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what's already known about this topic?

- Congenital malformations are more frequently diagnosed prenatally, possibly at viable stage. This may lead to decisions resulting in (late) termination of pregnancy (late TOP).
- No adequate registration of incidence, indication, decision-making process and medical acts of late TOP on population level in Flanders exists.
- As pregnancy termination can have a significant impact on both women's physical and mental health, a complete registration could identify strengths and opportunities to improve late TOP care.

what does this study add?

- Late pregnancy terminations preceded about 2 in 5 reported stillbirths after 22 weeks gestation, indicating severe underreportation when looking at limited available registration methods.
- Nearly all late TOPs were discussed with parents until agreement.
- A quarter of pregnancy terminations occurred after suggestion by the physician, rather than after an initial spontaneous parental request.
- 88% of late TOPs was discussed in multidisciplinairy open team meetings.

Data availability statement: Questionnaires and detailed research protocols (in Dutch) are available upon written request to the corresponding author (Laure.Dombrecht@vub.be). Data will not be made publicly available due to privacy constraints.

Details of Ethics Approval: For this study, approval was obtained from the Ethics Committee of Ghent University (Belgian Registration Number B670201628795), the Privacy Commission (CBPL, registration number SA3/VT005071970), the National Council of the Order of Physicians (registration number BD/wc/89997) and the Sectoral Committee of Social Security and health (registration number SCSZG/16/234).

Abstract

Objective Congenital malformations are frequently diagnosed prenatally, even at viable stage. No adequate registration of incidence and characteristics of late termination of pregnancy (TOP) or abortion for medical reasons in Flanders exists.

Methods Nationwide mortality follow-back survey, sent to physicians signing death certificates of all stillbirths from 22 weeks gestation onward (September 2016 - December 20217) in Flanders, Belgium. Questions measured whether late TOP preceded stillbirth, and which clinical and sociodemographic characteristics were indicated. Questionnaire data were linked with sociodemographic information from death certificates.

Results Response rate was 56% (203/366). 38% of stillbirths (77/203) concerned late TOP. In 88.3% of late TOPs, physicians classified congenital anomalies of the foetus as serious or very serious (incompatibility with life outside the womb or severe neurological or physical impairment). In 26% of cases, late TOP was first suggested by the physician rather than spontaneously requested by parents (73%). 88% of late TOPs was discussed in open team meetings.

Conclusions 2/5 stillbirths were preceded by late TOP, indicating severe underreportation by existing registrations and a dire need for adequate registration methods. Although late TOP was most often explicitly requested by parents, in ¼ cases termination was suggested first by physicians. Parents are sometimes hesitant to bring up late TOP themselves, indicating that TOP should always be counseled as an equivalent option.

INTRODUCTION

Due to quickly evolving prenatal diagnostic techniques, congenital malformations are more frequently diagnosed prenatally(1–3). These diagnoses may occur at viable stage, possibly leading to decisions resulting in (late) termination of pregnancy (TOP). Although pregnancy termination at viable stage is practiced in several countries, national and international guidelines are scarce. Late TOP in this publication will be defined as termination of pregnancy after 22 weeks gestation. Protocols regarding decision-making, indications and methods of performing TOP at a viable stage in pregnancy are not so widespread. Moreover, due to differences in national legislations, international uniformity (of consensus) is difficult to reach (3–5).

Internationally, legislation on TOP varies strongly(6–9), ranging from completely legal for any type of abortion regardless of pregnancy duration to TOP being allowed depending on certain preconditions such as pregnancy duration and presence of lethal foetal anomalies(10). Belgian abortion law is summarized in box 1. The 'National Evaluation Committee for supervision on the practice of Abortion Law' monitors abortion practice in Belgium and reports biennially. This report provides adequate data on TOPs less than 12 postconceptional weeks but falls short on TOP after 12 weeks gestation, only performed for medical reasons, indicating that even though law states that all pregnancy terminations regardless of gestational age should be reported to the evaluation committee, terminations in the second and third trimester are severely underreported.

For comparison, other (scarce) sources for registration of pregnancy terminations in Belgium can be investigated. First, the Flemish Agency of Care and Health registers all stillbirths, but this is only legally obliged from a pregnancy duration of 180 postconceptional days (27 5/7 weeks amenorrhoea) onward. Second, a rather complete registration of all stillbirths with a birthweight of 500g or more is done by the Flemish Study Centre for Perinatal Epidemiology which comprises data of 100% of the Flemish maternity wards. None of these registrations provide information on stillbirth circumstances (active termination or not). Third, additional information can be found in two previous population-based studies on end-of-life practices in late term pregnancy in parts of Belgium(11,12) and through the online available EUROCAT register(13) (European network of population-based registries for the epidemiologic surveillance of congenital anomalies), but none of these covers the whole country. Based on these three sources, the estimated number of late TOPs should be at least 4 times higher than reported by the National Evaluation Committee.

In conclusion, no adequate registration of incidence, indication, decision-making process and medical acts of late TOP on population level in Flanders exists. Moreover, monitoring and evaluation of late TOP practice on population level is completely lacking. Therefore, an accurate and uniform registration would be useful to gain insight in TOP practice in Belgium and to compare and benchmark with other countries, where registration is also often incomplete. As pregnancy termination can have a significant impact on both women's physical and mental health, a complete registration could identify strengths and opportunities to improve TOP care. This study examines the prevalence and characteristics of late TOP in Flanders, Belgium. In addition, the clinical practice of late TOP (parental counseling, interprofessional consultation and medical practice) will be described.

MATERIALS & METHODS

STUDY DESIGN

An adequate registration of late TOP in Belgium is missing. We thus conducted a survey of all stillbirths and/or late TOPs in Flanders with an in Flanders residing mother between January and December 2017 reported by physicians to the Flemish Agency of Care and Health. STROBE guidelines for reporting cross-sectional research were used(14). Inclusion criteria can be found in Box 2.

SETTING AND PARTICIPANTS

We defined stillbirth as birth of a deceased fetus after 22 weeks of gestation, which we consider as a viable gestational age, including both spontaneous stillbirths and pregnancy terminations. This because registration methods in Belgium do not allow a distinction between the two. Additionally, as our population is limited to a gestational age of 22 weeks, all reported pregnancy terminations are considered late terminations (or late TOP).

All stillbirths and/or late TOPs in Flanders should legally be reported to the Flemish Agency of Care and Health by means of a death certificate from 180 postconceptional days (27 5/7 weeks amenorrhoea) onward. Additionally, voluntary epidemiological registration from 140 postconceptional days (22 weeks amenorrhea) onward is strongly encouraged for epidemiological reasons to reach comparability with other countries. For each reported stillbirth and/or late TOP, the attending physician was asked within four months of its occurrence to complete a questionnaire. To maximize the response rate, the Total Design Method was followed, including a maximum of three follow-up postal mailings(15). To ensure anonymity of the responding physician, an in-between lawyer, bound by confidentiality, sent the questionnaires to the physician based on the death certificate information, and ensured that any possible identifying factor would be removed from the received questionnaires before providing it to the study group. A detailed description of the study design, mailing and anonymity procedure is described elsewhere(16) (see supporting information figure S1).

A second, additional and parallel survey method consisted of providing the same questionnaires to the ten largest maternity wards immediately following the occurrence of a stillbirth and/or late TOP starting from 22 weeks gestation and/or a birthweight >500g, attempting to maximize the number of received questionnaires and reducing reporting bias due to lag time between occurrence of stillbirth and/or late TOP and reception of questionnaire. A schematic overview of mailing and anonymization process and of the parallel procedure can be found in supporting information figure S1 and the description of the protocol(16).

Finally, the processing of the abovementioned registration of stillbirths and late TOPs by the Flemish Study Centre for Perinatal Epidemiology is only completed after 1,5 years. These data were used to gather reasonable information on the number of stillbirths and/or late TOPs and to complete the data of the Flemish Agency of Health and Care retrospectively.

VARIABLES AND DATA SOURCES

Demographic and clinical patient data (sex, gestational age at birth, presence and severity of congenital anomalies and causes of death) were obtained from the death certificates.

The questionnaire used was based on previously validated questionnaires on late termination of pregnancy after 22 weeks of gestation(11,17), combined with questionnaires that focused on end-of-life decisions in minors and neonates(18–20). It used a previously validated framework of end-of-life decisions in the fetal-infantile period(18), based on a series of core questions. Furthermore, it includes questions about the involvement of the parents, colleagues and experts, and the policy of the hospital in the decision-making process. In case of a sudden death, i.e. a death where no end-of-life decision was possible, the questionnaire is concluded after three questions. These questionnaires are still needed to create an overview of the entire population (denominator: total number of stillbirths and/or late TOPs). At the beginning of the questionnaire, the physician was asked whether he or she was involved in the follow-up and/or decision-making process of the pregnancy. If not, the questionnaire was concluded and the physician was asked to send the questionnaire to the physician involved in decision-making. The final questionnaire was pilot tested and validated with the targeted physicians, researchers specialized in end-of-life care, an ethicist and a lawyer in the field of End-of-Life care.

We used a deterministic linkage procedure to link death certificate data with questionnaire data. This was performed by a trusted third party to ensure anonymity and to avoid socially desirable answers.

To ensure that linked death certificate data would prevent reidentification, small cell analysis was performed.

Causes of death were clinically categorized in order to group similar causes without revealing case-specific information. This categorization was based on neonatal causes of death defined by four physicians working in neonatal and prenatal care(21) and adapted to the prenatal setting by two prenatal diagnosis specialists (one of them ER) and a researcher with experience in neonatal end-of-life care research (LD). Finally, six categories were defined to group the underlying cause of death, denoted by ICD-10 codes, on the death certificate and to avoid recognizability of small cells. On the death certificate, main cause of death and associated causes of death are denoted. When main cause of death was inconclusive or insufficient to classify, ICD-10 codes of other associated causes of death were taken into account. Categories are mutually exclusive.

STATISTICAL METHODS

Descriptive statistics were calculated for demographic and clinical characteristics of the total population and the subpopulation that underwent late TOP as well as for characteristics of the decision-making process and the medical interventions in late TOP. To examine non-response bias demographic variables were compared by means of chi-square tests, Fisher's exact tests or Kruskal Wallis tests. As significant differences between the non-response and response group were found according to sex, all presented percentages and p-values will be weighed accordingly. To compare late TOP versus all stillbirths and/or late TOPs two-tailed Fisher's exact tests, Pearson Chi-square tests and Kruskal Wallis tests were used.

RESULTS

Starting from data received from either Flemish Agency (death certificates) or the Flemish Study centre for Perinatal Epidemiology (SPE), a total population of 399 stillbirths and/or late TOPs were registered. Of these, 366 stillbirths and/or late TOPs were included (stillbirth of an in Flanders residing mother) according to our inclusion criteria. We were able to successfully link 203 (56%) of these cases with filled-out questionnaires through either the mailing procedure or by filling out available questionnaires in 10 largest maternity wards. Details on number of registered stillbirths and/or late TOPs, received questionnaires and successfully linked cases are shown in figure 1. A total of 33 cases were excluded post-hoc for not complying with eligibility criteria (not born in 2017, no Flemish mother, less than 22 weeks gestation).

PREVALENCE AND CHARACTERISTICS OF LATE TOP IN FLANDERS

Epidemiological characteristics of late TOPs in Flanders are presented in Table 1. Of 203 stillbirths and/or late TOPs of which a questionnaire was received, 77 concerned a late TOP (38%). Late TOP cases significantly differed from stillbirths according to gestational age ($p<.001$), presence of congenital anomalies ($p<.001$) and cause of death ($p<.001$). Late TOPs more often have a lower gestational age (32% 22-25 weeks, 31% 26-28 weeks) than stillbirths (19% 32-36 weeks, 34% $\geq$ 37 weeks). 88% of late TOP cases had one or more congenital anomalies (versus 41% of stillbirths), of which 93% the physician classified them as (very) serious (see Table 1 for detailed descriptions). In 71% of late TOP cases, reported causes of death were multiple, systemic or single congenital anomalies (versus 13% in stillbirths). In the other late TOP cases, pregnancy complications (5%), maternal complications with fetal repercussions (12%) and prematurity (7%) were the reported causes of death.

DECISION MAKING PROCESS PRECEDING LATE TOP

The main reasons for late TOP (Table 2) were severely reduced fetal/neonatal expected quality of life due to congenital anomalies (61%), no realistic survival chances due to congenital anomalies (28%) and pregnancy endangered maternal physical health (12%). In cases where late TOP was discussed with parents (n=75), consensus with parents was always reached. In one case, the treating physician judged

the parents not fully capable of decision-making. In 26% of late TOP cases, TOP was not primarily requested by the parents, but rather suggested as an option by the physician and subsequently followed. Of all late TOPs, 1 case (1.2%) was not discussed, neither with parents, nor with colleagues (not in table). Late TOP decisions are most often discussed among healthcare professionals in open team meeting (89.4%), rather than individually among two physicians (10.5%) as requested by the Belgian law. Other involved disciplines in decision-making are most often neonatologists (91%), fellow gynaecologists (46.1%), geneticists (78.6%) or organ specialists (41.4%). In less than half of cases, parents consult other specialists to guide their decision (33.1%-43.1% is counseled by another gynaecologist, neonatologist, organ specialist or geneticist). Paramedical professionals such as a midwife, a psychologist or a social nurse, provide support to parents in 24%, 23% and 16% of all cases respectively.

USED MEDICAL TECHNIQUES

Medical techniques used are presented in Table 3. In 16% (N=12), no prenatal intervention was undertaken to achieve fetal demise. Of these, the majority consisted of pregnancies below 25 weeks; 1 pregnancy was between 26 and 31 weeks and one was more than 32 weeks. No fetus showed signs of viability at birth; the explicit question whether medical interventions were needed postnatally (comfort care or lethal drug administration) was answered negatively in all cases.

DISCUSSION

MAIN FINDINGS

This population-level mortality follow-back survey showed that nearly 40% of registered stillbirths and/or late TOPs after 22 weeks concerned an active pregnancy termination. In the vast majority (88.3%) of pregnancy terminations, physicians classified the congenital anomalies of the foetus as serious or very serious, indicating incompatibility with life outside the womb or severe neurological or physical impairment. Thirteen percent of all late TOPs was performed for endangered maternal health. In at least one case, serious concerns on maternal psychological health was indicated. Nearly all late TOPs were discussed with parents until agreement. A quarter of all pregnancy terminations was suggested by a physician rather than by an initial spontaneous parental request. 88% of late TOPs was discussed in open team meetings comprising several medical and paramedical professionals. Although all foetuses were beyond 22 weeks of pregnancy indicating viability and 16% received no prenatal intervention to achieve foetal demise, yet all foetuses were reported as stillborn.

STRENGTHS AND LIMITATIONS

This is the most accurate estimation of the proportion of late pregnancy terminations among the stillbirth and/or late TOP population in Flanders. A direct registration of late TOP in Belgium is unavailable and thus our current estimates are based on an indirect measure, namely all stillbirths and/or late TOPs. Hereby, late TOP that resulted in live births with or without comfort care are missed. A response rate of 54%, though comparable with population-based mortality follow-back studies in adults(22) is lower than that in deceased neonates(21). This might be attributed to the geographic spread of gynaecologists compared to that of neonatologists making targeted motivational efforts less feasible. However, our study is still, to our knowledge, the only available population based prevalence estimate in Flanders.

The rigorous requirements for non-recognizability in the anonymization procedure as well as in data processing and presentation did not allow in-depth analysis of certain intriguing cases.

Recall and memory bias cannot be excluded since questionnaires were filled out up to four months after death.

There is a risk of reporting bias among healthcare professionals, first of all due the ethical delicacy of the subject. Secondly, possibly medical practices ‘on the edge of what is legally allowed’ in Belgium

have a lower chance of being reported (e.g. neonatal life-ending treatment or late TOP because of solely maternal psychological or social reasons).

INTERPRETATION

We found that nearly 40% of reported stillborns concerned an active pregnancy termination. Considering the total population of stillbirths and/or late TOPs reported to the Flemish Agency, the proportion of late pregnancy terminations among all stillbirths after 22 weeks gestation in Flanders is at least 21%. This proportion is higher than data provided by the European Euro-Peristat Project on stillbirths and/or late TOPs in 2010, which aims to monitor maternal and child health across several European countries in the perinatal period based on health indicators acquired trough routine statistics(23). In the Euro-Peristat Project, late TOPs accounted for 1-22% of stillbirths of 22 weeks gestation and more, but accounted for less than 5% of stillbirths of 24 weeks and more(23). Similarly, the MOSAIC study reports on 23.6% TOPs among very preterm stillbirths (22-31 weeks) in Flanders(11), which is also considerably lower than our current estimates. More strikingly, the official registration of the practice of the Abortion Law by the National Evaluation Committee reported a mere 121 abortions after 12 weeks gestation in Belgium in 2017(24). Considering the fact that a significant number of pregnancy terminations is done before the viable stage(11,12,23,25,26) and that our study only included stillbirths and/or late TOPs of the Flemish region, registration is obviously incomplete. Incomplete registration fails to deliver a realistic image of existing healthcare and its needs and shortcomings. Without adequate prevalence estimates, ethical and legal discussions and even legislative decision-making is based on skewed results. An adequate TOP registration system in Belgium is thus needed to systematically monitor daily clinical practice. Additionally, an adequate registration system would facilitate international comparison which today is nearly impossible, as stillbirth and/or late TOP data from countries where late TOP is permitted are currently only reliable after exclusion of late TOP data(23) and registration of these late TOPs should be performed separately. International comparisons, which is to our knowledge unavailable, can identify country or region-specific factors influencing late TOP decisions, evidence of differing medical cultures, and even abortion tourism(27). Our monitoring technique is robust, anonymous, and replicable internationally. We therefore recommend replication of the study in other countries so that adequate international comparisons are possible, as uniform registration methods are currently unavailable.

Comparable with other European countries(12,17,28), the vast majority (88.3%) of pregnancy terminations in Flanders were foetuses with (very) serious anomalies, indicating either incompatibility with life outside the womb or severe neurological and/or physical impairment. Unlike some other countries, Belgian law permits pregnancy termination at viable stage for a serious, incurable but not necessarily lethal foetal condition. This is reflected in our data as 61% of all late TOPs did not concern a lethal anomaly, but rather a condition with reduced quality of life. Even more, 8% of congenital anomalies found in late TOPs was categorized by the treating physician as moderate or mild. This was defined in the questionnaire as risk of mortality or long-term morbidity, yet treatment with realistic chance of a good outcome was available. Remarkably, these pregnancies are not part of the 10 late TOPs performed for endangered physical or psychological maternal health. One could assume that these late TOPs are situated in the very preterm birth group (22-26 weeks) as ending a pregnancy for maternal health reasons usually results in preterm birth with admittance at a neonatal care unit rather than a pregnancy termination.

Although in three quarters of cases pregnancy termination was explicitly requested by parents, in 25.7% of cases termination was suggested by a physician. In case of the diagnosis of a severe condition at viable stage, parents either do not always realize that late TOP is possible in a serious foetal condition or are hesitant to ask for it. Existing literature states that counselling should be non-directive, neutral(29) and should be complete and offer all possible options(30). Some authors even recommend selective counselling of management alternatives such as termination of pregnancy, palliative care after birth or active neonatal management based on a continuum of beneficence-based obligations to

the foetus instead(31). Our results are unclear on whether the late TOPs suggested by the physician and subsequently followed by parents was part of global counseling, rather than counseled as the only available option. In any case, our results show that late TOP should always be counseled as an equivalent option, because some parents do not initiate this.

Belgian law states that pregnancy termination after 14 postmenstrual weeks of gestation requires the advice of one other physician. We found only one case in which this was not done. Rather than consulting just one other physician, our data showed that in 88% late TOP was discussed in open team comprising several medical and paramedical professions. This illustrates the desire for a broadly supported decision for physicians because of ethical and professional considerations. Not only professionals long for this broad support; 43% of parents seek advice of a gynaecologist other than the treating physician, or another specialty (31-40%) for counselling. As counselling by healthcare professionals is influenced by their specialty(32) and by personal and religious beliefs(33), consultation of at least one other specialist should be considered to acquire complete and appropriate counselling. Only 18% of parents receives support from a psychologist or social worker. Nevertheless, there is enough agreement (29,34,35) in literature and guidelines that paramedical support is useful in bereavement care. Psychological and social support should be accessible and part of the care path.

An intervention to achieve foetal demise was undertaken in 83% of late TOPs. Usually this consisted of administering either potassium chloride or local anaesthetics, whether or not in combination with opiates, to the foetus to achieve cardiac arrest. When a pregnancy is terminated at viable stage, the possibility of a liveborn foetus is present. Feticide is considered necessary in case of a foetal non-lethal condition, when occurrence of spontaneous neonatal death is difficult to predict or even unlikely. Palliative care and/or nonaggressive obstetric management is only considered as an option when neonatal death is inevitable within a reasonable time and/or parents prefer palliative care for their child(36). We already demonstrated that this option is less preferred by physicians than by paramedical professionals(37). In 16% of all late TOPs in this study, no prenatal intervention to achieve foetal demise was taken, some of them beyond 26 weeks of pregnancy. Yet no foetus showed signs of viability after birth and no postnatal intervention was required. It is not entirely clear whether these answers are consistent with reality. Postnatal interventions to achieve neonatal demise are not legally allowed in Belgium and it might be possible that signs of viability, as well as the following intervention, are not reported. In addition, pregnancy termination with subsequent neonatal demise after palliative care will be reported as a live birth and are consequently not questioned.

CONCLUSION

Late pregnancy terminations preceded about 2 in 5 reported stillbirths after 22 weeks gestation. Late pregnancy terminations are thus severely underreported when looking at the limited available registration methods. Adequate reports on late TOP should above all be a public health tool rather than a politicized discussion, on which ethical and legal debates could then be based on. As the current study was based on stillbirths after late TOP, thus missing cases with severe prenatal diagnosis without late TOP decision and late TOP resulting in live birth, future research should aim to include both groups equally. Additionally, more in-depth qualitative research is recommended to provide context on such ethically challenging decisions.

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BOX 1: Belgian Abortion Law

LAW ON VOLUNTARY PREGNANCY TERMINATION

ART 2 – The pregnant woman is allowed to ask a doctor for pregnancy termination for any reason under the following conditions:

1. Pregnancy termination should be done
   i) before 12 postconceptional weeks;
   ii) with use of appropriate medical techniques.
2. The doctor should
   i) inform the woman of immediate and future medical risks;
   ii) inform her of possible alternatives to pregnancy termination;
   iii) ascertain the firm will of the woman.
3. Unless for an urgent medical reason, 6 days should pass between first contact and pregnancy termination except in the case of an urgent medical reason or first contact later than 11 1/7 postconceptional weeks.
4. The woman should give written consent on the day of the pregnancy termination.
5. After 12 postconceptional weeks, pregnancy can only be terminated
   i) when continuing the pregnancy is a serious threat to the health of the woman;
   ii) OR if the child to be born suffers from a very serious condition considered incurable at the time of diagnosis.

   In this case, pregnancy termination should be performed under the same conditions as described in 2°-4° and with the written cooperation of a second doctor.

LAW ON ESTABLISHMENT OF COMMITTEE FOR EVALUATION OF LAW

National Evaluation Committee on practice of abortion law must be established (...).
This committee must prepare a bi-annual report on (a) statistical data of the law; (b) a report on the daily practice and evolution of practice of the law; (c) recommendations to diminish the number of abortions.

BOX 2: inclusion criteria

Inclusion criteria for stillbirths were as follows:

- Stillbirths from 22 weeks of gestation or more, and/or a birthweight of 500 gram or higher;
- occurring in Flanders and Brussels where the mother is a Flemish resident;
- occuring between January and December 2017

TABLES

TABLE 1: EPIDEMIOLOGICAL CHARACTERISTICS OF LATE TOPs IN FLANDERS

Prevalence	
All stillbirths for which a response was received	203 (56% response rate)
Prevalence of late termination of pregnancy within all stillbirths for which a response was received	77 (38%)

	All stillbirths n/N (%)	Late TOPs n/N (%)	Non-TOP stillbirths n/N (%)	p-value
Sex of the fetus[a]				.309
Male	117/203 (53%)	48/77 (58%)	69/126 (50%)	
Female	86/203 (47%)	29/77 (42%)	57/126 (50%)	
Gestational age at birth[b]				<.001
22-25 weeks	55/194 (28%)	25/75 (32%)	30/119 (25%)	
26-28 weeks	36/194 (19%)	23/75 (31%)	13/119 (11%)	
29-31 weeks	24/194 (12%)	11/75 (15%)	13/119 (11%)	
32-36 weeks	35/194 (18%)	12/75 (16%)	23/119 (19%)	
≥ 37 weeks	44/194 (23%)	4/75 (5%)	40/119 (34%)	
Congenital anomalies[a]				<.001
Yes (single or multiple)	75/96 (77%)	66/75 (88%)	9/21[c] (41%)	
No	21/96 (23%)	9/75 (12%)	12/21 (59%)	
Severity of congenital anomalies[a,d]				.278
Very serious Not compatible with life or with certainty resulting in a very serious outcome with no possibility of treatment	36/74 (48%)	32/66 (48%)	4/8 (50%)	
Serious Treatment would have been possible but even if successful, the child would certainly suffer from a severe neurological or physical impairment	31/74 (43%)	29/66 (45%)	2/8 (25%)	
Moderate Treatment was possible with a realistic chance of a good outcome, but still with a significant risk of mortality or long-term morbidity	6/74 (8%)	4/66 (6%)	2/8 (25%)	
Mild Treatment was possible with a reasonably good chance of a good outcome	1/74 (1%)	1/66 (2%)	0/8 (0%)	
Cause of death[e]				<.001
Congenital anomalies singular	39/203 (19%)	33/77 (42%)	6/126 (5%)	

Congenital anomalies multiple or systemic disorders	32/203 (16%)	22/77 (29%)	10/126 (8%)
(Acute) pregnancy complications with or without foetal repercussions	58/203 (29%)	4/77 (5%)	54/126 (44%)
Prematurity and related disorders[f]	33/203 (16%)	5/77 (7%)	28/126 (21%)
Maternal complications unrelated to pregnancy with foetal repercussions	14/203 (7%)	9/77 (12%)	5/126 (4%)
Other	27/203 (13%)	4/77 (5%)	23/126 (18%)

Absolute cases, weighted percentages (weighted for significant differences in response and non-response group according to sex).
Missing values: 9 missing values in gestational age at birth (4.4%), 2 missing values in presence of congenital anomalies (2.1%) and 1 missing value in severity of congenital anomalies (1.0%). Percentages calculated without missing values.
[a] Two-tailed Fisher's exact tests were used to compare differences in sex and presence of congenital anomalies between groups with and without TOP preceding the stillbirth
[b] Kruskal Wallis tests were used to compare differences for gestational age at birth between groups with and without TOP preceding the stillbirth
[c] Due to skips in the questionnaire in case of an unexpected (sudden) stillbirths, these questions were not answered by the majority of stillbirths without TOP
[d] Could only be filled in for the 75 cases where a congenital anomaly was indicated.
[e] Pearson Chi-square test was used to compare differences in cause of death between groups with and without TOP preceding the stillbirth
[f] The main reason for pregnancy termination is not always equal to the cause of foetal death, as 7% of cases the treating physician indicated prematurity as main cause of death.

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488 **TABLE 2: FEATURES OF DECISION-MAKING PROCESS PRECEDING LATE TOP**
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	Infants whose stillbirth was preceded by TOP	
	N = 77	**%**
Factors playing a role in TOP decision[a]		
No realistic fetal/neonatal survival chance due to congenital anomalies	22	28.0
Minimal fetal/neonatal expected quality of life due to congenital anomalies	47	60.9
Pregnancy endangered maternal physical health	9	11.6
Pregnancy endangered maternal psychological health	1	1.2
Other reason [b]	1	1.2
Top decision was discussed with parents		
Yes	75	98.8
No	1	1.2
When discussed, agreement between doctor and parents		
With both or the only parent(s)	75	100
With one of two parents	0	0
No	0	0
Doctor's estimate of capability of parents to decide		

Fully capable	75	98.8
Partially capable	1	1.2
Not capable	0	0
TOP decision was based on…		
Explicit request by parents	55	73.1
Agreement of parents following proposed action by physician	20	25.7
Other [c]	1	1.2
Discussion on TOP decision with other healthcare professionals[a]		
In open team	66	89.4
On individual basis	8	10.5
No discussion	1	1.2
Healthcare professionals consulted by doctor on TOP decision [a]		
Colleague gynaecologist	72	97.2
Neonatologist	67	91.0
Geneticist	58	78.6
Pediatrician	30	40.8
Organ specialist	30	41.4
Psychologist	14	18.6
Social nurse	13	17.9
Midwife	39	53.8
Other	10	13.3
(Other than treating) healthcare professionals consulted by parents on TOP decision [a]		
Colleague gynaecologist	33	43.1
Neonatologist	29	40.1
Organ specialist	27	36.6
Geneticist	24	31.1
Psychologist	18	23.2
Midwife	18	24.1
Social nurse	12	15.7
Pediatrician	5	6.6
None	3	3.6

Absolute cases, weighted percentages (weighted for significant differences in response and non-response group according to sex).
[a] more than one answer possible.
[b] Other reason was indicated as being an intrauterine death.
[c] Other reason was indicated as being an intrauterine death.
Missing values: 1 missing in discussion with parents, agreement between parents and physician, reason for the decision, capability of the parents, and consultation of parents with other healthcare professionals (1.3%). 3 missings in discussion with other healthcare professionals (3.9%). 2 missings in who healthcare professionals consulted and factors playing a role in TOP decision (2.6%). Percentages calculated without these missing values.

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493 **TABLE 3: USED TECHNIQUES FOR LATE TOP ACCORDING TO GESTATIONAL AGE**
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	All TOPs n/N (%)	22-25w n/N (%)	26-31w n/N (%)	≥32w n/N (%)	p-value*
Prenatal drug administration / technical act to achieve fetal demise					<.001
Yes	63/75 (84%)	15/25 (60%)	33/34 (97%)	15/16 (94%)	
No	12/75 (16%)	10/25 (40%)	1/34 (3%)	1/16 (6%)	
If so, which prenatal drug administration / technical act was used to achieve fetal demise					.039
Potassiumchloride	24/63 (37%)	11/15 (71%)	8/33 (24%)	5/15 (33%)	
Local anaesthetics with or without opioids	38/63 (61%)	4/15 (29%)	24/33 (73%)	10/15 (67%)	
Cord coagulation	1/63 (2%)	0/15 (0%)	1/33 (3%)	0/15 (%)	
Presence of viability signs at birth					N/A
Yes	0/75 (0%)	0/25 (0%)	0/34 (0%)	0/16 (0%)	
No	75/75 (100%)	25/25 (100%)	34/34 (100%)	16/16 (100%)	

* Pearson Chi-square test
Absolute cases, weighted percentages and p-values (weighted for significant differences in response and non-response group according to sex).
Missing values: 2 cases with TOP preceding stillbirth have missings on all variables mentioned in the table (3.8%). Percentages calculated without these missing values.

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Figure 1: Details on number of registered stillbirths, received questionnaires and successfully linked cases