



## EDITORIAL

# Autopsy in a neonatal intensive care unit: do we still need it in 2022? ☆



Floris Groenendaal <sup>a,\*</sup>, Peter G.J. Nikkels <sup>b</sup>

<sup>a</sup> Department of Neonatology, Wilhelmina Children's Hospital, University Medical Center Utrecht and Utrecht University, Utrecht, the Netherlands

<sup>b</sup> Department of Pathology, Wilhelmina Children's Hospital, University Medical Center Utrecht and Utrecht University, Utrecht, the Netherlands

Received 6 May 2022; accepted 6 May 2022

Available online 22 May 2022

In a recent paper, Penso et al. described postmortem findings of infants who died while being admitted to a large neonatal intensive care unit in the southern part of Brazil.<sup>1</sup>

While rates of autopsy in high-income countries appeared to be declining in particular following the discussion on retained tissue after pediatric autopsy in the United Kingdom,<sup>2</sup> the authors have been able to stabilize and even increase the rate of neonatal autopsies.

In addition, the suggestion that improved non-invasive diagnostics such as postmortem MRI could replace autopsies has influenced the discussion on the value of autopsies. Although the postmortem MRI added valuable information to the autopsy, the current opinion is that it cannot fully replace autopsies.<sup>3</sup> In practice, tissue or organs that have been retained for further examinations such as the heart or brain is sometimes collected by the parents at a later stage to be buried.

Penso and co-authors have demonstrated that in more than one-third of cases additional findings were obtained from neonatal autopsies, which contributed to subsequent genetic counseling or would have changed patient management if the knowledge had been present antemortem.<sup>1</sup>

Their findings are highly relevant and the authors must be applauded for performing this thorough study. Interestingly, the findings are not very dissimilar from a recent study in a level III NICU in a high-income country. In 24% of the patients, the autopsy revealed major additional findings (Goldman<sup>4</sup> class I or class II), most frequently in the circulatory system.<sup>5</sup> Differences between this study and the study by Penso might be explained by the postnatal age at death. When infants die at a later time point after birth, there are more opportunities for advanced diagnostic procedures.

In neonatal intensive care, the questions from clinicians and parents that can be answered by autopsy are reaching far beyond establishing the cause of death. In most neonates who pass away while being admitted to a NICU the cause of death is known, and in many high-income countries death follows redirection of care.<sup>6</sup>

However, neonatal autopsies also answer questions that are extremely relevant for improving neonatal care, such as disclosing diseases or malformations of the infant that otherwise would have stayed undetected.

Infants in the study by Penso et al died at a median age of 1 day, so these infants may not have lived long enough to undergo relevant postnatal examinations such as cardiac ultrasonography. However, the results of the autopsies may serve as a guide for the development of obstetric diagnostics including fetal ultrasonography in that particular area of the country.

DOI of original article: <http://dx.doi.org/10.1016/j.jpmed.2022.01.002>

\* Corresponding author.

E-mail: [F.Groenendaal@umcutrecht.nl](mailto:F.Groenendaal@umcutrecht.nl) (F. Groenendaal).

<sup>†</sup> See paper by Penso et al. in pages 471–6.

<https://doi.org/10.1016/j.jpmed.2022.05.001>

0021-7557/© 2022 Sociedade Brasileira de Pediatria. Published by Elsevier Editora Ltda. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

In other settings, postmortem findings may support or contradict radiological or microbiological test results and therefore serve to improve clinical care.

In addition to providing information for parents and medical staff, autopsies may also provide scientific data. A few decades ago, the authors published discordance of congenital malformations in genotypically identical twins with trisomy 18. These findings suggested that nongenetic factors played an important role in the etiology of congenital malformations in these twins.<sup>7</sup> Some parents give permission for an autopsy to “help other parents” and to “advance medical knowledge”.<sup>8,9</sup>

Although the report of Penso et al is important, a few aspects have not been addressed in much detail. Consent to perform an autopsy was obtained by 19.1%. The authors do not provide the backgrounds of the parents who did not give permission, and what potential bias this could create. The attitude of doctors and nurses toward autopsies, the duration of admission to the NICU, the religion of the parents, or financial aspects could all influence the rate of consent for autopsy.<sup>10</sup>

Informing the parents of the deceased infant by means of written or digital information can assist in obtaining permission for an autopsy.

It is important that the parents receive information that they understand and from a person they trust.<sup>8,11</sup> In most settings, the neonatologist will provide the information obtained to the parents, but in adults, direct communication between pathologists and family has been shown to be very effective.<sup>12</sup> Most studies indicate that the number of parents who regret *not* giving consent is much larger than the percentage of parents who did give consent for autopsy.<sup>8,11</sup> This is also shown in autopsies of stillborn infants.<sup>13,14</sup>

Medical and nursing staff is much more positive towards autopsies and therefore ask permission when the results of autopsies are discussed in regular audits.

The value of autopsies has been summarized by Burton and Underwood in 2007, and is still relevant.<sup>15</sup>

Finally, the medical community must continue to convince governments and insurers that autopsies are part of routine medical care and that adequate funding for autopsies is mandatory. In some countries like the Netherlands, medical insurance stops when a person dies and the costs of autopsies must be covered by the hospital. Needless to say that this will limit autopsy rates, in particular for people who died at home.

Optimal neonatal care in the 21<sup>st</sup> century still needs autopsies. As Rankin et al. state: “Every family should be offered the opportunity for a postmortem examination” after the death of their newborn baby.<sup>8</sup> The paper by Penso et al. provides an excellent example of this policy.

## Conflicts of interest

The authors declare no conflict of interest.

## References

1. Penso C, Corso AL, Hentges CR, Silveira RC, Rivero RC, Rojas BS, et al. Autopsy in a Neonatal Intensive Care Unit: pathological and clinical agreement. *J Pediatr (Rio J)*. 2022;98:471–6.
2. Khong TY, Tanner AR. Foetal and neonatal autopsy rates and use of tissue for research: the influence of 'organ retention' controversy and new consent process. *J Paediatr Child Health*. 2006;42:366–9.
3. Cohen MC, Paley MN, Griffiths PD, Whitby EH. Less invasive autopsy: benefits and limitations of the use of magnetic resonance imaging in the perinatal postmortem. *Pediatr Dev Pathol*. 2008;11:1–9.
4. Goldman L, Sayson R, Robbins S, Cohn LH, Bettmann M, Weisberg M. The value of the autopsy in three medical eras. *N Engl J Med*. 1983;308:1000–5.
5. de Sévaux JL, Nikkels PG, Lequin MH, Groenendaal F. The Value of Autopsy in Neonates in the 21st Century. *Neonatology*. 2019;115:89–93.
6. Snoep MC, Jansen NJ, Groenendaal F. Deaths and end-of-life decisions differed between neonatal and paediatric intensive care units at the same children's hospital. *Acta Paediatr*. 2018;107:270–5.
7. Mulder AF, van Eyck J, Groenendaal F, Wladimiroff JW. Trisomy 18 in monozygotic twins. *Hum Genet*. 1989;83:300–1.
8. Rankin J, Wright C, Lind T. Cross sectional survey of parents' experience and views of the postmortem examination. *BMJ*. 2002;324:816–8.
9. Breeze AC, Statham H, Hackett GA, Jessop FA, Lees CC. Perinatal postmortems: what is important to parents and how do they decide? *Birth*. 2012;39:57–64.
10. Gordijn SJ, Erwich JJ, Khong TY. The perinatal autopsy: pertinent issues in multicultural Western Europe. *Eur J Obstet Gynecol Reprod Biol*. 2007;132:3–7.
11. McHaffie HE, Fowlie PW, Hume R, Laing IA, Lloyd DJ, Lyon AJ. Consent to autopsy for neonates. *Arch Dis Child Fetal Neonatal Ed*. 2001;85:F4–7.
12. Juskewitch JE, Griffin JM, Maleszewski JJ, Asiedu GB, Paolini MA, Regnier AK, et al. Resurrecting the Hospital Autopsy: Impact of an Office of Decedent Affairs on Consent Rates, Providers, and Next-of-Kin. *Arch Pathol Lab Med*. 2021;145:55–65.
13. Horey D, Flenady V, Conway L, McLeod E, Yee Khong T. Decision influences and aftermath: parents, stillbirth and autopsy. *Health Expect*. 2014;17:534–44.
14. Human M, Goldstein RD, Groenewald CA, Kinney HC, Odendaal HJ, Network PASS. Bereaved mothers' attitudes regarding autopsy of their stillborn baby. *S Afr J Obstet Gynaecol*. 1999;23:93–6. 2017.
15. Burton JL, Underwood J. Clinical, educational, and epidemiological value of autopsy. *Lancet*. 2007;369:1471–80.