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Reproductive and perinatal epidemiology using official statistics: What future for Switzerland?

A century ago, about 150 of 1000 liveborn infants did not survive the first year of life and about 350 mothers died every year due to pregnancy or childbirth in Switzerland. That's why official statistics were targeted towards mortality and the conditions leading to infant or maternal death as well as on population growth and fertility patterns. However, reproductive and perinatal epidemiology changed its focus since infant mortality has fallen to 6 per 1000 liveborns and maternal deaths have become rather rare events. But in most industrialized countries official statistics are not yet adapted in order to collect epidemiological data providing some answers to the important questions of our time.

How should official Swiss statistics be developed in the future to collect the information needed to answer the public health questions in the field of reproductive and perinatal medicine?

Following a short overview of the existing data in Switzerland and in selected other industrialized countries this paper presents some options for such future developments including their advantages and disadvantages.

Information needed in reproductive and perinatal epidemiology

Despite of the progress made, i.e. reduction of mortality, prevention and treatment of illnesses, some old problems are still existing and new questions emerged. Many of these questions can be studied with epidemiological methods and some of them – the important questions if possible – should be included in the national programmes of official statistics. The most important demographic and public health questions are summarized on Table 1.

Firstly, we have to identify the risk factors associated with infant or maternal death and to assess the incidence of malformations. Such knowledge is required in order to develop new and effective prevention programmes. Secondly, we have to know what kind of antenatal and perinatal services are being used and whether the use of these services has been appropriate and effective in terms of perinatal conditions, infant or maternal death.

The information needed to answer

Demography
• Fertility patterns by place, time and person
• Population growth
Public health
• Risk factors associated with infant or maternal death
• Conditions leading to infant or maternal death
• Incidence of malformations by place, time and person
• Causes of perinatal conditions and congenital malformations
• Level of utilization of services
• Effectiveness of antenatal and perinatal care

Table 1. *Questions to be answered.*

The views expressed in this paper are those of the author and they represent neither the policy of the Swiss Federal Statistical Office nor that of the Federal Government.

Demographic variables	
• Child:	Place, date and time of birth, sex, plurality, evidence of life
• Mother:	Civil state, residence, nationality, date of birth, education, date of marriage, no. of previous births
• Father:	(If married to mother): date of birth, nationality (for all the fathers); education
Medical and health variables	
• Pregnancy:	– Risk factors for this pregnancy – Pregnancy history (births and other terminations) – Duration of gestation – Obstetric procedures
• Labour/delivery:	– Complications of labour and/or delivery – Method of delivery
• Child:	– Birth weight and apgar score – Abnormal conditions of newborn – Congenital malformations
• Health care:	– Prenatal (visits, transfer of mother) – Name and type of facility (birth place) – Neonatal (advanced technology, transfer of infant)

Table 2. *Information needed to answer the questions.*

Risk factors for this pregnancy	Obstetric procedures	Method of delivery
Anemia	Artifical insemination	Vaginal
Cardiac disease	IVF	Vaginal birth after previous C-section
Acute or chronic lung disease	Amniocentesis	Primary C-section
Diabetes	Electronic fetal monitoring	Repeat C-section
AIDS	Induction of labour	Forceps
Hydramnios/oligohydramnios	Stimulation of labour	Vacuum
Hemoglobinopathy	Tocolysis	
Hypertension, chronic	Ultrasound	
Hypertension, pregnancy assoc.	None	
Eclampsia	Other (specify)	
Incompetent cervix		
Previous infant 4000 + grams		
Previous preterm or small-for-gestational-age infant		
Renal disease		
RH sensitization		
Uterine bleeding		
None		
Other (specify)		
Tobacco use during pregnancy: Yes/no		
Average number cigarettes per day		
Alcohol use during pregnancy: Yes/no		
Average number drinks per week		
Weight gained during pregnancy (kg)		

Table 3. *Proposal for variable lists based on the standard U.S. birth certificate*[1].

Complications of labour/delivery	Abnormal conditions of the newborn	Congenital anomalies of child
Febrile (> 38 °C.)	Anemia (HCT.< 39/HGB.< 13)	Anencephalus
Meconium, moderate/heavy	Birth injury	Spina bifida/meningocele
Premature rupture of membrane (> 12 hours)	Hyaline membrane disease/RDS	Hydrocephalus
Abruptio placenta	Meconium aspiration syndrome	Microcephalus
Placenta previa	Assisted ventilation < 30 min	Other central nervous system Anomalies (specify)
Other excessive bleeding	Assisted ventilation ≥ 30 min	Heart malformations
Seizures during labour	Seizures	Other circulatory/respiratory Anomalies (specify)
Precipitous labour (< 3 hours)	None	Rectal atresia/stenosis
Prolonged labour (> 20 hours)	Other (specify)	Tracheo-esophageal Fistula/esphageal atresia
Dysfunctional labour		Omphalocele/gastroschisis
Breech/malpresentation		Other gastrointestinal anomalies (specify)
Cephalopelvic disproportion		Malformed genitalia
Cord prolapse		Renal agenesis
Anesthetic complications		Other urogenital anomalies (specify)
Fetal distress		Clef. lip/palate
None		Polydactyly/syndactyly/adactyly
Other (specify)		Club foot
		Diaphragmatic hernia
		Other musculoskeletal/integumental anomalies (specify)
		Down's syndrome
		Other chromosomal anomalies (specify)
		None
		Other (specify)

Table 3 *(continued).*

Demographic variables	
• Child:	Place, date and time of birth, sex, plurality, evidence of life
• Mother:	Civil state, residence, nationality, date of birth, date of marriage, no. of previous births for current marriage
• Father:	(If married to mother): date of birth, nationality
Medical and health variables	
• Child:	– Birth weight and body length

Table 4. *Information currently collected at birth in Switzerland (abstract from the 1987 birth certificate).*

these questions is summarize on table 2. As can be seen, information on current and previous pregnancies, on labour and/or delivery, on the health status of the infant as well as the health care institutions delivering services has to be collected. Table 3 presents detailed variable lists for risk factors for pregnancy, obstetric procedures, methods of delivery, complications of labour, abnormal conditions of the newborn and congenital anomalies. These variable lists, based on the Standard US Birth Certificate[1], may be seen as a proposal which enables to answer many of the important public health questions.

Information collected at birth by official statistics in Switzerland and other industrialized countries

In Switzerland the information collected at birth by the vital registration system is of almost exclusively demograhic nature. The information collected in 1993 is not very different from the information collected in 1878 when vital registration was introduced (Table 4).

The above table clearly indicates that the Swiss vital registration of births[2] does not include any item needed to answer the main public health questions. In addition to the vital statistics there are two additional data sources, the registries of congenital malformations[3] and the morbidity statistics of the "Arbeitsgemeinschaft Schweiz. Frauenkliniken"[4], which are both incomplete due to a lack of obligation to report.

What is being done in other industrialized countries? A comparison was made with vital registration of births in neighbouring countries, France (F), Germany (D) and Austria (A), in three European countries with developed statistical systems, the Netherlands (NL), Denmark (DK) and the United Kingdom (UK) and, finally, in the United States (USA) where both a developed system of official statistics and a tradition of public health are existing. Three levels of data collected at birth can be distinguished, as shown on Table 5. On the first – and lowest – level we find Switzerland, Germany[5], France[6], the Netherlands[7] and the United Kingdom[8]. These countries do not collect the important medical and health data, although supplementary unofficial and/or local registration systems for such purposes may exist. In England and Wales, an additional reporting system for congenital malformations is existing. Austria[9], with a collection of some important information on the current and previous pregnancy as well as congenital anomalies represents an intermediate level. On the third level, where all or most of the information needed is being collected, are Denmark[10] and the United States[1].

Variables	Country							
	CH	A	D	DK	F	NL	UK	USA
Demographic variables								
Place of birth	•	•	•	•	•	•	•	•
Date and time of birth	•	•	•	•	•	•	•	•
Sex	•	•	•	•	•	•	•	•
Plurality	•	•	•	•	•	•	•	•
Evidence of life	•	•	•	•	•	•	•	•
Civil state	•	•	•	•	•	•	•	•
Residence	•	•	•	•	•	•	•	•
Nationality	•	•	•		•	•	•	•
Date of birth of the mother	•	•	•	•	•	•	•	•
Education (mother and father)		•						•
Date of marriage	•	•	•		•	•	•	
No. of previous births for current marriage	•	•	•		•	•	•	
Father married to mother:								
date of birth	•	•	•	•	•	•	•	•
nationality	•	•	•		•	•	•	•
Medical and health variables								
Risk factors for this pregnancy				•				•
Pregnancy history (births, etc.)		•		•				•
Duration of gestation		•		•				•
Obstetric procedures				•				•
Complications of labour/delivery				•				•
Method of delivery				•				•
Birth weight	•	•	•	•			•	•
Apgar score		•		•				•
Abnormal conditions of newborn								•
Congenital malformations		•	•	•				•
Prenatal care (visits, transfer of mother)								•
Name and type of facility (birth place)							(•)	•
Neonatal care (adv. technology, transfers)								•

Table 5. *Information collected at birth: an international comparison of vital registration of births.*

Options for the future of vital registration of births in Switzerland

The vital registration system offers some possibilities to collect health data on births (as well as stillbirths and/or deaths). The main advantages of vital registration are the completeness of data due to obligation to report, the confidentiality and the accessibility of the data for research purposes.

What will be the likely future of birth registration? Among the many possibilities I would like to propose two options. Option A is characterized by minor changes to the status quo and option B is comprising major changes.

Option A: Minor changes to status quo

The following changes have to be made in the existing databases:

– births: adding an additional question on duration of gestation;
– deaths: linked data set with births on a regular basis;
– registries of congenital malformations: extension to the whole of Switzerland (without obligation to report);
– morbidity statistics of the "Arbeitsgemeinschaft Schweiz. Frauenkliniken": officialising data collection and access to data.

A statistical system based on such minor improvements would have some important consequences (Table 6).

Advantages	Disadvantages
maintaining existing structures	public health questions can not be fully answered
low additional investments	practical problems in combining 4 databases from 3 institutions
relatively quickly in place	one of the important data sources is biased (hospital births only)

Table 6. *Consequences of option A.*

Option B: Major changes to status quo

This option would cause a series of radical changes for three data collection systems, the vital registration of births, the register of congenital anomalies and the morbidity statistics of the "Arbeitsgemeinschaft". These major changes are summarized below:

– births: adding an additional set of medical and health questions (examples: USA, Denmark, German Perinatal Survey);
– deaths: linked data set with births on a regular basis;
– registries of congenital malformations: transformation to a national register based on the malformations registered at birth, hospital treatments and malformations registered at the invalidity insurance;

– Morbidity statistics of the "Arbeitsgemeinschaft Schweiz. Frauenkliniken": dropping data collection on births.

The following consequences would be expected with such a future system (Table 7).
Finally, the main question is which option should be preferred. Those who dislike to change existing structures and don't mind if important public health questions can't be answered by official statistics will support option A, while those who like to have answers to the questions from offical statistics will favour option B.

Advantages	Disadvantages
public health questions could be answered	restructuring of the existing information systems
complete and regular data collection	high additional investments
public data available for research	impossible to set up quickly

Table 7. *Consequences of option B.*

Steps needed to achieve changes

If one is in favour of changes of official statistics to the benefit of reproductive and perinatal epidemiology in Switzerland, it will be necessary to initiate and to support them with the following steps:

Clarification of the concept

The objectives and the data collection methods have to be determined precisely. Additionally, the role of the official health statistics system has to defined.

Importance of data providers

They must identify themselves with the concept and they have to agree to provide the data.

Role of data users

They should support the concept and they should also agree to maintain confidentiality and to respect data protection.

Data protection

The concept has to consider data protection laws and regulations. Probably, a permission to disclose medical confidentiality will be necessary.

Initiation of the decision process

The last but most important step will be to start the decision process, which will be different for the two options presented.
For option A: direct influence on institutions concerned will probably be successful. However, new structures for statistical analysis of combined data have to be created by use of private or public funds.
For option B: a recommendation of

the Swiss commission for health statistics will be a necessary first action, followed by measures to convince health policy leaders to provide resources.

Conclusions

There is evidence that the existing data on reproductive and perinatal health do not allow to answer some of the important public health questions of the ending 20th century in Switzerland. In fact, the vital registration of births remained basically in existence as it was developed more than 100 years ago. Therefore, it seems to be both useful and justified to develop the vital registration system in order to get one single database with all the information needed. The international comparison showed that more adequate systems are already existing in other industrialized countries. High additional investments in order to set up a better information system may well be repaid by benefits from better care and renunciation of adhoc studies or incomplete databases. However, success will greatly depend on the support of the medical profession, especially those involved in reproductive and perinatal health, e.g. obstetricians, paediatricians, pathologists and epidemiologists.

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