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Round Table One

Do we need more or different information to evaluate perinatal care in Switzerland?

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UA: *Keeping in mind the title of this round table, I would like to open the discussion on evaluation of perinatal care with the following question: what is our objective and what is the minimal data set we need? What do we wish to prove or to show? Do we need very detailed information or can we achieve our goals with a restricted data set? We, epidemiologists, always think that most of the more important points can be made with rather limited data sets of reasonable quality. I think Prof. Wigglesworth made a very convincing statement earlier this morning for a very simple way of classifying perinatal deaths. We shall hear the opinions of an obstetrician, of a neonatologist, and of two neonatal pathologists. So, I would like to start this discussion by asking Prof. Duc how he sees, as a neonatologist, the need for perinatal statistics; what is his main problem in perinatal care today, and how could improved vital statistics help. I would like to limit the question to what he sees as the main problem in neonatology in Switzerland today?*

GD: I must confess that I feel uncomfortable to be acting at this podium today because I don't know yet what we are looking for. I understand that we are all interested to know more about perinatal statistics in our country, but I am not sure that we are all looking for the same answer. In fact, as long as we haven't formulated the question, we cannot agree upon the answer. (La Palisse!).

Are we looking for more information in order to improve neonatal survival or to decrease long term morbidity? (Two phenomena which are not always parallel!). Or, are we looking for a reduction of the costs of neonatal care? Or, are we trying to solve the misery of lack in acute "beds" in our intensive care units?

The data we are going to collect depend on the question we are asking. Personally, I am particularly interested in the solution of the problem of the lack of acute beds in our units. I must confess that we, the neonatologists, did not see this growing problem until Prof. Schneider, an obstetrician, showed us the increasing dimension of the new needs. I urge you to read his report ("Alle Schwerpunkt-Regionen wie Lausanne, Zürich, Bern, Luzern, St. Gallen, Chur betrachten die Versorgung der kranken Neugeborenen als kritisch. Legt man die in der Literatur angegebene Richtzahl von 1,5 Intensivpflegeplätzen pro 1000 Lebendgeburten zugrunde, so besteht gesamthaft in der Schweiz ein Defizit von mindestens 35% oder 47 Plätzen"[1]).

In Zürich, the neonatal intensive care unit couldn't admit 100 sick babies in one year, the neonatal

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[1] *"Engpass Intensivmedizin in der Neonatologie in der Schweiz". Schlussbericht der Kommission der Schweiz. Gynäkologische Chefärztekonferenz vom 8.8.1991.*

clinic of the University Hospital 56. These sick babies travelled by helicopter or ambulance from one hospital to the other until we found a cot or an incubator. Risk associated with transport are known to all of us. On the other hand, the impossibility for neonatologists to admit babies in the unit jeopardize the whole programme of centralization of high risk pregnancies in perinatal centers. In fact, I have some reasons to suspect that the whole system of centralization of high risk delivery in perinatal centers is starting to collapse in Switzerland. One important question for today could be: which perinatal data are needed to describe the need of a perinatal center (neonatal intensive care unit integrated in obstetrics) in Switzerland?

UA: *I would be grateful now for Prof. Béguin to put to us the obstetrical point of view: what is the main problem today in perinatal care in Switzerland?*

FB: Excusez – moi de parler en français, je pense que vous le comprendrez mieux que mon mauvais anglais. Je ne peux que confirmer ce que Prof. Duc a dit pour Zurich, c'est vrai aussi à l'autre bout de la Suisse. Nous avons les même types de problèmes avec la nécessité maintenant pratiquement chaque mois, de déplacer des mères ou des nouveau-nés à Lausane, à Berne et même jusqu' à Zurich, ou de recevoir des enfants de ces endroits-là. Il y a, au niveau des emplois et au niveau des surfaces dont nous disposons, à Genève comme ailleurs, une difficulté majeure. Je crois que c'est une des questions à laquelle, en effet, nous devons répondre, puisque le problème ne va que s'accentuer. Et cela parceque les grossesses et les accouchements augmentent, et ils continueront d'augmenter. Notre efficacité dans les grossesses de moins de 28 semaines augmente, et cela continuera à augmenter. Les grossesses multiples ont beaucoup augmenté, nous espérons convaincre nos collègues qui s'occupent de stérilité de cesser de réimplanter trop d'embryons dans les utérus quand on sait que, par exemple en France, à Paris, plus de la moitié des prématurés dans les soins intensifs sont les produits de grossesses multiples obtenues par des méthodes de fécondation médicalement assistée et aussi parce que les contacts avec la France, malgré les votations récentes, augmentent beaucoup, et que nous recevrons beaucoup de cas, et que cela continuera d'augmenter également. Or, nous ne savons rien pour un canton comme le nôtre. Nous savons quel est le taux de prématurité à la maternité de Genève, il est entre 10 et 12% chaque année, mais nous ne savons rien en ce qui concerne les cliniques privées. Nous ne savons rien par exemple non plus, en ce qui concerne les cliniques privées, pour un geste aussi important que les césariennes. Nous sommes donc en train d'établir un programme de données périnatales à partir de zéro. C'est, je crois, sur cette base qu'il faut réfléchir et voir ce qui est souhaitable ou, encore mieux, ce qui est possible.

UA: *We have heard about the problems of the obstetricians and the neonatologists who see an increasing number of low birth weight babies, needing intensive care. And for these babies there are not enough hospital beds availabe in Switzerland at the moment. Now, what do we know about this increase? Little, because we have no figures about the number of artificially conceived pregnancies. We have some figures about the increase in twins or multiple births. How much did they increase, does this actually explain the increasing demand, or are there other factors? Is low birth weight increasing in Switzerland in general? Will the recession contribute to an increase in low birth weight? We dont know, at the moment, and we certainly need to continue our analyses of birth weight specific mortality rates to see this.*

GD: We have some information about the increase in very low birth weight infants, below 1 kg. We had a survey in the Neonatal Group of Switzerland, done by Dr. Bucher. For the year 1979 we had 0.13% of all deliveries in Switzerland below 1000 g and in 1991, 0.22% so it is almost a doubling. We had in 1979/81 314 babies below 1 kg who survived, in 1989/91 almost 500. These very small babies are occupying our beds for a very long time before they can go home. In 1979, we ventilated 20% of these babies, in 1991, 67%. So the data exist, we know that these needs are steadily increasing.

UA: *Now, of course, this problem is one that involves other questions. What effect does this increase in small survivors have at the Public Health level? Do we create more problems, and long-term patients, or do we in fact create healthy babies who will survive? And we will of course only be able to answer this question with some additional data.*
Now, I would like to hear the point of view of Prof. Laurini, as a perinatal pathologist. Is it enough to just evaluate perinatal death? Should we not also look at later deaths, after the perinatal period, because the neonatologist may keep these low birth weight babies alive for a long time and they might die later, within the first year of life?

RL: As a developmental pathologist, frequently involved with perinatal epidemiology and with the perinatal audit, I will answer this part of the question with 3 simple points. I think that an epidemiological evaluation of perinatal death in any given population is a major source of reliable information that must not be limited to the perinatal period, but also include the prenatal and postneonatal periods. This aim will be fulfilled only if we have access to the results of a properly performed developmental postmortem including developmental neuropathology and placental pathology. The safe application of a classification such as that of Wigglesworth in the absence of a postmortem fails to fully achieve the needs of a meaningful epidemiological evaluation. My feelings are that this will then allow us, as a team, to better plan and audit antenatal as well as perinatal care and improve our understanding of postneonatal conditions. Furthermore, I would like to finish by saying that I am convinced that, in today's economical climate, this type of information is vital to decide the best investment of available resources in order to better treat and/or prevent disease on a local basis.

UA: *The need to realize the best use of our limited resources is in fact one of the main arguments calling for perinatal statistics. From the epidemiological point of view, our first aim is to better know the risk factors for perinatal death in our population and to decrease these risks, where they can be decreased. This is for me the main question which should be answered in any perinatal survey. Where can we put our resouces to avoid more perinatal deaths? For this we need some information on perinatal deaths which we dont have at the moment in Switzerland. Dr. Cox, could you please define for us the essential information on perinatat death in this respect. Because we not only need good information, but also complete information, in other word, we need valid information.*

JC: The problem here, I think, has been discussed with eloquence by Drs. Paneth and Spuhler. They have shown us the hurdles which we have, and which we have to overcome. In my opinion for the whole of Switzerland you would need probably to get the information from the various hospitals, including teaching hospitals, district and regional hospitals, from maternity centers and from private clinics. It would be necessary to harmonize this information and to do so, it might be preferrable to have very simple definitions so that you can include for data collection the personnel available, i.e. nurses, midwives, etc. If your definitions are simple, and if you can devise means of showing to these participants the simple findings to look for in newborn or stillborn infants, you would then have a certain number of items registered, which would eventually give you an idea of what is happening in the country. This calls for teaching, which would evidently be an added expenditure. But if you use people available on the spot, it would not be that difficult. I have been working with the Wigglesworth classification, which I think is simple, and can be easily applied to most personnel. I think that these are the important elements that I have to add here.

UA: *Of course the Wigglesworth classification is used for children who die. Can it be used for all children born, what do you think Prof. Duc?*

GD: I think the classification would be useful if all the pathologists would use it in the whole country. Do you see a possibility, Dr. Cox, that you are going to sit together with all the pathologists performing perinatal autopsies, and agree on definitions? It seems to me an important part of this meeting that we try to define clearly some main aspects of perinatal medicine, and get a view of the needs in the whole country. Until now, as you know very well, we are all from cantons, we are not from Switzerland.

JC: I thought that this point would be coming on later, in the second Round Table. That is why I left it out for now. The problem of autopsies, classifications, and the special techniques which are needed in the pathology departments to define certain conditions would come, in my opinion, later. We should then also add the SNOMED classification.

UA: *What is the view of Prof. Laurini on that one?*

RL: As I said before once a comprehensive developmental postmortem has been carried out, I find Prof. Wigglesworth classification very useful and one that I use myself. Together with Dr. D'Armiento (developmental pathologist from the University of Napoli), present here today, we are using it to classify 1000 perinatal deaths. I think that there is a willingness, due to the very simple way he has designed the classification to use this classification. I think that the problem is not to standardise the use of the classification of Prof. Wigglesworth, but to standardise the comprehensive protocol you need to do a developmental postmortem.

UA: *Do you think there are enough centers for the whole country to do postmortems? Are there many perinatal deaths where there is no autopsy done? I thing the proportion is about 70 %.*

RL: In Lausanne we are running at a rate of about 82 to 86 % of fetal and perinatal postmortems. I think you are going to find that, on the whole, despite a diminishing rate for adults postmortems, there is still an interest and respect for the information provided by a developmental postmortem. The only problem, and I repeat myself, is that many times they are poorly performed and then our clinicians get wearied with our poor services.

JC: In Geneva we have roughly 80 to 85 %, which is not bad. And we get quite a bit from the outside hospitals.

UA: *But that is obviously not the Swiss average. What is exactly the Swiss average. Do you know Thomas?*

Thomas Spuhler: The rates of autopsy for perinatal death in 1991 was 67 %.

UA: *67% last year. So we are missing one third, and of course we don't know at the moment which ones are missing unless we can link birth and death certificates. This is where we would need the birth weight specific mortality and autopsy rates, to see what is happening. So, I think probably there is a consensus here on proper postmortem, with proper classification of the causes of death. This certainly belongs to the minimum of the data set we should have on perinatal mortality. After all, we have not that many cases per year in Switzerland, it could be done with the existing resources.*
Of course, this is only one aspect. In order to have good perinatal data, we don't only need data on the dead babies, but also on the living babies. What do you think would be optimal on that point? I would like to start with Prof. Béguin.

FB: En ce qui concerne les données de l'accouchement, il ne faut pas confondre 3 besoins. Un besoin de tout hôpital, ou de toute clinique, de pouvoir juger son propre travail est de pouvoir analyser ses points forts et ses points faibles. Deuxièmement tous les besoins de la recherche qui sont essentiels bien entendu. Enfin, et c'est ce dont nous parlons aujourd'hui, les données que nous devrions obtenir sur un plan plus général et, si possible, sur le plan national. Je crois que, en ce qui concerne cette dernière exigence, les propositions qui ont souvent été faites ont le désavantage, dans un pays plein d'individualistes comme le nôtre, d'être trop lourdes et trop longues pour être remplies véritablement sérieusement. Les données qu'il serait indispensable de connaître ne sont pas tellement nombreuses, je vous les cite rapidement:

- la semaine de grossesse
- le poids de naissance
- le mode d'accouchement
- les présentations foetales, céphaliques, podaliques, transverses
- la mortalité, qu'elle soit maternelle ou périnatale, avec sa chronologie, y compris la mort pendant le travail bien endendu
- le taux d'Apgar
- la présence d'une malformation
- le lieu de l'accouchement
- les grossesses multiples
- la demande d'allaitement de la mère.

Je m'arrête ici, le reste étant du domaine du néonatologue. Voilà par exemple une liste courte de données que nous aimerions bien connaître sur le plan suisse.

UA: *I would like to hear Prof. Duc's views on that point.*

GD: Moi j'aimerai beaucoup savoir, mais je suis très modeste sur la demande générale parce que j'ai fait de mauvaises expériences avec toutes sortes de protocoles que j'ai envoyés à travers le pays et qui ont, après un certain temps, entrainé des réactions de fatigue. Je ne crois pas que nous pouvons, à long terme, enregistrer tous les risques tels qu'ils sont enregistrés aux Etats Unis et que Monsieur Spuhler nous a présentés ce matin. Pour mon compte je serai déjà satisfait avec la proposition A de Monsieur Spuhler (données modestes). Bien entendu, l'âge de gestation est très important pour tous. II serait aussi important que nous enregistrions les malformations. Nous avons quatre grands facteurs qui influencent la mortalité néonatale. Ce sont l'âge de gestation, le poids de naissance, les malformations et le niveau socio-économique. Pour le reste, il y aurait toute la pathologie néonatale, qui ne peut pas être enregistrée au niveau national. Si on veut atteindre ce but, ce sont les unités de néonatologie qui doivent échanger leurs données et obtenir ainsi des bilans annuels. Je ne crois pas que l'on puisse enregistrer à long terme un grand nombre de données. Les formulaires sont habituellement long à remplir. Les personnes qui les remplissent ne sont pas directement intéressées aux résultats et finissent par mal faire leur travail. Les statistiques qui incluent des chiffres impressionants sont souvent les plus imprécises et les plus utilisées parce qu'elle permettent toutes sortes d'interprétations!

UA: *I think that this is probably one of the points on which we will come back this afternoon, in the round table on "Agenda for the Future". I think that I would like now to hear also the pathologists point of view on the optimal data set. What do you think of the quality of the death certificates now? Is there improvement needed?*

JC: It is one of the most difficult problems, at least in Geneva. The certificates are filled out by the obstetrician, and the pathologist has very little to do with the certification of death. The pathology report usually goes in weeks later and I really don't know exactly what happens to the document once it is submitted.

RL: I want to underline once again that we are not just evaluating the perinatal period, but assessing a biological continuum that goes from conception to one year of age. We not only carry out comprehensive perinatal postmortems, but do the same for the fetal deaths (between 12 and 23 weeks' gestation) and postneonatal deaths (4 weeks to 1 year of age). In this context we must bear in mind that there is a difference between a classification based on the biological age and that following the postnatal age for the purpose of vital statistics. For example a preterm baby born at 26 weeks that survived 10 weeks will be registered as a postneonatal death, but the biological age for the specific pathology is going to be that of about 36 weeks.

UA: *The problem we are facing now is that resources may not increase like they did in the past years. At this time we have to use whatever we have in the most efficient way. This probably means that we should not plan too many too ambitious projects, but we should improve what we do anyway, such as birth and death registrations. We should make what we register today better available and improve its content to better answer the questions we have. We should aim to improve the quality of life for our children but not to improve survival at all cost. This is the balance with which we have to make the judgement. Well, not we, but finally the neonatologist, will have to make the judgement.*

RL: The resources we have in developmental pathology are too restricted and many times absent. Perinatal and fetal medicine has developed enormously in the last 5 years. Unfortunately, the services in pathology have never been taken into consideration in that development.

UA: *We do hope that less babies will die. I would like to now open the discussion with the audience. I think many of you may have thoughts too, what is our aim? Did we make a clear enough statement of what the aims of perinatal statistics are? What data should be collected, or what data should be improved? We will come back to this question later on, but many of you may also have questions to Prof. Paneth and to Prof. Wigglesworth and I would like to open the discussion for everybody.*

Emilio Bossi: I would like to be a little provocative. I do not doubt at all the importance of the postmortems for our own education and for our self evaluation, and maybe even for some kind of progress. However, I think that, and I am talking of neonatal mortality, birth till 28 days, this mortality has now left the field of epidemiology in Switzerland. We have reached neonatal mortality of 5–6 per 1000 live births, and the newborn infants who die today within the first 28 days are individual tragedies but no epidemiologic statistical babies any more. If we have little manpower and financial resources, we should not stress death too much, but rather look for the outcome of these babies. Prof. Duc was very pessimistic about registering morbidity data and I, unfortunately, must agree with him. It would be very important basically, that's what Prof. Laurini said, to extend the concept of neonatal mortality to a later age, because in the first 28 days, I repeat, there are very few children who die nowadays, and the ones who die after 2–3 months with chronic pulmonary disease or central nervous problems are those representing an increasing concern. We should try to extend this perinatal period, I don't know for how long, but for certainly more than 28 days[2].

UA: *That's a series of comments more than a question. From the point of view of epidemiology, the average mortality rate does not necessarily mean that there are no specific subgroups which still do have very high mortality rates, which we have to look at more carefully. We do know that our low overall mortality rate is due mainly to the very low mortality rates of the normal birth weight babies, but we also know that we do have a problem with the very low birth weight babies, and that this problem is increasing. We would have to reach an agreement on this, but I do think that there is a problem of quality of life, and there is also a problem of avoidable death. We have seen clearly for the State of Michigan (presentation of Dr. Paneth) that you can improve things with prenatal transferrals, and I don't see why a child, say for instance in the Bernese Oberland, should die when it has a better chance of survival if it were born in Berne City. I don't really see any justification for these differences. The aim of our health service is to avoid deaths and to improve health.*

Nigel S. Paneth: I would like to ask a question, which is addressed to you Tom, or other people involved in the vital registration system in Switzerland. The thing that surprised me most this morning was to discover that the location of the birth is not recorded, not only in Switzerland but also in every other European country that you showed us in your slide earlier (see above, presentation of Thomas Spuhler). The importance of this information is so evident for us in the USA, that it never occured to me that it might not be present in any other system. It is an absolutely essential information to see how the system is doing, because the whole system is about getting babies born in the right places. I would like to know what is the nature of the resistence to putting this on the birth certificate or making it available, and what are the chances of changing this?

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[2] *Of the 537 infants (birth to one year of age) who died in 1991 over 2/3 died within the first 28 days and of these 2/3 over 3/4 died during the first week after birth, (NED).*

Thomas Spuhler: I dont know why it's not there. I think that birth registration in central Europe is a means for demographic statistics, and not for public health purposes. I am not sure whether this is the main reason. It is certainly not difficult to have it on it.

UA: *I wish you were right in saying that it is not difficult to have this information. I have had a different experience in the past. I do think there that the point Fred Paccaud made this morning is important. We do not have a Minister of Health in Switzerland and the people responsible for care and quality of care are the Cantonal Ministers of Health. They may have difficulties to agree on which is the most important information they need, and those who think they need certain information will obtain this information, but on a cantonal level.*

Jonathan Wigglesworth: Prof. Duc said that initially he wasn't quite sure why he wanted statistics. Then he said that what he did want was more neonatal care cots. In the UK, and I would guess probably also in the US, if you want better facilities, you get publicity for your problem. The way you do this is to produce statistics showing that you have now more low birth weight babies, needing longer stays, and that it is very difficult to find intensive care cots for them. And that, as a result, you have a higher mortality than some other jurisdiction, perhaps particularly one that has a lower standard of living. And you say that they do much better for their babies, therefore, you need more facilities. This is why you have to produce your statistics, because you have to convince the people of this point. Once you get it into newspapers and everyone says 4 out of six babies who die would be saved if we had better facilities, you are more likely to get the money. What statistics do you want for live babies? Clearly, it seems to me that you have got to have gestational age as well as birth weight available. You presumably want something about state at birth and you obviously, for this survivors need something about length of care. It would be nice to have something like intensivity of care available. Length of care would be useful, even if it means only number of days. In Britain we have a form called "hospital activity analysis". How easy it is to get them back at a later stage, I dont know. That type of information needs to be collected if you are to find out how well you are doing in efficiency of care, particularly with live births.

UA: *It is important to know that in many ways we envy the british system and its statistical tools. It is not by chance alone that the UK was not on the comparative Table that Thomas Spuhler showed us earlier. It would have been quite a complete one. It also has a linkage system which goes much beyond what can be done in Switzerland.*

GD: I want to comment on your remark, Prof. Wigglesworth, because I am afraid that I was not clear. The vital statistics in Switzerland have been collected to study movements of population, and not for perinatal purposes. We have now good informations about the movements of our population. If we want to integrate new data in this system, we have first to articulate the questions we want to answer.

RL: Coming back to resources, I agree with you that we do have overall resouces we are not using. There is an aspect that one seems to avoid systematically and that is the establishment of the Perinatal Audit, and the creation of Perinatal Committees on a regional basis. Having participated in a number of perinatal audits in different European countries (not in Switzerland), I am convinced of its role in the planning of fetal and perinatal health care. This facilitates the allocation of resources in accordance with an objective evaluation of workload and pathology in a given population. Perinatal audits are now compulsory in Great Britain and the developmental pathologist is an obligatory member. We must evaluate to know exactly where we are. Not to criticize, but to know where we are.

UA: *I am very grateful for this one, because I have, in the past, made several efforts to introduce perinatal audits in several countries. I must admit that I have not been very successful in this. It is one of the tools to show where the weakness of the system is. But again, we heard earlier about the independance of the cantonal governements, and of the lack of collaboration between different partners in health services. This is one of the characteristics of our health care system. We should concentrate on what we can achieve now and what we would like to achieve later. What can easily be achieved is an improvement of existing statistics so that they will better serve the purposes we have. Some of the data we clearly don't have today; we don't have gestational age, we don't know about the malformations, and in order to look at care, we don't know about places of delivery. For the sick babies we would need places of care. I would like to put these points for the last three minutes for discussion from the point of view of the clinicians, neonatologists and obstetricians. Is there some essential other thing that you would like to add to this?*

GD: I would be very pleased, Prof. Ackermann, if we could have that, because yourself and Dr. Paccaud have produced a fantastic document in 1985 on birthweight and mortality in Switzerland 1979–1981[3]. It would be beautiful if you could publish this kind of analysis every 5 years, including gestational age and place of delivery. I know that it is not very easy in Switzerland to get this kind of information. Prof. Sam Prod'hom, the father of swiss neonatology, who is with us today, has been fighting for years to get birthweight on the birth certificate. As you know, this information which is available in most industrial countries for years, was registered for the first time in 1979. We have now to fight to get on the birth certificate gestational age and the place of delivery. If the question is: what are the needs of perinatal medicine in Switzerland, we have to know at least where the babies are born, where there are taken care of and in case they don't survive their neonatal period, where they died? Combining this information with birthweight and gestational age, we would know a lot more than now.

FB: Je ne peux que soussigner ces déclarations et, en effet, si on avait quelques éléments supplémentaires, comme je l'ai dit tout à l'heure, on serait très heureux. Ces éléments que nous demandons maintenant, la plupart des hôpitaux, cliniques, médecins ou sages-femmes ont ces informations-là. Quel est le moyen pour que tout le monde les donne? Quel est le moyen d'autorité ou de coercition qui fera que tout le monde participe? C'est peut-être aussi ça la question qu'il faut se poser. Sans une discipline, peut-être imposée, est-ce que nous ne sommes pas en train de tomber dans l'illusion?

JC: The list you propose is not very long, but I think that some of the most important items that are missing from our discussions are collaboration and teaching. If you don't teach the people what you desire to obtain with this, you will just be without any resources.

RL: Although it is very important to determine the percentage and type of malformations, most problems are related to fetal and perinatal asphyxia, including intrauterine growth retardation, SIDS etc. I insist on the fact that to the list you are proposing we should add a 5th point, which is a standardised developmental postmortem and the classification of the findings following an anatomical classification as well as the Wigglesworth's classification.

UA: *I thank you all for your contributions.*

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[3] *Geburtsgewicht und Säuglingssterblichkeit in der Schweiz. Bundesamt für Statistik, Heft 126, 1985.*