
Preface

In 1964, a few years after the thalidomide tragedy, the National Board of Health and Welfare in Sweden decided to start a register of congenital malformations for surveillance purposes. Together with Jan Winberg, pediatrician, I was tasked with arranging and running the register which I continued with until 1997, a third of a century. Since then I have worked with the National Board of Health on a free-lance basis. In 2014, I will have been working within the field of reproductive epidemiology for 50 years. For natural reasons I do not expect to be able to continue this work more than for a relatively short time. I therefore thought it would be a good idea to collect data and present them in a book with some comments and conclusions I have reached, based on these experiences. I decided to restrict the period of data analysis to 1998–2010. The 1998 limit was put because that was the first year when the new ICD-10 classification system was used in Sweden which made malformation registration in some registers more uniform and more detailed than previously.

Much birth defect epidemiology is based on the identification of outcome (malformations) and exposures. After having performed a few retrospective case-control studies and experienced the problems with recall bias and non-responders, I decided to exclusively rely on prospectively collected exposure information, ascertained in a similar way during pregnancy for women who had malformed infants and women who had non-malformed infants. This was possible because in 1973 the National Board of Health and Welfare started a nationwide registration of medical information on all births, and in 1982, 1992 and 1995 data on some exposures were entered, ascertained by midwife interviews at the first prenatal care visit. Practically all pregnant women come to the prenatal care centers and the medical record forms used were identical throughout the country since 1982. This thus represents a large, ongoing prospective study even though data are recorded in a national health register. The draw-back is, of course, that only recorded exposures can be studied and many of the putative risk factors which have been discussed in the literature are not possible to collect in a system like this. It is always a balance between what could be of interest and what is possible to achieve. The midwives who make the interviews around the country and the women who answer them must feel that the questions are realistic and can be of significance for the clinical situation.

One can, for instance, hardly register information on nutrition (because of the complexity in description) or personal matters like showering or hot tub baths. Maternal chemical exposure is important information but unfortunately the only realistic data which can be recorded are occupation which is too crude – and often recorded in such an unspecific way that it is not useful. Efforts to register important but sensitive matters like alcohol consumption were not successful. One tried a simple question, “Have you used alcohol during your pregnancy?” Answer alternatives: No, Seldom, Regularly. I went through 500 randomly selected records and there was only one woman who said she had used alcohol regularly and a note said it meant drinking low-alcohol beer at dinner every day. It seems rather unlikely that none had drunk wine or strong liquor during pregnancy but the general knowledge of the hazards of alcohol drinking during pregnancy may have made the women unwilling to disclose their behavior.

It is obvious that the data and the conclusions I draw from them only refer to the Swedish population but they could be valid at least for North European and perhaps for Western populations.

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