



Colin L. Soskolne*

LINKAGES BETWEEN EPIDEMIOLOGY AND HEALTH POLICY

Abstract

Epidemiology is the science basic to rational public health policy-making. Thus, it behooves the epidemiologist to recognize the social responsibility dimension of the profession. Recognition involves understanding relevant linkages between the discipline and policy formulation. It is apparent that many competing forces represent the diverse interests of society and these are brought to bear on governments. By understanding the linkages among the different interests, epidemiologists can become more effective in honoring the core professional value of protecting public health. If epidemiologists are not at the table when issues influencing policy are discussed, it is not likely that the epidemiology perspective will be heard. For example, it is in the profession's self-interest to ensure access to data. Data protectionists, on the other hand, would rather that data not be accessed. Thus, an engagement between these two opposing views is needed if mutual understandings are to emerge. Additional examples are provided. By recognizing that the epidemiologist's role is to protect the public health interest, several logical extensions emerge. For example, by building partnerships with stakeholder interests from the community, epidemiologists are more likely to be effective in the policy domain by virtue of the bridges that already will have been built. Such engagement will more ensure vigilance and sensitivity to changes in social values. A challenge for the new millennium will be in establishing professional infrastructure that will

* Department of Public Health Sciences Faculty of Medicine and Dentistry University of Alberta, Canada

facilitate partnership building that best serves the public interest. Greater transparency among all stakeholders is likely to lead to policies that, in turn, result in a more sustainable future.

Introduction

Because epidemiology is the study of the distribution, determinants and dynamics of disease and health in populations, it is an applied science that informs the public health policy process. It therefore is the science basic to public health.

Health policy is the embodiment of society's governance on matters pertaining to public health. It includes general principles and directions to guide the public financing (both on the revenue and the expenditure sides) relating to the restoration, maintenance and improvement of public health. It is reflected in both law and regulation, including incentives and disincentives, designed to encourage compliance.

By its nature, epidemiology thus is a major health intervention. Because of this, the application of epidemiology exposes one through one's research to the practice environment and hence to the application of one's discipline to policy.

Competing interests

The purpose of this paper is to demonstrate how epidemiology can be more effectively linked to public policy. To achieve this, it is necessary first to recognize and to distinguish between two opposing forces: those of self-interest versus those of the public interest. If human conduct were always fashioned on The Golden Rule, then there likely would be no need to raise the concerns identified in this paper. The Golden Rule (adapted) requires of us that:

- We treat others as we would want them to treat us or our loved ones;
- Do our level best; and
- Assert ourselves if we find someone else who has done ill.

If humanity were capable of living according to these principles, then concerns about the agendas of those with vested interests would be minimal. Unfortunately, however, this is not the case. Hence the need to understand the interplay of competing interests in the policy-formulation context.

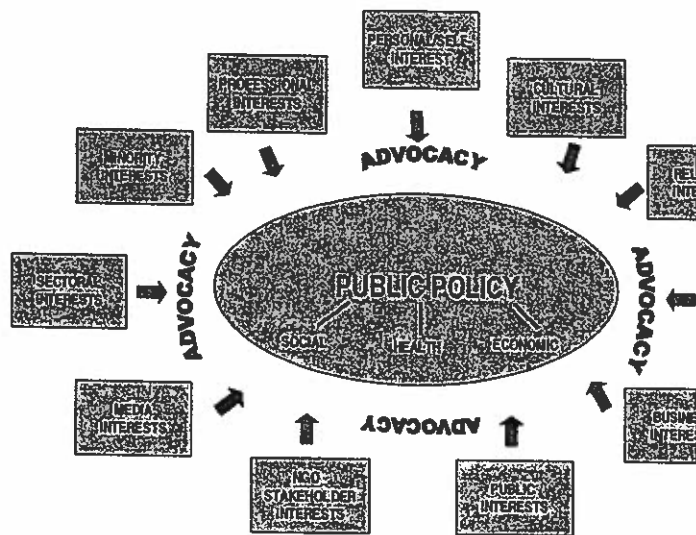


Figure 1. Interests, Advocacy and Public Policy.

In the Figure, eleven different interest areas that bear on policy formulation are identified. Each of these interest areas represents a source of advocacy and/or lobbying in attempts to influence public policy.

Working clockwise from the top, *personal/self interest* relates to the individual epidemiologist's values that sometimes can confuse the role that the epidemiologist plays in making public pronouncements. For example, in moving away from interpretations associated with one's data, one can inject one's personal values and beliefs into recommendations. Caution needs to be exercised in recognizing this potential. *Cultural and religious interests* often have carried much sway with policy-makers in part, because these interests are among the most organized in lobbying. Letter-writing campaigns are one such method. *Foreign interests* include the role that foreign governments might play in influencing policy in any other country. *Corporate/multinational business interests* are gaining more attention as free trade in the world allows multinational corporate interests to influence policy through legal mechanisms. *International agency and public interests* include the United Nations and its related agencies internationally, as well as the public interests that these agencies represent. By declaring positions on issues around the world, these agencies can influence public policy at the country level. *Non-governmental organization (NGO) stakeholder interests* include more and more specialized interests be they related to specific diseases or to environmental concerns.

Media interests include the role of the media as watchdogs over social/public interests. *Sectoral interests* include any of the various social sectors in society. *Minority interests* include those social groups which, under democracy, require protection under majority rule. Finally, *professional interests* include the role of the various professions in serving the constituencies that they, through their core values, represent.

For each of the various interests, there are established official and unofficial channels and/or mechanisms for lobbying, and therefore for potentially influencing those elected to government whose task it is to make public policy.

Risk assessment, management and communication

Epidemiology is concerned directly with risk assessment. The nature of the dose-response relationship is critical to risk assessment. While one way of gaining the attention of policy-makers is through the disclosure of a "body count", in epidemiology, our main mission is "prevention". Thus we work towards primary intervention as an ideal.

Risk management and risk communication are two related steps, but removed from the direct application of epidemiology. However, epidemiology informs each of the management and communication steps.

Information is power

Uncertainty erodes the power that information can provide and uncertainty is inherent to science. Hence, the more upstream the determinants that we are considering, the weaker becomes the power of the information that we generate to inform policy (because upstream determinants tends to have greater uncertainties). Thus, when we concern ourselves with globalization impacts (as presented by McMichael earlier (4)), we are dealing with distant determinants and their putative effects on health. The uncertainties associated with these estimates can be large. Hence, the utility to policy-makers of such information for policy is less apparent. The question that manifests for the next millennium, however, is what degree of risk is the policy-maker taking should a determinant with high stakes (i.e., with severe harms/consequences) have a moderate-high degree of uncertainty associated with it? While information is power, uncertainty weakens that power.

The consequence of uncertainty is to erode the utility of the information for the policy-maker. Yet, out of respect for the autonomy of the populations that we serve, we inform the public of our research as we progress. We believe, in so doing, that we bring society along with us in our understanding of the relationships between putative causes and outcomes. In the case of margarine having been touted as a healthy alternative to butter, this belief now appears to be enjoying less credibility, and butter indeed may have been healthier than margarine all along. The public becomes confused by this kind of "flip-flop" of science, and this confusion could lead to a general distrust of science, and of epidemiology, in particular.

Influencing policy

Scientists can be overly zealous when it comes to the readiness of their findings to influence policy. Some scientists may feel that their scientific evidence should be referred directly to government, thereby resulting in a direct impact on policy. However, this is far from practical if only because it fails to recognize that science is but one player in the arena of policy formulation. Public engagement should be secured prior to any government top-down policy approach. Thus, we tend find science media reports, which in turn influence public opinion; in turn, these bring pressure to bear on government.

Other interests also can come to bear related to the potential influence that the scientific data could have on policy. This raises the question of whether governments lead, or whether governments only respond to public pressure. John Snow, a hundred and fifty years ago, probably would never have impacted the London cholera outbreak in the way he did had he first had to attempt to impact policy that would have resulted in the removal of the Broad Street pump handle!

Perhaps among the most sophisticated of mechanisms for ensuring the influence of science on policy is the existence of the International Agency for Research on Cancer (IARC), in Lyon, France. This agency convenes three workshops per year upon which a monograph series on the "Evaluation of Carcinogenic Risks to Humans" is based. Also, the World Health Organization (WHO), through the production of its reports and guidelines, also serves to impact policy at the country level. The reports generated from these agencies tend to impact policy both from the top-down as well as from the bottom-up.

The former occurs through the reports being distributed to all agency member-country governments; the governments, in turn, through their appropriate administrations, enquire as to the local response to the content of the reports. On the other hand, the bottom-up mechanism takes effect through such reports entering libraries with public access.

The IARC workshops consider both human and animal data in establishing the degree of evidence for carcinogenicity. These workshops are planned well in advance with "expert" reviews. The workshop itself extends over a period of eight days of intensive deliberation. Invited experts, observers and the IARC secretariat are involved in these deliberations. Various subgroups are convened in the areas of epidemiology, animal carcinogenicity, other relevant data, genetic and related effects, and one to do with exposure assessment. The workshops are a dynamic process between plenary sessions, working subgroups and final plenary sessions through which the monograph text evolves. A full assessment of the body of evidence is made. The final designation of the chemical(s) assessed can have a profound impact on policy.

Case Studies

1. Tobacco-use

Enormous policy shifts over the years have taken effect as a consequence, from the early 1950s, of evidence generated from epidemiologic research. In earlier years, it was not uncommon to find tobacco-filled environments in cinemas, theatres, restaurants, public buildings, sports events, and the like. However, with the body of evidence indicating not only direct, but also second-hand effects of tobacco smoke, policies have been introduced to eliminate such exposures. The impact of policy on the ability of business interests to advertise and sell their products has been severely constrained. The ability to seduce non-smokers into the habit is being impacted. Product-labelling is something that is commonly seen. Non-smoking areas are commonplace today. While it took males about forty years to recognize the negative impacts of tobacco-use on their health, the increasing frequency of tobacco-use among females is a primary concern today.

2. Data protectionism in the European Union

Almost nine years ago, a directive was developed at the European Union parliament to limit access to data by prohibiting any type of linkage study. The directive passed through three readings over an almost 4-year period.

Finally, an approximately forty-five page document was issued. It excluded the potential for linkages of data that would severely impact, if not eliminate, much health and social research. It was only through last minute interventions on the part several organizations, including the International Society for Environmental Epidemiology (ISEE), that a half-page exclusion was tacked on to the end of the directive. This directive subsequently, as with other European Union Directives, was transmitted to the member country governments for implementation through locally-developed legislation.

3. Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS)

When AIDS first was recognized in 1981, in North America, right wing-dominated movements were vocal in impacting policy both in the United States and in Canada. Religious-based movements engaged in highly organized letter-writing campaigns which served, over the initial years of the epidemic, to delay the delivery of targeted educational messages that could have led to early prevention and hence to the reduced prevalence of infection in this part of the world.

One strategy that was brought to the author's attention was one where, in Canada, these groups would persuade individual members to write to their parliamentary representatives, expressing their negative position against the delivery of messages directed at targeted groups that would be explicit enough to have an effect. These people were further encouraged to write letters on heavy bond stationary, recognizing what they claimed to be a reality within government that the letters "for" as opposed to those "against" are physically weighed. This concept gives new meaning to the "weight of evidence" for scientists!

4. Climate change

Here is an example in which vested interests were recognized for having fabricated petitions debunking the concerns expressed for the future of global warming and its consequences for human well being. How confusing this must be for the policy-maker!

5. Alcohol and breast cancer, and induced abortion and breast cancer

Weed (1997) made several points about the role of values in the interpretation of epidemiologic findings (2). The examples that he provides are not dissimilar from the margarine and butter scenario described earlier. Weed makes the point that, depending on the weights assigned to the

various causal criteria articulated by Henle-Koch more than 100 years ago, the Surgeon-General's Committee on Chronic Diseases in 1964, and the Bradford Hill criteria in 1965, different conclusions can be reached from scrutiny of the same or equivalent data sets. Resultant possible conflicting interpretations can lead to confusion that serve to make the policy-makers' job all the more difficult. Thus, I propose that any theory of causal inference might be enhanced if a dimension were added that transparently assigns weights to each of the ethical principles associated with each of the respective causal criteria.

The ethics of science

Science has as its role to ensure impartiality. Yet, there are innumerable instances of evidence that have implicated sciences serving the interests of constituencies whose primary function is not the public interest. The old maxim "he who pays the piper calls the tune", has been seen to be operative among scientists. In such situations, scientists are accused of having conflicting interests by virtue of the fact that they are caught between trying to serve the public interest on the one hand, and that of their employer/sponsor on the other hand. Because of this reality, role clarification becomes necessary. Role clarification is essential when advocacy/lobbying is a function of a scientist.

Advocacy can take place by professional organizations or by individual researchers. In the case where professional organizations engage in advocacy, for the example on data privacy issues and data access issues, it is clear that the public interest is the primary motivation for such advocacy. On the other hand, where advocacy takes place by individual researchers this could be occurring for the advancement one's own research agenda. As scientists, it remains our duty to be cognizant of this distinction.

An advocate is a person who advances the case of another. From this the following questions can be framed: "Should epidemiologists be advocates, or should they remain detached from advocacy?" What hat do we wear? Should the advocacy role be left to those in appointed public health positions (e.g., Medical Officers of Health)? Is the Medical Officer of Health a political appointee? Does the Medical Officer of Health have any science or epidemiology training? Should this matter?

Public health professionals would be more capable than research epidemiologists of relating the research findings from a single study to a

community in terms of that community's values, beliefs, economic factors, feasibility issues, and the like. They would have a broader conceptualization of the context in which the research may have some relevance.

Partnerships in action

At the European Union Third Ministerial Conference in London, England, June 1999, it was proposed that partnerships were necessary for effective public policy (5). What we mean by "partnerships in action" includes multi-disciplinary, multi-sectoral, multi-stakeholder involvement's at all levels of management or of governance.

As epidemiologists, we can translate this into the nature of our research. Our research is conducted on communities or on populations, and these entities are composed of people. It is people who participate in our studies, and the more we regard these people as participants in our research enterprise, the sooner we will recognize that participatory research requires participation not only in the role of "research subject/participant", but first as partners – as full members of the project team. Thus, in formulating research agendas for the new millennium, we might find better success in impacting policy if we cultivate relationships with the various interest groups and the constituencies in whose service we work, by establishing Steering Committees comprising academic, community, government, industry, and other stakeholder representatives.

Steering Committees then should be involved from the inception (defined as the final conceptualization stage) through the hypothesis formulation stage, the design, conduct, analysis, interpretation, documentation, dissemination, publication, data archival and control stages of our research. While such collaborations and partnerships are a challenge in themselves, their great benefit comes in impacting policy. By virtue of multi-stakeholder involvement from the inception, foundations and bridges already are in place for the translation of research findings into policy.

Ethics in health risk communication

From a doctoral thesis completed in 1998, Lambert (6) showed that risk managers make decisions under ignorance (i.e., scientific uncertainty is but one dimension of this state of ignorance); other dimensions include community

values, legal frameworks, religious and cultural norms, and so on. Stakeholder interests come to bear on such decisions including stakeholders having a vested interest in the situation (e.g., economic interests, labour unions, government and/or private enterprise can have a stake in a particular policy issue).

Lambert extends the work of John Rawls who suggested that a decision procedure for determining the timing and nature of risk communication requires two groups of moral judges (or, risk managers).

- "Competent Judges" who analyze the particulars of a series of cases and generate a set of principles that guide decisions and actions; and
- "Explicators" who test the principles through a process of explication.

Lambert goes on to suggest that a second set or panel of "explicators" is needed. He labels these as participatory stakeholders who establish a flow of meaning through the dissemination of information which, in turn, would be designed to foster autonomy in the communities in whose service we work. The underlying ethical basis for this interaction is founded in "relational ethics".

Professional truths for the new millennium

There are several take home messages from this paper that bear directly on the epidemiology-policy interface:

1. Uncertainty is inherent to science.
2. Science is not value-neutral/value-free.
3. Causal inference is a function of who it is that is making the inference which, in turn, is a function of the study design, the causal criteria invoked, and the weights assigned to each of the causal criteria.
4. The weights assigned to each of the causal criteria are tied to ethical principles of respect for autonomy, beneficence, and non-maleficence.
5. Ethics in the professions is applied ethics resulting in normative statements that are derived through thoughtful discussion. A dialectic is the essential component associated with professional ethics.
6. Dialectics are derived from Sophistry, from the Socratic period where Socrates was engaged in fostering autonomy in a relational ethics framework. His hallmark was engaging with the public in enhancing understanding.
7. Partnerships of stakeholders are needed to make "decisions under ignorance" to more ensure that information serves the community's best interests.

Conclusions

The challenges for epidemiology in the next millennium are several in terms of the linkages that need to be understood if epidemiology is to play a fuller role in influencing policy. The following are the ones that this author deems most worthy of consideration:

1. Vigilance and engagement of our professional organizations with other stakeholders will be essential for remaining sensitive to community values and for building partnerships. This will require the establishment of infrastructure within our professional organizations to maintain vigilance and ensure engagement on matters of mutual interest.
2. We need to improve our methods for causal inference by assigning weights to each of the ethics principles associated with each of the causal criteria so that greater transparency in causal inference becomes evident.
3. As uncertainties grow, especially when developing methods for making risk projections or risk assessments when modelling multiple ecological factors in the face of ever-growing uncertainties from diverse disciplines, transparent methods must be developed. It is the public trust that has to be maintained. In each of these domains, transparency in communicating risks is essential.
4. A legal route needs to be created for establishing penalties for lawyers and others serving interests whose agendas can be shown to be "creating mischief" in derailing science. The tobacco industry provides a clear example through its recent confessions to several decades of such deceptive behaviours.
5. As with "warnings" on packages of cigarettes, society should require of politicians that they declare the value system in which each of their policy recommendations is rooted. In this way, greater public education as to the underlying values inherent to their appointed political leaders is transparent.

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Address for correspondence:

Prof. Colin L. Soskolne, Ph. D., F.A.C.E.
Department of Public Health Sciences Faculty of Medicine and Dentistry
13-103 Clinical Sciences Bldg
University of Alberta
Edmonton, Alberta
Canada T6G 2G3
Phone: 1 780 492-6013
fax: 1 780 492-0364
e-Mail: colin.soskolne@ualberta.ca
Acknowledgement:
Dr Roberto Bertollini, Director
European Center for Environment and Health
World Health Organization, Rome Division, at which the author was a
Visiting Scientist from July 1998 through June 1999.

Disclaimer:

This paper was presented in the session theme "Existing and missing links of epidemiology with public health decision-making". A disclaimer is in order. The author is not policy-trained, but is policy-experienced through on-the-job training.