Epidemiology, medical demography and data quality issues in the former Soviet Union

At the end of the 1980s and early 1990s, all the countries of the former Soviet Union experienced a dramatic mortality crisis leading to considerable losses in life expectancy. Nowhere was this so important as in Russia, where between 1988 and 1994 men lost nearly eight years of life expectancy and women 3.5 years. Surprisingly, there was little attention to this in Russia, and in particular virtually no epidemiological attempt made to understand what was happening.

However, this is perhaps not as unexpected as it first seems because, as Vasily Vlassov clearly describes in this issue, epidemiology in Russia (and almost everywhere else in the former Soviet Union) was exclusively concerned with infectious diseases. Epidemiology of non-communicable diseases was not even part of the curriculum of medical students, and although infectious diseases did increase during the early 1990s, the leading causes of the mortality crisis were cardiovascular diseases and accidents and violence.

One remarkable exception to the apparent indifference of scientists to the increasing mortality was a team of Russian demographers from Moscow’s Centre for Demography and Human Ecology, who in collaboration with demographers from the French Institut des Études Démographiques investigated thoroughly the reasons for this decreasing life expectancy. This seminal work was followed by further collaborative studies with Western groups leading to a much better understanding, albeit still incomplete, of the mortality crisis, underlining the role of alcohol in a population subject to high psychosocial stress.

One striking feature, however, of all these studies is that they are based on relatively little information on the validity of causes of death data, information that is vital for both epidemiological and demographic studies. Investigators had to base their estimation of data quality on indirect observations, such as the stability of cancer death rates during the crisis. Cancer cannot be affected by such short-term changes in circumstances: the absence of fluctuation in cancer validates the large fluctuations in all other causes.

The culture of secrecy that prevailed in the former Soviet Union prevented criticism. Admission of failure was not considered possible or was at best tantamount to political suicide. It was therefore difficult to admit that even in the best Soviet system something could be found wanting. Studies of the reliability of vital statistics were rare. The Russian and French team found four studies of reliability of causes of death. They concluded that although the proportion of error was often high, especially in rural areas, these were mostly confined inside a large diagnostic category. Therefore by using a whole ICD chapter one avoids the risk of recording bias.

We recently conducted a literature review in Russian and Ukrainian languages of studies of death certificate reliability and identified 10 papers published between 1963 and 1991—that is, during the Soviet period. Without going into too much detail, the first striking feature of all 10 studies is the poor quality of the reporting and the lack of clarity. Only five studies actually give the total number of cases reviewed, and although most of them present their results using percentages, sometimes only absolute figures are given. Criteria used to ascertain data quality vary, but half of the studies use necropsy reports as a gold standard to measure validity despite the fact that the earliest study already demonstrated a high proportion of errors in necropsy protocol, indicating either unwillingness or difficulty in accessing even Soviet literature.

For all their shortcomings, the studies paint a grim picture of data reliability in the former Soviet Union. While it is true that most errors occur within a particular disease category, inter category misclassification is not rare. For example, Smirnova et al report that 366 (12.7%) of the 2886 cardiovascular deaths they investigated were in fact poisonings, while 286 deaths (9.9%) were attributable to cancer. A necropsy is by no mean a guarantee of reliability apparently for two reasons: pathologists and forensic doctors are themselves likely to erroneously diagnose the cause of death and according to Bystrova et al the referring physicians do not always wait for the necropsy results before filling in a death certificate. Finally, coding errors also frequently occur.

Many epidemiological and demographic studies are based on routinely collected vital statistics. It seems that the rare studies that have investigated reliability of these statistics find them wanting. There are various reasons for this: the training of physicians might have been inadequate, particularly regarding coding; poor salary and working conditions do not encourage best practice; and official pressure of health authorities also influenced reliability of death certification. The official doctrine about the advantage of a socialist lifestyle and Soviet health system had to be proved by vital statistics. For the time being, scientists will have to use these data but must be aware of their possible flaws. Immediate attention must be paid to data quality improvement, although the introduction of ICD10 in many countries is likely to increase the occurrence of coding error in the near future.

Without even going into the sophisticated methods mentioned by Vlassov, the teaching of epidemiology has to be greatly developed to introduce the study of non-communicable diseases, which are by far the most important causes of death in the former Soviet Union. This is even more important given the still not fully understood recent fluctuations of cardiovascular disease mortality. New concepts, such as the study of socioeconomic inequalities, denied during the Soviet period, will have to be introduced. It is also highly desirable, in the former Soviet Union as in the West, that the study of epidemiology is opened up to non-medical specialists.

Finally, epidemiological and demographic study results will have to be fed to policy makers to develop an adequate public health strategy so desperately lacking in many countries of the region. In other words, instead of the
doctrine influencing science, science will have to inform the doctrine. This might take a long time. Old habits die hard.

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