Epidemiology in transition

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In this address, an increasing role is suggested for epidemiology in assessing public health interventions, be they man-made or instituted by Nature. Epidemiologists should also be challenged by the ongoing transition in health and encouraged to approach global health issues, since only the best methods are good enough where health problems are great and resources scarce.

Epidemiology—a Value-free Tool-box?

Epidemiology relates to the distribution and determinants of diseases with the ultimate purpose of controlling and preventing health problems. Health problems in society may be identified at the bedside, in the community or at the political level. In 1978, Lilienfeld illustrated how the definition of epidemiology had changed over the previous 50 years. He pointed out that the subject had matured into a discipline, but also that it was still perceived by many as the ‘science of epidemics’. ‘The distribution of’ was a common feature of most definitions. Essentially, this implied statistical distribution, not the more value-charged perspective of social distribution characteristic of contemporary social epidemiology. Modern epidemiology, having developed into a set of generic methods, is a ‘mixed blessing’ and it has been suggested that we must now rediscover its population perspective and move towards an eco-epidemiology with multilevel analyses, instead of repeating ourselves at the individual risk factor level.

Despite a general improvement in health in Sweden, previously less visible health problems and risks, related to social and work environmental conditions, are on the rise. There are disquieting signs that the positive development in health may be breaking down in areas such as mental health, obesity, allergies, physical inactivity and dietary habits. Perceived health problems are thus increasingly recognized. Great social differences in health also persist. A public health and epidemiological research challenge is both to better understand the mechanisms behind social inequity and to design and evaluate measures to counteract this development.

Inequity means unfairness—nothing is as unfair as poverty. No epidemiological risk factor is as strong as poverty—it is a determinant of why you die, when you die and where you die.

Over the past 40 years life expectancy has increased from 40 to 63 years; more than during mankind’s entire past. Under-five mortality has similarly decreased from 28% to 10%, but in the poor areas of the world it remains ten times that in affluent countries. If mortality among children were to be lowered to the level of industrialized countries, 11 million fewer child deaths would occur every year. Maybe the greatest area of public health neglect is the half a million women dying each year from delivery complications. Such a death is 30 times more common among the poor of today and more common even than in 1880 in Sweden. We are aware that tobacco will soon generate more premature mortality and suffering than any single disease. Should current smoking rates persist, in 30 years tobacco will cause 12 million deaths annually, mainly in Third World countries.

Public health is facing new and re-emerging diseases. With increasing longevity and urbanization an epidemiological transition is ongoing and during this period many countries will have to carry the double burden of diseases at both ends of the welfare scale. The cardiovascular epidemic, which is now on the decline in most rich countries, is emerging as a major public health problem in the Third World. Already the number of cardiovascular deaths exceeds the number of deaths from infectious disease in many Latin American and Asian countries. It is estimated that half of all cardiovascular deaths now occur in the traditional developing countries. The concept of health transition includes not only changes in demographic patterns but also the social and behavioural changes which accompany and propel them, as well as the responses of health services to the changing patterns of disease. The ongoing transition allows for the chronic diseases of ‘welfare’ and ageing, but results also from the ‘export’ of well-known risk factors.

Epidemiology in Sweden during the 1990s—A Proposed Taxonomy

The textbook way of classifying epidemiological research is into descriptive, analytical, and intervention studies. Epidemiology also often appears ‘hyphenated’ to disease groups (e.g. cancer-, cardiovascular-, infectious disease-) and to exposure factors (occupational-, nutritional-, social-). Is this still a valid taxonomy for epidemiological research? This question was discussed in depth by a Swedish task force jointly appointed by the social (SFR) and medical (MFR) research councils. Each member of the task force independently attempted to review and classify epidemiology as it appeared in 129 randomly chosen project applications submitted to the two councils during the past 5 years and reviewed by their peer review committees respectively.

Based on the above, the task force identified three dimensions of a taxonomy for epidemiology; the group to be studied, the focus of the study, and the level of explanation. ‘Group’ essentially refers to the patient or population group. ‘Focus’ concerns whether the main area of interest of the study involves disease, exposure, social distribution/psychosocial consequences, or the function of the health care system. ‘Level’ refers to whether the aim is to survey and/or monitor disease or exposure, identify its aetiology, or evaluate an intervention.

This taxonomy was used as a basis for a questionnaire which was mailed to the 345 registered members of the Swedish...
Epidemiological Association (SVEP) in May 1995. The response rate was approximately 70%. In total, 251 epidemiological projects were reported by 143 researchers. Population studies were included in 75% of the 251 projects, patient data in 22%. Disease was the focus in 51% of the investigations, exposure conditions in 68%, social/psychosocial conditions in 11%, and function of the health care system in 13% of studies. Roughly one-third of the projects aimed at surveillance, three-quarters at identifying disease aetiology, and 19% at evaluating interventions. The dominance of disease- and exposure-oriented studies, especially those of an aetiological nature, clearly emerges among population studies. The social dimension is weak and examples of intervention projects are few. Of the ‘hyphenated epidemiologies’, cancer- and occupational-epidemiology were dominant, representing 27% and 20% of the projects respectively. Projects were classified as methodology studies in only 9% of the cases.13

Epidemiology for Public Health Interventions

The development of modern epidemiology parallels the evolution of public health. However, the elaboration of methods and concepts within epidemiology has focused on causal analysis (rather than on the evaluation of interventions) and on the effects of individual exposure (rather than on community-based public health work), thus leaving prevention through community intervention on the sidelines.

There is a considerable gap between the epidemiological identification of risk factors and the scanty documentation of the effects of intervention. Even when an association with many risk factors has been confirmed, their importance in the population may not be as evident, either because only a limited proportion of the population carries the risk factor, or because its prevalence in the population is not known with certainty. Regardless of the known value of an intervention, a medical technology or treatment, its uptake is also dependent upon its dissemination and acceptance. This process is often informal, sometimes scientifically rigid and awaiting proofs within the current paradigm.

Medical technology is primarily assessed with respect to its efficacy and risk of causing harm. Lately, the costs as well as the ethical and social consequences of its use have begun to be considered. However, few established technologies have been tested using all of these criteria. There is indeed no general agreement as to which criteria of usefulness and harm should be applied. Aims may thus be to prolong life, to reduce suffering or to improve the quality of life. These aims may also conflict with one another and differ depending on who has specified them—patients or professional assessors.

Interventions may take very different forms, from narrow and well-identified treatments to broad societal and structural changes. They may be initiated by researchers, by policy makers or simply by Nature. Evaluation of interventions may be through randomized or non-randomized experiments or by non-experimental observational studies. Sometimes one has to sacrifice the scientifically ideal for the ethically justified and feasible. Interventions may be aimed at individuals or communities. The dose or the acceptance of the intervention may be controlled or uncontrolled. A randomized controlled trial deliberately instituted by a researcher is the exact opposite of the description of a disastrous or haphazard natural experiment.

I will try to identify some methodological and conceptual issues that, from an epidemiological viewpoint, may be addressed within an interdisciplinary framework, here outlined by reference to the evaluation process:

Identifying the public health intervention

A key problem in public health intervention is assessing the degree of exposure required for the intervention. So far methodological interest in the intervention itself has been much lower than the interest devoted to the outcome of it.

Designing the evaluation

To design an evaluation means exercising some degree of control over the intervention process. The possibility of control is generally much lower in public health interventions than in situations which are more experimental in character. How should the ethical principles of autonomy, benefit, lack of harm and justice be interpreted in the field of public health evaluation? Who’s values determine the choice of intervention strategy?

Selecting the study population

In public health interventions it is often not possible to isolate exposure to selected individuals. Rather, the basic idea is to initiate a process within a social context and to utilize the group dynamics and interactions inherent in that context to generate change. Here, the methodologies of intervention and evaluation come into classical conflict with each other.

Measuring the exposure

In contrast to the randomized controlled trial, where the exposure is defined and often dichotomized, the exposures in a community intervention are multiple, consisting of many interacting parts and partners. It is important to understand which components work and which do not, and why assessments must be based on processes as well as effects.

Defining the outcome criteria

Similar to clinical medicine, proper outcome measures are mandatory for the evaluation of public health interventions. They may be ‘harder’ e.g. mortality changes or ‘softer’ such as perceived health or behaviour changes. In most public health interventions there is a need for developing outcome criteria combining these measures. In interventions targeting health problems with a long latency, e.g. cardiovascular disease or cancer, it is necessary to employ intermediate outcome measures, e.g. biological markers or risk behaviour.

Assessing the social consequences

Public health interventions are directed towards social systems by trying to influence people’s attitudes and actual behaviour. Despite the fact that social inequality prevails for most diseases (whether measured in terms of morbidity or mortality or based on self-reports or medical diagnoses) and occurs early in life, the social dimension is rarely included when assessing prevention: during the 1990s, a total of 150 000 articles in MEDLINE had ‘prevention’ as a keyword. ‘Community-based intervention or prevention’ cut the number to about 8000. Health or social
differences, as indicated by using ‘equality’, ‘inequality’, ‘equity’ or ‘inequity’ gave a total of 847 references. However, only 24 of these were related to community intervention studies. Many public health interventions recognize the health divide, but very few have tried to tackle the problem.

Moving from efficacy to effectiveness
Effects shown in clinical trials may be difficult to confirm in a public health setting. Acceptance of or compliance with the programme will also influence the outcome. The biological efficacy of the medication may be demonstrated in a randomized controlled study. However, when this is implemented in community intervention programmes there will be less pressure on individuals to take the medication as recommended and the impact of the intervention will not be so marked. Community-based intervention must therefore evaluate and measure the public’s involvement and participation.

Public Health and Epidemiology in Transition
Epidemiological studies have played a decisive role in identifying risk factors related to lifestyles and the environment. Results from epidemiological studies often attract widespread public interest. They address central issues regarding lifestyle, environment, and social conditions, hence attracting the attention of the media. Hence, epidemiology has a special responsibility to inform the public in an accurate and understandable manner. Terris has provocatively suggested that if the results of epidemiological research were really adopted, widespread change would occur in the agricultural and industrial sectors, with decreased production of tobacco, alcohol, animal fat products, and pharmaceuticals. Effective prevention of injury would also require trespassing into the everyday life of the individual.

I have previously discussed the role of epidemiology in prevention and indicated that methodological problems in the evaluation of intervention studies often mean that they fail to live up to expectations in terms of prevention. Outcome indicators must be developed and the traditional appraisal of effects supplemented with process analyses using both quantitative and qualitative methods. There is an epidemiological potential in prevention and one challenge lies in bringing the development of epidemiological theory and methods nearer to public health efforts. With this as a starting point a number of problem areas may be identified, some of which have special bearing on social epidemiology. Some may also respond to the unfinished health research agenda and the ongoing epidemiological transition.

Epidemiologists may certainly contribute to conceptual and methodological development of the changing public health in terms of its efficacy, cost-effectiveness and social and ethical implications. Specifically, this implies:

— paying greater attention to structural and macro-epidemiology that analyses the effect of societal, economical, political and environmental changes on morbidity and mortality,
— developing theoretical and methodological measures of outcome in preventive programmes accounting for the exposure intensity of interventions,
— analysing the social consequences of community-oriented health work, its benefits and possible harm for public health and
— assessing the preventive potentials of health care involvement in different intervention strategies.

In conclusion, I will illustrate the above by reference to some ongoing projects and extract the epidemiological issues therein—the questions rather than the answers:

Swedish adolescents have decreased their fat intake substantially over recent decades and it is in fact today lower than the fat intake among adults. What made this change occur? Was it the effect of health education in schools? Can it be explained by changes in the composition of school lunches? Are adolescents picking up health messages meant for adults? Have dietary health campaigns contributed to the increasing numbers of eating disorders now seen in the adolescent population?

In many European countries coeliac disease has emerged as an increasing public health problem. An epidemiological surveillance system has demonstrated the rise and fall of the disease in Swedish children under 2 years of age. In a case-control study, an increased risk in early childhood was associated with breast and supplementary feeding habits. As a result, dietary recommendations and baby food content have been changed. What is the importance of this for the ‘epidemic’ change in incidence? What is the role of breastfeeding, infections, or immunization? This illustrates the processes operating in a modern society when facing a new health problem.

In order to reduce the high incidence of cardiovascular diseases and diabetes the Västerbotten County Council decided to start an intervention programme in 1985. Since there were no Swedish prototypes for this type of intervention a model adapted to Swedish conditions had to be created. It was developed in the municipality of Norsjö and was later disseminated to the 14 other municipalities in the county. Up to June 1998, more than 52 000 people, aged 30, 40, 50 and 60 years participated, almost everyone also filled in a questionnaire and donated blood samples to be stored in the Northern Sweden Medical Bank. Using the primary care system as a partner, the programme carried out systematic risk factor screening, gave counselling through its family medicine providers and at the same time the community intervention programme used strategies to raise public awareness.

We found this long-term community intervention to be effective in influencing important cardiovascular disease risk factors. Based on the observed risk factor changes we predicted a 36% decline in mortality in the intervention area compared to 1% in the reference population. The decline in predicted mortality risk was even more pronounced among the less educated. The study suggests that a key issue for success is to actively involve the health sector and health professionals within the larger framework of a community intervention programme.

There is, however, a need for further empirical studies on the feasibility and effectiveness of different prevention models, characterized by different health care system involvement and inter-sector co-operation. This becomes even more important as all health care systems are continually challenged by new demands and shrinking resources for meeting these demands.

Few interventions have been as carefully evaluated and may be therefore so intensely questioned as mammography screening.
So far seven randomized controlled trials have been performed worldwide, four of these in Sweden. Although each trial was supposed to determine whether mammography screening could reduce breast cancer mortality in the age group studied, the researchers could not refrain from subgroup analysis. This showed that the effect varied by age and was one of the reasons for merging the Swedish trials. It was also demonstrated that it takes time to show an effect and that most trials were evaluated much too early. Today all county councils in Sweden offer mammography screening, the so-called Swedish service screening programme. The question is now whether it will be possible, when screening is made a routine activity, to reproduce the results from the randomized trials.

Epidemiological reasoning and methodology are central to disease surveillance, and in the search for risk factors as well as in the planning and evaluation of intervention programmes. In a Third World situation in particular, planning for health must be based on knowledge of the population including those who do not use the health services. The largest death toll in periods of crisis and warfare in low-income countries is usually among infants and children under 5 years. Based on bilateral research collaborations with universities in the South we have been able to study the consequences of rapid social and political change.

In Somalia 1987–1989, prior to the onset of the civil war, we had the opportunity to monitor child mortality through a village-based epidemiological surveillance system. Mortality increased twofold among those under 5 years from 21% in 1987 to 41% in 1989. For infants the increase was threefold. War is the ultimate intervention, the consequences of which could be predicted from even these routine data, illustrating also that national and global ‘exposures’ may manifest themselves at the village level.

In Nicaragua, in contrast to the African experience, infant mortality decreased markedly during the period of transition 1979–1985. A decline in fertility was a reflection of the expansion of women’s education, while the decrease in infant mortality was mainly due to improved survival among children of less-educated mothers. Infant mortality again mirrors the face of poverty—being poor among the rich seems to be worse than being poor among equals.

In Ethiopia, we have established a demographic study base for research on essential health problems in a rural area and strengthened and developed research capacity and infrastructure for this purpose. The study base and its surveillance system has ‘detected’ an epidemic of malaria and meningitis among children in its lowland communities and highlighted a gross discrepancy between the need for and access to organized health care at district level.

In Tanzania, the first cases of AIDS were reported from the Kagera region in 1983 and since then the number of reported cases has increased at alarming rates. A population-based study in the region revealing that one in four were HIV infected in urban areas was the epidemiological starting point. The basic epidemiological and behavioural data have later revealed much of the despair following the first decade of the pandemic. A forthcoming thesis will have the privilege of conveying a more optimistic scenario with declining HIV trends and suggestions for how to monitor trends through, for instance, sentinel surveillance. I can hardly find a better example of how epidemiologists from the North have been taught how to approach the community, how data can be used in a dialogue with people and how important culture competence is when trying to intervene to prevent disease.

In Somalia, the research results reflect the continuous deterioration of Somali society. It may seem misplaced to show a historical, however recent, epidemiological picture of such a development. The chronic and pandemic nature of poverty and health needs should, however, be brought to the attention of the world’s conscience. Epidemiologists have the tools—do we have the value premises? The current situation in Somalia has caused huge difficulties and delays in analysing and reporting results, thus illustrating that for epidemiology to talk we need timely data; for one billion people living in the world’s poorest countries, where the burden of disease is highest, those who are born or who die are still not counted. I propose this should be the challenge for future epidemiologists.

References


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