CHAPTER 3

THE PERINATAL AUTOPSY:
PERTINENT ISSUES IN
MULTICULTURAL WESTERN EUROPE

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Abstract

Western Europe is in a demographic transition with increasing multicultural societies. Health professionals have to understand the background, religious and cultural aspects of parents to counsel them regarding an autopsy in the event of a perinatal loss. Autopsy rates have declined over the past decades, the major limiting factor being the granting of permission for an autopsy, possibly because of adverse publicity or reluctance of doctors to obtain consent. Autopsy has proved its value in revealing unsuspected findings. The public can be convinced of this utility by means of good information notwithstanding their religious or cultural background.
Introduction
Western Europe is in a demographic transition with migration and reproductive health choices influencing its population make up. Internal European migration and, particularly, an external migration into Europe from the Muslim world and from Asia and Africa have brought a multicultural diversity. Reproductive health and lifestyle choices have generally resulted in small family size in Europe in recent decades. Urbanisation has resulted in fracturing of the traditional nuclear family support and has contributed to the trend to smaller families. This demographic transition has meant that when there is a perinatal loss, health professionals have to understand the changed cultural aspects to counsel parents regarding an autopsy. Furthermore, health professionals have to counsel the parents against a background of recent adverse publicity about the autopsy that has also influenced the public perception of its usefulness.

One of the limiting factors for the autopsy is the granting of permission by a doctor who is insecure about the inquiries and procedures of the autopsy in relation to parental background or religion and who is not always convinced of its value.\textsuperscript{1,2} The purpose of this paper is to provide all necessary information for health professionals who counsel parents for a perinatal autopsy. In the following sections, we will discuss the reasons for declining autopsy rates, the quality of autopsies, the role of autopsy in the subgroups of perinatal mortality, the procedures of autopsy and its alternatives, the issue of organ retention and the religious and cultural proscriptions to the autopsy.

Perinatal autopsy rates and the quality of the autopsy
Perinatal autopsy rates were stable in comparison to the (low) adult autopsy rate until the 1990s.\textsuperscript{3} However, a drop in the perinatal autopsy rate was found over the past decades.\textsuperscript{4} The major rate-limiting factor is the granting of permission from the parents to a postmortem examination.\textsuperscript{5,6} Adverse publicity could have contributed to this decrease. It can also be due to the reluctance of some doctors to ask permission for the autopsy because of personal reasons or due to the assumption of clinicians that current techniques can replace the autopsy.\textsuperscript{1} The autopsy rates for perinatal deaths vary between 16 and 100\% (mean 38\%), for stillbirths between 5 and 100\%, for neonatal deaths between 33 and 100\% and for terminations of pregnancy between 79 and 100\%.\textsuperscript{7}

Another limiting factor for granting permission to the autopsy may be the finding that a high percentage of the autopsies in the perinatal period did not reach the arbitrary minimum quality.\textsuperscript{8,9} Poorly performed autopsies or substandard autopsy reports are likely to dissuade clinicians from vigorously requesting permission. Despite the fact
that the perinatal autopsy is important for many reasons, approximately 25-50% of the autopsy reports fail to reach the minimum standard.\textsuperscript{8,10-12} It has been suggested that the perinatal autopsy should be performed by a trained perinatal pathologist or should be referred to a regional perinatal/paediatric pathology Center.\textsuperscript{8,12,13} Following publication of an updated \textit{Guidelines for Postmortem Reports}, Vujanic et al. evaluated the implementation of these recommendations and guidelines and found that autopsies then failed to reach the minimum quality in 7%.\textsuperscript{13}

**Why perform a perinatal autopsy?**

The primary reason for performing a perinatal autopsy is to ascertain the cause of death or, in the case of (therapeutic) terminations, to confirm the indications for the termination.\textsuperscript{14} A review of contemporary studies on the value of perinatal autopsy showed that the autopsy could reveal a previously undiscovered diagnosis, a change in the diagnosis or additional information in 22-76% of cases.\textsuperscript{7} The cause of death is important for counseling the parents and family about recurrence risks in future pregnancies and to allay any fears, guilt or doubts that the family may have.\textsuperscript{7,14-17}

Secondarily, the autopsy aids the audit of perinatal deaths. It may uncover causes of death or may suggest substandard care. The autopsy also provides information for audit of medical treatment.\textsuperscript{6,14,18} Another reason to perform autopsies, and one which transcends religious or cultural boundaries, is the role of the perinatal autopsy in research and education. However, unless these benefits are explained properly, compliance with legal and bureaucratic consent forms may deter parents from consenting to the use of the tissue from the autopsy for research or education purposes.\textsuperscript{6}

**The use of autopsy in different subgroups of perinatal mortality**

Different definitions for subgroups of perinatal mortality have been used over time and between countries.\textsuperscript{19,20} The autopsy has proved to be useful in these separate groups. Generally, perinatal losses can be divided in three subgroups.

The first group consists of (therapeutic) terminations. This group would comprise mainly fetuses terminated for anomalies, but may also comprise terminations for maternal reasons in case of illness or for psychosocial reasons. Antenatal ultrasound diagnoses of anomalies can be evaluated by performing an autopsy. In confirming the anomalies, they reassure parents that their, often difficult, choice of terminating the pregnancy was not inappropriate. The autopsy serves in clinical audit, especially in the field of antenatal diagnosis for fetal malformations. When pregnancies are terminated
for maternal reasons, important pathophysiological mechanisms can be revealed, as demonstrated, for example, by a study on isotretinoin (Roaccutane) embryopathy. The second group consists of intrauterine fetal deaths. Autopsies may not always demonstrate an anatomic demonstrable cause of death, but in combination with clinical history and additional laboratory investigations, associated factors may often be revealed. For example, extensive avascular placental villi may bring about investigations of parental thrombophilias and suggest a likely cause of placental failure.

The third group comprises neonatal deaths. Autopsies in this group of perinatal losses have declined compared with the other two groups but, in recent years, have increased again. Iatrogenic disease, so often a side-effect of neonatal intensive care, can be revealed by the neonatal autopsy but this needs to be distinguished from endogenous disease. For example, tracheomalacia may be a rare acquired complication in the chronically ventilated preterm infant, but it may also be found with other congenital abnormalities, such as the charge association.

How to perform the autopsy, what are the alternatives?

The autopsy in general involves an incision into the body. The autopsy should consist of a thorough macroscopic examination of the body and the internal organs. Tissue samples can be taken for microscopy, but no more tissue than necessary for establishing the diagnosis. In certain cases, additional laboratory tests for virology, bacteriology, cytogenetics and molecular studies are desirable.

Some parents may not give permission for a complete autopsy. They may, however, permit a limited autopsy or needle biopsy where examination is confined to a body cavity or specified organ(s). Frequently this occurs when parents of infants who died of a suspected cardiac cause may allow only the heart or the thoracic cavity organs to be examined. While this is less conclusive than a complete autopsy, at least it allows suspected pathology to be confirmed. Other parents may wish to have an external examination only; the value here may be even more limited, but may be sufficient for certain syndromes and some skeletal dysplasias that may have a characteristic phenotype.

The placenta has been a neglected source of information. The value of placental autopsy is proven and it should therefore thoroughly be investigated as well, particularly where parents do not consent to autopsy of the fetus.

Besides limited autopsy and needle biopsy, imaging techniques form other alternatives for the perinatal autopsy. Radiography showed abnormalities in 30% and is of
vital importance in 0.9% for finding the cause of death in a population-based study. Other non-population-based studies showed radiographic abnormalities in 18.2-68% of cases. It is not recommended to perform radiography as routine examination in non-deformed perinatal deaths, but it can serve as an alternative in cases where the parents do not consent to an autopsy. The autopsies have been useful in the audit for alternatives to the autopsy itself; for example, magnetic imaging studies have shown a good complement to the autopsy for cranial anomalies and central nervous system anomalies but less so for other organ systems.

**Tissue and organ retention**

The "organ retention" controversy in the wake of tissue retained following paediatric autopsy in United Kingdom has had a profound effect on the granting of consent for autopsy. Parents are likely to ask and wish to know their choices with regard to this topic and may find it useful to discuss this directly with the pathologist. Practices may differ between institutions but, in general, portions of tissue are taken to be fixed before trimming for histopathological processing.

A contentious issue arises with examination of the brain. Ideally, brains need to be fixed for 3-4 weeks before being sliced and sampled, especially fetal and infant brains which are soft. Furthermore, they should be retained until microscopic examination as further sampling may be required; this whole process may take up to 3 months. Alternatives include fixing the brain in high strength formalin for about 1 week or, for smaller brains, in a modified Bouin's solution for 1-2 days. Lungs may be perfused-fixed for morphometric analysis, but this inflating-perfusion could be accomplished in about 1 h. Generally, other organs do not need to be retained for diagnostic purposes.

There is an argument that the slides, tissue blocks from which the histological slides were cut and any residual tissues from the trimmings should be retained as they are of potential value to the families as well as for research. Retention of whole organs or of additional tissue for educational or research purposes would rightly warrant discussion with the parents.

**Religion and autopsy in multicultural societies**

In the Netherlands in 2005, approximately 10% of the inhabitants were migrants and the percentage of immigrants is still increasing in the Dutch population. The religious distribution in 2002-2003 in the Netherlands is: Roman Catholic: 31%, protestant: 21%, Islam: 5%, other (Buddhist, Jewish, Hindu): 3% and non-religious: 40%.
Germany, approximately 9% of the inhabitants are migrants. The German religious distribution is: Roman Catholic: 32%, protestants: 32%, Islam: 4%, other (Buddhist, Jewish, Hindu): 2%, non-religious: 30%.\textsuperscript{34} Approximately 7% of the French are migrants. The religious distribution in France is: Roman Catholic: 70-80%, Islam: 5-7%, protestant: 2%, non-religious: 10-20%.\textsuperscript{35} This religious distribution and percentage of migrants will vary in other Western European countries but it serves to illustrate the ethnic and religious diversity now current in Western Europe. This presents a challenge to the perinatal autopsy as “religious objections to the autopsies are as old as the autopsies themselves”.\textsuperscript{36} Earlier we discussed some aspects of religious backgrounds and the autopsy.\textsuperscript{37} There is actually no real proscription against the performance of an autopsy amongst the major religions (Table 1). However, it has been shown that even in communities where there is a perceived religious proscription against autopsies, with appropriate counselling and explanation of the autopsy, it is possible to obtain consent for different clinical situations.\textsuperscript{38}

Devout Hindus always cremate their dead and burial is not allowed by tradition. The ashes are ceremoniously committed to a river or ocean. In Hinduism it is believed that autopsies are disturbing to the still-aware soul which has just separated from the body. Death is not viewed as a finite event and it is therefore important to provide a smooth transition from life to death with altering the body as little as possible. Autopsy should therefore be avoided unless required by law. Similarly, embalming, which replaces the blood with a preservative fluid, is not permitted.\textsuperscript{39}

Buddhists believe that the body, which is a temporary shell for the spirit, should be treated with great respect and care so the mind can concentrate on pursuing enlightenment. They also cremate their dead. According to the Buddhist belief, the body should be left undisturbed until three days after death so that the soul can make its transition. However, an autopsy may be permitted after a religious teacher determines that the soul has left the body.\textsuperscript{40}
## Table 1. Major religions and conditions

<table>
<thead>
<tr>
<th>Religion</th>
<th>Generally</th>
<th>Exceptions</th>
<th>In practice</th>
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<tbody>
<tr>
<td>Hinduism</td>
<td>Cremation and not burial; reincarnation.</td>
<td>Autopsy avoided.</td>
<td>Imaging techniques, macroscopic examination, placenta investigations and maybe needle biopsy.</td>
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<td></td>
<td>Funeral should be celebration and remembrance service.</td>
<td>Autopsy if required by law.</td>
<td></td>
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<tr>
<td>Buddhism</td>
<td>Cremation and not burial. Body should be left undisturbed for three days as the soul makes its transition.</td>
<td>Autopsy permitted when soul pronounced to have left body.</td>
<td>Autopsy after permission of a religious teacher.</td>
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<td>Alternatives if autopsy not permitted</td>
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<tr>
<td>Judaism</td>
<td>Burial as soon as possible.</td>
<td>Autopsy permitted for public or family benefit. Also permitted if three doctors cannot ascertain the cause of death.</td>
<td>Good counseling of benefits of the autopsy. Perform the autopsy as soon as possible after death and make sure the body is as complete as possible after the autopsy.</td>
</tr>
<tr>
<td>Islam</td>
<td>Burial before sunset the next day (within 24 h). Cremation is forbidden.</td>
<td>Autopsy permitted where there is public benefit or required by law.</td>
<td>If required by law and by means of explanation of the (public) benefits. Autopsy during the day/night after death.</td>
</tr>
<tr>
<td>Roman Catholicism</td>
<td>Either burial or cremation preferably burial.</td>
<td>Autopsy (scientific research) permitted with family consent.</td>
<td>Good counseling</td>
</tr>
<tr>
<td>Protestants</td>
<td>Either burial or cremation permitted.</td>
<td>Autopsy permitted with family consent.</td>
<td>Good counseling</td>
</tr>
<tr>
<td>Eastern Church</td>
<td>Burial not cremation</td>
<td>Autopsy permitted (with the utmost respect to the earthly remains of the body.)</td>
<td>Good counseling</td>
</tr>
</tbody>
</table>
Jewish law requires immediate burial, including all internal organs and the blood. It is believed that while the soul or spirit leaves the body upon death, it is nevertheless aware and conscious of its surroundings, until after its return to the earth. Any invasive procedure is seen as a desecration. Burial should be as soon as possible in consecrated ground and any delay is seen as unnecessary painful. Permission for autopsy can be granted when there is a benefit for public health, in case of unclear cause of death, or when a hereditary cause is possible and the family can benefit from this diagnosis. The autopsy should be performed in a body pouch and the samples for pathologic investigations should be as small as possible. All instruments should be buried with the body as well as all the blood stained material and clothing. The sutures should be as tight as possible and leak-proof.

The teaching of Islam does not allow for voluntary autopsy because it is considered a "disfigurement" of a person. In certain subdivisions of the Islam, the body should be buried before sunset on the day of death. The benefits of the autopsy outweigh the drawbacks if public health profits by an autopsy (for example, by unexpected death or contagious disease) and the autopsy can be performed. If the autopsy is required by law (for example, in criminal death), the autopsy can be performed as well.

In the Roman Catholic tradition, there is no law or edict that forbids autopsy. Pope Sixtus IV allowed in the 15th century the dissection of bodies in Bologna and Padua. Pope Pius XII declared in the 20th century that autopsy can be morally permitted as long as the family has consented to the autopsy and the body is treated with respect. It is justified for legal inquests but also for scientific research.

The Eastern Church includes the Orthodox Church, Greek (Orthodox), the Russian Orthodox Church and others. Although the term Greek Orthodox is often used as a name for the Eastern Church, it is used most accurately for the Patriarch of Constantinople, the Church of Greece and related churches that use the Byzantine rite. The Ethiopian, Coptic, Armenian, Syrian and Indian Churches are considered by some in the Eastern Church to be heretical. The Eastern Church believes that an autopsy may lead to finding the cause of death or to enlightenment for physicians in treating similar cases in future and, as such, is not opposed to the autopsy. The religion insists on the utmost respect to the earthly remains of the body. Donation of the entire body for medical research is seen as not in keeping with traditional orthodox practice nor is dismemberment of the body during an autopsy.

In perinatal autopsy, there is the aspect of the religious discussion on investigations of human bodily tissue in relation to therapeutic terminations of pregnancy. Whether
the fetus is considered a human being or not is outside the scope of this review, but it should be treated with the same respect as other human beings.\textsuperscript{42}

\textbf{Conclusions}

The perinatal autopsy is an integral part of perinatal care and management in cases of perinatal mortality. Contemporary studies have demonstrated the value of the perinatal autopsy in revealing unsuspected findings.\textsuperscript{4,7,16,18} Convincing the public of this utility by means of good information has already been demonstrated to reverse falling neonatal autopsy rates.\textsuperscript{22} This process can be further enhanced by understanding possible religious or cultural sensitivities to the autopsy as clinicians and paramedical staff have a role to play in requesting an autopsy or to persuade parents to allow use of tissue for research and educational purposes.\textsuperscript{2}
Reference list

Chapter 3

48. S.A. Geller, To see or not to see: the status of the autopsy at The Mount Sinai Medical Center, Mt Sinai J Med 46 (1979) (1), pp. 33-38.