour and decisions have to be based on the specific needs of each pregnancy. Each case should be examined individually and maternal discomfort and requests, parity and suitability for induction, and presence or absence of pregnancy complications should all be taken into account. Local legal and ethical practice need also to be given due consideration. Early induction of labour where the fetus has a lethal anomaly is not an option in the UK; it may in some jurisdictions be considered termination of pregnancy and not be legally possible. If early induction is planned then the woman should be fully aware of the potential for failure,³ which may necessitate repeat attempts at induction at a later date, or even caesarean section (CS).

Consideration also needs to be given to the location of labour. Ideally women should be given the opportunity to labour in private, in a single room. A senior midwife who has had experience in dealing with pregnancies complicated by lethal fetal anomaly should be present. This helps to reduce both parental and staff stress and anxiety at this crucial time. All usual forms of analgesia should be available – entonox, pethidine, diamorphine, epidural analgesia. Also if polyhydramnios has been an issue or maternal pre-eclampsia is present it may be necessary to site an intravenous cannula, check haematology and biochemistry indices and have blood cross-matched, in anticipation of the increased risk of postpartum haemorrhage.

Continuous monitoring of the fetal heart is not routinely advocated during labour and women should be appropriately counselled in this regard. There should be a detailed discussion including an agreed approach with the parents and neonatologists on the issue of monitoring. This should be clearly documented and provision made for care around delivery if the on-call team are uncomfortable with the approach. This is mainly to avoid emergency CS for an abnormal fetal heart rate during labour. CS is associated with significant maternal complications including venous thromboembolism, postoperative infection and potential damage to the maternal structures and vessels. It also has a significant psychological impact on the mother given the persistence of a CS scar and the implications for risk of uterine rupture in a subsequent pregnancy. Nevertheless, some women will request the option of an emergency caesarean section in labour; although not the preferred option, it may be appropriate after detailed discussion. It is usual practice to auscultate the fetal heart intermittently, for parental information, and in the second stage of labour, so that the parents as well as neonatologists can be updated on the condition of the fetus immediately prior to delivery.

In one case series where four labours associated with lethal fetal anomalies were managed with continuous fetal heart rate auscultation, the authors reported that mothers found significant comfort in the live births and the time spent with the neonate before death. In these cases, the maternal desire to avoid an intrapartum stillbirth was deemed so strong that it 'would result in significant psychological impairment if it occurred.'²² There has also been another case report where a CS for an abnormal fetal heart trace in a baby with lethal fetal anomaly was carried out.² Again this was at maternal request, and was determined by clinicians involved to have benefited the mother psychologically.

There are certain scenarios, where elective CS delivery is clearly the best and safest method of delivery. Women with three previous CS scars have a high chance of uterine scar rupture and unless very premature spontaneous labour occurs these women are best delivered by CS. Some units do undertake induction of labour in this clinical situation, under strict protocol and commonly using mechanical devices (balloon catheter) for cervical dilatation. Women with two or fewer uncomplicated caesarean sections may be allowed attempt a vaginal birth after caesarean (VBAC), assuming the risk of scar rupture, and increased risk of blood transfusion is addressed.²³ Other indications for elective CS include spontaneous labour with a transverse lie, or if there is a high suspicion of birth dystocia, for example pregnancies with severe fetal hydrops. Shoulder dystocia is a significant risk factor with macrosomic or hydropic babies and can result in both physical and psychological maternal trauma. Some parents may request elective CS in the absence of any maternal medical condition. This request should be treated the same as a request for CS in a routine pregnancy. Following appropriate counselling, the lead obstetrician and the mother may decide that elective CS is in the maternal best interest and proceed to same, however, wherever possible, vaginal delivery should be advocated and CS limited to appropriate indications.

Certain fetal anomalies increase the time spent in labour and increase the risk of dystocia. Anencephaly can be associated with inadequate cervical dilation or inadequate descent of the presenting part. Because of this, a longer passive second stage of labour has been advocated. This aims to ensure good descent of the fetal head and prevent CS at full dilatation. The use of Neville-Barnes forceps has also been associated with anencephalic vaginal deliveries. Destructive procedures such as craniotomy, decapitation, and cleidectomy were common in the 19th century to enable vaginal delivery of a dead baby that had become obstructed in the pelvis during labour.²³ These procedures have almost completely disappeared from western medicine although are still carried out in the developing world. Fluid drainage procedures should be considered where fluid filled cavities are a cause for obstruction or dystocia. A senior obstetrician

should be either available or in attendance at delivery. Active management of the third stage of labour is advised, using oxytocics to ensure adequate uterine tone.

The experience of delivery when the parents see their baby for the first time will always be remembered. They may have lost their baby but they have still become parents and this needs to be acknowledged. The first half hour while the baby is still soft and warm is a vital time and can never be recaptured.²⁵ The parents may need to be supported in holding and caring for their baby if they wish and helped with creating memories such as time alone together. While it is common practice to encourage the parents and siblings to hold the baby; it is not evidence based and in fact may have adverse effects including post-traumatic stress disorder.²⁶

Neonatal care

If the neonate is born alive then senior neonatal input is necessary to avoid inappropriate attempts at resuscitation from more inexperienced members of the neonatal team. The presence of an agreed and documented plan of care is vital. If the baby is born alive then comfort care should be offered. The neonate should be kept warm and comfortable and if needed analgesia may be offered. Human touch is important both for soothing the infant and for creating a bond between baby and parents. Not all parents will wish for this approach and in certain conditions it may be reasonable for the neonate to be admitted to the neonatal unit for further care. Other family members such as siblings should be encouraged to be involved.

Whether to feed the baby can be of significant concern to the parents. If the baby suckles then feeding can be encouraged as this can be a source of comfort to the neonate. If the baby dies in hospital, where possible this should happen in a private setting, making provision for all family members to attend.

Some babies are born with anomalies that are not immediately fatal and in these cases provision can be made to allow the parents to bring the baby home. This aids with bonding, can profoundly help with the parental grief reaction and can allow older siblings time to adjust to the perinatal death. Home care can be utilised in liaison with the hospice team or with the neonatal team, depending on local protocols. A visit from the bereavement and loss team, who have been liaising with the family, may also be helpful. Taking the baby home may not be an option for parents and hospice care may be provided in the neonatal unit or local hospice if suitable for babies.

Postnatal parental follow-up

Postnatal follow-up, ideally by the same team who looked after the mother during pregnancy is experienced by parents

as a vital milestone in their grieving process. Receiving postmortem reports and other test results may also allow some sense of closure. For most parents it will also be an opportunity to begin to invest in the future and raise the subject of subsequent pregnancies. They will need to be reassured that the team are aware that any subsequent pregnancy will be very stressful and that a plan for additional support is available. This is also an opportunity to address significant physical and emotional issues, which presented in the postnatal period that may be traumatic to both the mother and her family.

Routine postnatal care in relation to observing lochia, ensuring adequate healing of perineal tears or episiotomies needs to be continued. Lactation can be a sensitive issue for mothers in the postnatal period. It has been shown that cessation of lactation can cause moderate to severe breast engorgement in 66% of women when no treatment is given. This can progress to mastitis in a minority. There is no consensus on whether agents to suppress lactation should be used in this setting. One of the more common drugs used is the dopamine receptor agonist Cabergoline; while unlicensed it is found effective in clinical practice and could be used if there are no contraindications (such as, hypersensitivity, CYP450 drug interaction potential, liver abnormalities).

If the diagnosis of fetal anomaly was suspected but not confirmed antenatally then a postmortem examination should be offered and encouraged. This is both important in helping the family come to terms with the loss and in helping to estimate a recurrence risk for subsequent pregnancies. If a postmortem is declined then a placental or cord biopsy should be sent for cytogenetic analysis and DNA storage (more and more conditions are amenable to genetic diagnosis) and consideration should be given to further investigations, including X-rays, computerised tomography or magnetic resonance imaging, and geneticist review according to local protocols.

Finally, continued liaison between the family and the bereavement and loss services is encouraged and a postnatal follow-up appointment with clinicians to discuss events surrounding the death of the baby should be arranged when the parents are ready. Subsequent pregnancies may need to be managed by a fetal medicine specialist with anomaly ultrasound and/or invasive prenatal diagnostic techniques. It may also be necessary to refer the family to a clinical geneticist for genetic counselling and/or testing. As subsequent pregnancies are associated with significant depression and anxiety,⁶ multidisciplinary support should be continued.

Staff debriefing

It is important to note that often during the process of caring for parents who have experienced a lethal fetal anomaly

resulting in a stillbirth or neonatal death, or indeed any pregnancy loss, staff members can also be affected. This can be hugely traumatic for all staff members involved. Given the lack of adequate training in this field of obstetrics and midwifery, particularly if it is their first time involved in the management of these pregnancies, junior staff members are particularly at risk. All units involved in delivering these babies should have adequate provisions in place for debriefing staff not just following stillbirth but all adverse pregnancy outcomes.

Conclusion

In summary, the diagnosis of a lethal fetal anomaly is a difficult time for both parents and clinicians. Options, including termination of pregnancy and continuation of the pregnancy with palliative care of the infant, should be discussed in a non-judgmental manner and parents supported through the necessary decision-making process. A multidisciplinary approach with continuity of care is essential in helping these families understand and adjust to the diagnosis, and is also necessary to ensure quality of care through pregnancy, labour and delivery. The emotional and spiritual needs of the family are just as important as the physical management of these pregnancies. There is a paucity of published literature to guide clinicians in the management of these difficult and sometimes complex pregnancies. This review aims to provide a framework for the management of pregnancies complicated by lethal fetal anomaly.

Disclosure of interests

None declared.

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