Epidemiology and Bioethics: A Plea for Reconnecting With the Public

Simon M. Outram, PhD, MA, MSc, BA

ABSTRACT

The author takes the position that both epidemiology and bioethics, as practiced within academic establishments, have largely although not entirely abstracted the public context of health and well-being from their respective disciplines. It is argued that by and large both disciplines have been highly successful at what they do. However, this success can in part be attributed to each limiting its ability to look beyond its respective academic niche and thus embrace challenges which are socially challenging, politically charged, and academically messy. This narrow focus has become self-serving and ultimately detracts from fundamental remits of both disciplines in protecting the public from harm. Furthermore, it may re-enforce the inequalities of research into health overall, whereby the greatest concentration of effort remains firmly focused upon those who already have the most. Currently marginalized approaches to each of these disciplines – such as social epidemiology, global bioethics, and critical bioethics – provide us with platforms that challenge mainstream academic epidemiologists and bioethicists to seek out and reconnect their expertise with questions that are more relevant to real-world situations.

Key words: Bioethics; epidemiology; public health

La traduction du résumé se trouve à la fin de l'article.

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Epidemiology and bioethics share a common goal. Both seek to protect the public from harm and in doing so potentially improve the health and well-being of the public. These are not disciplines founded upon theories and methods; instead they are mandated by practicalities. Epidemiology is mandated to understand the causes of illness in populations and thus suggest ways to eliminate or alleviate these causes. Epidemiological methods are not an end in themselves; they are means to an end. Bioethics is similarly mandated by practicalities. Although definitions of the discipline vary considerably, in the main bioethics is mandated to address the social implications and concerns of developments in medical science. The argument taken is that without maintaining an awareness of public duty, both disciplines will find themselves increasingly addressing issues that are largely irrelevant to the public, while those issues that affect the greatest numbers of people and the most disadvantaged populations of the world will be largely ignored.

One extended quote will suffice to demonstrate the issue at hand within epidemiology. Neil Pearce (2007) has argued that “Traditional approaches to epidemiology started from the standpoint of populations, which involved messy considerations such as context, culture, history and socioeconomic status, all of which strongly influenced health. ‘Modern epidemiology’ strips away all of that ‘noise’ and follows a randomized clinical trial paradigm in which risk factors and disease outcomes are considered in isolation, and the aim of an epidemiologic study is to obtain the same findings that would have been obtained with a randomized controlled

trial.”¹ How, one might ask, can a discipline engage with the public while it is simultaneously attempting to remove context, culture and history; in other words to remove that which constitutes a population, and more significantly that which is of fundamental importance in understanding the unequal burden of disease in populations? There are parallel issues in bioethics. Whether one agrees fully or not with the characterization bioethics is given, few would not recognize some elements of truth in Larry Churchill’s (1999) critique that “bioethical disputes – as measured by the debates in journals and conferences in the United States – often seem to be remote from the values of ordinary people and largely irrelevant to the decisions they encounter in health care. In this sense, philosophical theorizing might be considered harmless entertainment, which if taken too seriously would look ridiculous, as several Monty Python skits have skilfully demonstrated.”² Churchill’s critique appears unduly harsh; although many of these debates appear speculative, they often serve a purpose in revealing hidden inconsistencies and spotting the potentially harmful consequences of some forms of new health technology. However, the underlying critique

Author Affiliations

Post Doctoral Research Fellow, Novel Tech Ethics, Dalhousie University, 1234 Le Marchant Street, Halifax, NS B3H 3P7, Tel: 902-494-2873, E-mail: simon.outram@dal.ca

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remains valid; there appears to be little desire to get involved with the ethics of health care as experienced by the public.

Critiques of trends in bioethics and epidemiology are plentiful from within and outside their respective disciplines.³⁻⁵ However, potentially more concerning than academic critique is that in maintaining a limited approach to their respective tasks, both disciplines limit their ability to make a public difference. For Bhopal, the narrowing of epidemiology has resulted in a fundamental shift in epidemiological thinking whereby “the student may infer, rightly or wrongly, that epidemiology is primarily about measuring disease in populations and not primarily about how diseases develop, propagate, and are prevented in populations”.⁶ If, as a student of epidemiology, one’s focus becomes solely the measurement of illness, there will be no room left for consideration of health and illness as part of social inequity. Similarly, bioethics has been heavily critiqued for being aloof from public concerns. But aside from potentially being irrelevant, what is the problem with a continuation along these lines? One problem, it is argued, is that bioethics may become characterized as obsessed with rehearsing (without progression) age-old arguments based on new technologies. This is exemplified by the case of cognitive enhancement – the use of pharmaceuticals and other forms of technology to enhance the abilities of healthy individuals to rise above the norm – which has become something of a *cause célèbre* within bioethics circles. It is argued that the attraction for debating cognitive enhancement appears to lie not in any real threat to society but in its suitability as a platform to re-launch debates about authenticity and the morality of effort;⁷ debates which are divorced from the experiences of all but a tiny section of the public. The danger is that in focusing upon such issues, bioethicists become fixated on academically interesting but socially trivial issues. By contrast, as argued by Paul Farmer, “to this day, the poorest people in the poorest countries are likely to appear only in the margins of the bioethics literature if they appear at all.” As Farmer argues, one way of making bioethics into a socially relevant discipline would simply be to “spend time interviewing the destitute sick about what they regard as their ranking problems; it is also possible, we have discovered, to interview them about the ethics of research.”⁸ For both bioethicists and epidemiologists, this would provide both new questions and socially relevant versions of long-standing questions – an opportunity that should be welcomed.

It could be claimed that we are witnessing the fruition of the success of both epidemiology and bioethics. In epidemiology – at least in the richer countries of the world – questions pertaining to clean water and access to food are apparently no longer relevant. However, one has only to look at the within-country statistics concerning population health burdens of minority populations in some of the richest countries in the world to know that this perception is false. Similarly, with respect to bioethics it could be argued that the democratized world has largely ended the outright abuse of humans in the name of medical science post-WWII. However, as the case of Henrietta Lacks’ HeLa tumour cell line usage demonstrates, vulnerable people from disadvantaged communities continue to be exploited in the name of medical science.⁹ It is argued that without a social approach to developing research, it is far too easy for questions stemming from economic, gender and racial inequalities in access to treatment (and care within the health care system) to be missed within bioethics and epidemiology.

Within epidemiology, the currently marginalized public health approach to the discipline is making a comeback. In part this may be seen as a reaction against allowing health research to be led by genetic associational studies.¹⁰ More positively, social epidemiologists from various perspectives are revitalizing the public approach to health.^{11,12} However, it remains to be seen whether these calls will turn the tide away from the view that epidemiology is almost exclusively an exercise in statistical health modelling. Similarly, within bioethics there is a strong element of socially and politically aware bioethics emerging which combines bioethics with political and social awareness.¹³⁻¹⁵ These renewed or newly-innovative approaches to their disciplines (depending upon how one defines and interprets the history of each discipline) seem to offer a way to expand upon the positive work already done within each discipline, rather than threaten them with self-implosion.

In summary, it has been argued that in the cause of staking a claim to academic expertise, both disciplines have largely distanced themselves from the realities of a contentious, messy and inherently unequal public context. In doing so, they have carved out an academic niche at the expense of being able to influence policy making on the basis of the greater public good. While it may be true to say that as long as multiple disciplines from the science and arts work together to fill in the gaps in disciplinary knowledge, this isolation from public issues would not matter. However, in practice this idealized scenario remains rare within academia and disciplines continue to compete for authority even within the health sector.¹⁶ This paper has not set out to argue that disciplinary research is futile. It is certainly academically interesting and can produce practical offshoots which are in alignment with the mandates of protecting the public from harm. However, it is argued that a great deal more could be achieved if experts within each discipline began research by questioning the relevance of their research to the public health context. Within global health care, a commonly cited phrase is the ‘90/10 gap’ (attributable to the Global Forum for Health Research), whereby 90% of health research goes towards alleviating the suffering of the wealthiest 10% of the world. It would be to their detriment if these disciplines were ultimately seen as perpetuating, rather than challenging, this gap between rich and poor.

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RESUME

L'auteur avance que l'épidémiologie et la bioéthique, telle qu'elles sont exercées au sein des établissements d'enseignement, font de plus en plus abstraction du contexte public de la santé et du bien-être en général. Il fait valoir que ces deux disciplines ont connu un grand succès dans leurs entreprises respectives, mais que ce succès peut être attribué en partie au fait que toutes les deux limitent leur potentiel à leur propre sphère académique et, ainsi, s'empêchent de relever des défis sociaux difficiles, politiquement controversés et académiquement méandres. Selon l'auteur, cette vision étroite est devenue intéressée et se détourne à la longue de la mission fondamentale des deux disciplines, dont le rôle consiste à protéger le grand public. En conséquence, l'auteur avance que cela peut renforcer certaines inégalités de la recherche en santé, laquelle concentre trop souvent ses efforts sur des groupes socialement et financièrement avantagés. Certaines approches marginales de ces disciplines – telles que l'épidémiologie sociale, la bioéthique globale et la bioéthique critique – sont des plates-formes qui pourraient pousser les épidémiologistes et les bioéthiciens des milieux universitaires à retourner à des recherches dont les enjeux touchent un plus grand public.

Mots clés : bioéthique; épidémiologie; santé publique

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