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EDITORIAL

Hemos dedicado este número del Acta Bioethica a las relaciones entre Bioética y Salud Pública. Originalmente campos aislados pero, en la actualidad, es imposible desconocer las contribuciones concretas que cada uno puede hacer al trabajo del otro. Sin perder su especificidad, estas contribuciones se refieren a la necesidad de integrar distintas perspectivas para abordar fenómenos complejos y multidimensionales, como es el caso de la salud. Evidentemente, reconocer esta necesidad está lejos de ser original y se enmarca en la legitimación que ha adquirido el trabajo inter-multi-pluri o transdisciplinario, presente en diversos campos de reflexión y acción. Este caso, sin embargo, tiene una connotación particular. La bioética es precisamente un área de trabajo inter-pluri-multi o transdisciplinaria. Esta múltiple complementariedad, que se ha profundizado en los últimos años, se refiere a la incorporación de temas ausentes, lo que implica el paso de una ética médica a una bioética global. Destacan, en esta línea, los trabajos de Norman Daniels, quien llama la atención sobre la importancia de la justicia para la salud, o de Daniel Wikler que postula una *bioética de la salud de la población*. También es notoria la diversidad de temáticas revisadas en el último Congreso Mundial de Bioética realizado en Brasilia, muchas de ellas presentadas por latinoamericanos.

Lo que algunos llaman "bioética global" pasa por integrar temáticas nuevas y diversas, las cuales, en general, fueron, durante varias décadas, más propias de la salud pública. Junto con ampliar el campo de acción de la bioética, esto implica una revisión del enfoque y del objeto bioético: los niveles micro y macro pasan a ser interdependientes; las personas no pueden ser disociadas de sus contextos socioculturales y económicos; la resolución de conflictos pasa por balancear dilemas micro y macro éticos; los dilemas éticos generados por la tecnociencia no son ajenos a la política y la distribución del poder. El aumento sistemático de la inequidad entre los países y al interior de ellos hace evidente la imposibilidad de hacer respetar los principios de autonomía, beneficencia y no-maleficencia en condiciones de injusticia generalizada. El principio de justicia, frecuentemente relegado a un segundo plano, adquiere ahora un papel central. Esta centralidad implica conectarse con las temáticas y las acciones propias de la salud pública sin perder la especificidad: se trata de construir un *objeto bioético* que defina a esta disciplina como un campo particular de reflexión y acción. Esto cobra especial sentido en la construcción de una bioética latinoamericana, cuyo foco podría centrarse, como ya ha sido propuesto[1], en una ética social, con énfasis en el bienestar y la justicia social más que en los derechos individuales o virtudes personales; una macro ética de la salud –o de la salud pública–, como alternativa a la tradición anglo-americana de la micro-ética o ética clínica.

La búsqueda de interconexiones entre bioética y salud pública es un tema que adquiere cada vez mayor interés, destacado también por la bioética norteamericana. Baste mencionar el artículo que Daniel Callahan y Bruce Jennings publicaron recientemente en la Revista Americana de Sa-

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[1] Mainetti JA. Medical Ethics, History of: The Americas. D. Latin America. En: Reich WT, ed. *Encyclopedia of Bioethics*. New York: Macmillan; 1995:1639-1644.

lud Pública[2], llamando al trabajo conjunto de ambas disciplinas. El reconocimiento de la influencia de los factores sociales y económicos en la salud de las personas sería, entre otros factores, un elemento que haría necesario incorporar la perspectiva de la salud de la población al interior de la bioética, a la par de la necesaria incorporación de la bioética en la salud pública, dados los dilemas éticos que enfrentan los programas de este tipo de salud. Más que plantear una redefinición de la bioética o de la salud pública, Callahan y Jennings proponen construir un campo de trabajo colaborativo, a través de la construcción de una "ética en salud pública".

Los artículos comprendidos en esta edición del Acta están orientados en esa dirección. Con excepción de uno de ellos, tratan de responder a la pregunta sobre cómo incorporar la ética a la salud pública o cómo construir una "ética en salud pública". Esto no es casual, puesto que fueron escritos para el *Simposium* Internacional "Ética en Salud Pública", organizado por la Universidad de Toronto en mayo de 2002. El artículo que no formó parte de este seminario y que está incluido en el Acta, da un paso en la reflexión y nos muestra cómo un problema de salud pública generalizado en nuestra región, como es el de la violencia contra la mujer, puede ser abordado desde la bioética. Se trata, en este caso, de un ejemplo concreto que nos permite ilustrar las interrelaciones de bioética y salud pública y cómo la bioética tiene una particular perspectiva para abordar estos problemas.

Los trabajos incluyen distintos énfasis para abordar esta temática. El de Thompson, Robertson y Upshur *"Ética en salud pública: Hacia una agenda de investigación"*, analiza los artículos clave del *Simposium* publicados en esta edición. También enuncia las principales conclusiones emanadas del encuentro, entre ellas: que el campo de la ética en salud pública se caracteriza por su complejidad e incertidumbre. Siempre existe un conflicto ético potencial en salud pública y, por tanto, la necesidad de un balance entre aspectos tales como el bien personal y colectivo, la coerción y el deber de entregar atención de salud, la incertidumbre científica y la necesidad de acción. Para enfrentar estos dilemas se requiere un mayor desarrollo teórico e investigación, particularmente sobre las bases conceptuales y teóricas de la ética en salud pública. Este proceso es necesario pero no suficiente para madurar como disciplina. Se requiere también el desarrollo de capacidades con especial atención al currículo y al financiamiento de la investigación. Finalmente, no se trata de un ejercicio meramente académico: el uso de la imaginación moral y la fuerza para cambiar las inequidades globales debieran motivar a la ética en salud pública para ir más allá de la reflexión teórica.

El artículo de Bruce Jennings *"Marcos conceptuales para la ética en salud pública"*, nos ofrece una reflexión que sirve de introducción a los siguientes artículos del Acta. El autor plantea la necesidad de desarrollar una ética crítica para el estudio normativo de la salud pública, fundada en el reconocimiento del contexto social en que se actúa. Luego de analizar las principales teorías éticas y sus relaciones con diversas teorías políticas, Jennings ejemplifica la aplicación de cuatro diferentes discursos éticos a la salud pública: ética profesional, de la abogacía, aplicada y crítica. El desarrollo de este último discurso es, según Jennings, el más importante, en tanto la ética en salud pública no puede estar alejada de los valores de la sociedad general y de la comunidad en la cual se implementan sus acciones. Sin duda, la perspectiva de Jennings abre aún más el camino de

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[2] Callahan D, Jennings B. Ethics and Public Health: Forging a Strong Relationship. *American Journal of Public Health* 2002; 92 (2): 169-176.

la contribución de las ciencias sociales a la ética en salud pública, como también a esta última y a la bioética.

Mientras Jennings pone énfasis en la consideración del contexto para la definición de los marcos éticos en salud pública, Lawrence Gostin, desde una perspectiva más orientada a las políticas públicas, explora la relación entre ética en salud pública, legislación y derechos humanos. En su artículo *"Ética de la salud pública: Tradición, profesión y valores"*, Gostin toma la definición del Instituto de Medicina de los Estados Unidos y conceptualiza "salud pública" como "(...) lo que nosotros, como sociedad, hacemos colectivamente para asegurar las condiciones necesarias para que la gente se mantenga saludable". Además de abrir el campo para el trabajo interdisciplinario e intersectorial, esta disciplina, así entendida, se vincula necesariamente con las nociones de asociación, ciudadanía y comunidad. La ética contribuye a orientar las acciones para promover la salud y disminuir la enfermedad en la población, en tanto la legislación otorga y legitima las herramientas para que tales acciones sean realizadas. Precisamente por esto, dice Gostin, los debates sociales más importantes sobre salud pública tienen lugar en la esfera legal y en el lenguaje legislativo sobre derechos, deberes y justicia. El discurso de los derechos humanos adquiere relevancia en el ámbito de la salud pública por el reconocimiento del derecho a la salud. Como bien dice Gostin, aunque consignado en diversos documentos nacionales e internacionales el derecho a la salud sigue estando débilmente definido –y también escasamente ejercido. A la espera de una definición más precisa, el autor sugiere especificar elementos concretos, tales como el derecho a servicios esenciales de atención de salud, atención de salud accesible y de calidad, igualdad de acceso a los servicios de atención de salud, condiciones necesarias para proteger y mantener la salud, ausencia de amenazas ambientales, salud ocupacional, educación mínimamente adecuada y fortalecimiento de la protección de la salud de las poblaciones vulnerables. Sin duda, la inexistencia de una definición precisa del derecho a la salud es producto de la misma carencia respecto del concepto de salud. Más allá de esta ambigüedad conceptual, la Declaración Universal de Derechos Humanos entrega un marco ético para la acción en la salud global y permite continuar la línea que impulsó Jonathan Mann, centrada en la complementariedad de salud pública, ética y derechos humanos.

La dificultad de definir y medir lo que entendemos por salud es también destacada por Fernando Lolas en su artículo *"Salud pública y justicia social"*. Para el autor, la salud como valor es más un ideal que un estado específico; es más una cualidad humana que un objeto de estudio científico. En su nivel de intervención, la salud pública se refiere a todas las acciones destinadas a mantener el nivel de funcionamiento *culturalmente aceptable* de los miembros de una sociedad. La introducción de esta dimensión cultural, ausente en la definición de salud pública citada por Gostin y cercana a la perspectiva de Jennings, sitúa la formulación de las reglas morales en contextos específicos. La distinción entre las relaciones sociales en la comunidad y en la sociedad, *Gemeinschaft* y *Gesellschaft* –en palabras de Tönnies–, se refiere a dos tipos de construcción de tales reglas morales. En la comunidad las relaciones "cara a cara", la posibilidad de ver las consecuencias inmediatas de los actos y la empatía y comprensión de las motivaciones de los otros actúan como referentes. Esto es reemplazado en la sociedad por la "imaginación moral": la capacidad para inventar reglas morales que constituyen la traslación de valores y principios en las prácticas cotidianas. Haciendo un paralelo con el concepto de medicina sustentable de Daniel Callahan, Lolas introduce el concepto de "sustentabilidad ética", que implica el desafío de recuperar los aspectos positivos de la comunidad –o *Gemeinschaft*– en una sociedad –o *Gesellschaft*– que ha aprendido a reconocer que el progreso deshumanizado no es progreso. Las diferencias en el desarrollo tecnológico han generado inequidad en las oportunidades de vida y en el acceso a los servicios de atención de salud. Mientras más se invierte en alta tecnología médica, mayor diferencia existe entre quienes tienen y quienes no, generando mayores niveles de injusticia conducentes a la aparición de movimientos “antitecnología” o “anticiencia”. Sin embargo, dice Lolas, el progreso tecnológico no es en sí mismo peligroso o negativo. Es la utilización de la tecnología la que debe ser analizada en función de la justicia y la equidad. La bioética, como construcción dialógica del universo moral y sustento de la imaginación moral, se constituye en el actor clave para realizar este análisis.

Las brechas producidas por la utilización inequitativa del avance tecnocientífico, señaladas por Lolas, son también mencionadas por Solomon Benatar. En su artículo “*Salud pública y ética en salud pública”,* el autor nos recuerda la contradicción entre los avances de la ciencia médica, que han permitido significativas mejoras en la salud de los individuos, y el deterioro de las condiciones de salud de las poblaciones, especialmente por la reemergencia de enfermedades como la malaria y la tuberculosis, y la emergencia de otras enfermedades infecciosas, particularmente el VIH/SIDA. Sin embargo, para Benatar las injusticias en el acceso al avance de la tecnociencia no se deben sólo al modo en que se utiliza. Uno de los valores de este mundo, que caracteriza como polarizado e inmoral, es precisamente confiar en que muchos de los problemas actuales podrán ser solucionados por el progreso científico. Lograr mejoras en la salud de las poblaciones y en la vida humana a nivel global requiere de una agenda moral más amplia que incluya a la ética interpersonal y a los derechos civiles y políticos, pero ir también más allá de ellos. Debe incluir también los derechos económicos, sociales y culturales, como también los ambientales y el derecho a no ser explotado a nivel de las relaciones internacionales. Extender el discurso bioético implica, entonces, promover valores fundamentales; entre ellos: la preocupación por el bien común, la promoción de todos los derechos (y deberes) humanos, el sentido de solidaridad con los otros y el reconocimiento de la interdependencia y necesidad de cooperación global, cuyo ejemplo más claro se sitúa en el plano de la salud internacional. Es necesario cambiar desde un paradigma de derechos humanos excesivamente liberal a un modelo social que vincule beneficios y derechos a la aceptación de una serie de responsabilidades. Este es el punto de partida para que tales derechos sean el principio del respeto por todas las personas en el contexto de la comunidad. En este marco, la responsabilidad del médico y el enfoque de la bioética deben ampliarse para incluir los temas de acceso a los servicios de salud, salud pública y asignación de recursos, lo que implica balancear los intereses y necesidades individuales con el bien común de la sociedad.

Mientras Benatar describe el panorama de los valores predominantes que sustentan las inequidades a nivel global, y plantea algunos de los valores que pueden orientar el logro de menores niveles de injusticia, Ruth Chadwick nos invita a reflexionar sobre la utilidad de los paradigmas éticos para enfrentar los dilemas surgidos por el avance de la investigación genómica, particularmente los relativos a los bancos de datos genéticos. En su artículo *“Genómica, salud pública e identidad”*, la autora reconoce la importancia del contexto y afirma que es necesario moverse desde un enfoque centrado en el individuo hacia un enfoque más centrado en la comunidad, lo que implica la renegociación de la relación individuo-comunidad. Esto requiere repensar conceptos tales como “individuo”, “comunidad” e “identidad colectiva”, ejercicio que permite orientar la definición de los intereses en juego y balancear los riesgos que la investigación genómica genera en la identidad colectiva e individual.

Por último, el artículo de Jorge Álvarez, *“Las muertas de Juárez. Bioética, género, poder e injusticia”*, nos muestra cómo un grave problema de salud pública en la región, como es la violencia contra la mujer, puede ser abordado desde la bioética. En palabras del autor, la violencia debe ser analizada desde la bioética porque produce disminución de la calidad de vida, enfermedad, discapacidad y muerte. Surgida de las inequidades de género –fundadas en una desigual distribución del poder entre los sexos–, la violencia contra la mujer toma ribetes cinematográficos en Ciudad Juárez. Precisamente, nos dice el autor, este caso ha inspirado una pieza teatral que ha recorrido varias ciudades del mundo. Sin embargo, la realidad supera con creces la ficción. Entre un quinto y la mitad de las mujeres latinoamericanas vive la violencia cotidianamente. Su magnitud e impacto hacen imperiosa la necesidad de formular programas de prevención y atención, los que sin duda no están ajenos a dilemas éticos. Desde mi perspectiva, y por nombrar algunos, el derecho del Estado a interferir en las relaciones interpersonales sin mediar un proceso de autoconciencia de las víctimas –especialmente en el caso de la violencia al interior de la pareja– o los dilemas éticos presentes en la investigación que sirve de insumo para el diseño de tales programas. Son precisamente esos dilemas los que abren el campo del trabajo conjunto de la bioética y la salud pública o que perfilan la construcción de una ética en salud pública.

En síntesis, los artículos de esta edición del Acta discuten temas fundamentales para abordar la relación bioética y salud pública. Entre ellos la importancia del contexto sociocultural, económico, político y ambiental; la necesidad de recuperar lo colectivo y redefinir su relación con los individuos; las descarnadas inequidades a nivel global; las conexiones entre salud y derechos humanos; las diferencias de género y poder y su relación con la salud. Aunque sugiriendo diversas alternativas de análisis o modos de interpretación, todos plantean la necesidad de repensar los paradigmas éticos vigentes y el enfoque bioético. El desafío es grande, porque implica no sólo el ejercicio teórico sino también su manifestación en la práctica concreta. La defensa de los derechos de los pacientes, praxis original de la bioética, se amplía a la defensa de la salud de las poblaciones y a la búsqueda de la equidad global.

Marcela Ferrer Lues

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PUBLIC HEALTH ETHICS: TOWARDS A RESEARCH AGENDA

Alison Thompson, Ann Robertson, Ross Upshur*

Abstract: Public health ethics, as distinct from clinical/medical bioethics, is an emerging field of study in academic settings. As part of a larger effort to address what the conceptual and content boundaries of this field are, or ought to be, a group at the University of Toronto hosted an international working symposium to discuss and outline a research agenda for public health ethics.

The symposium, which took place in May 2002, was organized into four major areas of ethical concern central to public health: individual rights and the common good; risk and precaution; surveillance and regulation; and social justice and global health equity. This paper will provide an overview of some of the main themes and issues that emerged from the key papers that were developed from the symposium and discuss their importance in the emerging field of public health ethics.

Significant issues were identified, such as the importance of distinguishing public health ethics from traditional bioethics; the development of the notion of common interests; broad definitions of public health, that include upstream sources of health inequities, and an understanding of the theoretical landscape from which public health ethics has emerged.

Key words: Public health, public health ethics, rights, global health equity, social justice

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ÉTICA EN SALUD PÚBLICA: HACIA UNA AGENDA DE INVESTIGACIÓN

Resumen: La ética en salud pública, como distinta de la bioética clínica/médica, es un campo de estudio emergente en el ámbito académico. Como parte de un mayor esfuerzo para abordar el contenido y los límites que este campo tiene o debiera tener, un grupo de la Universidad de Toronto realizó un Simposio Internacional con el fin de discutir y definir una agenda de investigación para la ética en salud pública.

El Simposio, realizado en mayo de 2002, fue organizado en torno a cuatro mayores áreas de preocupación ética sobre salud pública: derechos individuales y bien común; riesgos y precaución; vigilancia y regulación; y justicia social y equidad en la salud global. Este artículo proveerá un panorama de algunos de los principales temas y tópicos que emergieron de los artículos clave desarrollados para el simposio y discutirá su importancia para el emergente campo de la ética de la salud pública.

Temas significativos fueron identificados, tales como la importancia de distinguir la ética en salud pública de la bioética tradicional; el desarrollo de la noción de intereses comunes; amplias definiciones de salud pública, que incluyen las fuentes de las inequidades en salud, y una comprensión del campo teórico desde el cual ha emergido la ética en salud pública.

Palabras clave: Salud pública, ética en salud pública, derechos, equidad en la salud global, justicia social

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ÉTICA NA SAÚDE PÚBLICA: EM DIREÇÃO A UM TEMÁRIO DE PESQUISAS

Resumo: A ética na saúde pública, como diferente da bioética clínica/médica, é um campo do estudo emergente na área acadêmica. Segundo uma parte de um maior esforço para abordar o conteúdo e os limites que esse campo tem ou deve ter, um grupo da Universidade de Toronto levou a cabo um Simpósio Internacional para tratar e definir um programa da pesquisa para a ética na saúde pública.

O Simpósio, levado a cabo em maio de 2002, organizou-se ao redor de quatro maiores áreas da inquietude ética pela saúde pública: direitos individuais e bem comun; riscos e a precaução; a vigilância e regulamentação; e a justiça social e a equidade na saúde global. Esse artigo conterá um panorama com alguns dos temas principais que originan-se dos artigos chave desenvolvidos para o simpósio e debatera e tratará sua importância para o campo emergente da ética da saúde pública.

Temas significativos identificaram-se, como a importância de distinguir a ética na saúde pública da bioética tradicional; o desenvolvimento da noção de juros comuns; definições amplas de saúde pública, que incluem as fontes das inequidades na saúde, e uma compreensão da estrutura teórica do que tem surgido a ética na saúde pública.

Palavras chave: Saúde pública, ética na saúde pública, direito, equidade na saúde global, justiça social

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Introduction: Rationale for Symposium

Public health ethics represents an emerging domain of scholarly investigation and discussion. Some, like Dan Beauchamp*(1)*, would argue that public health is fundamentally an ethical enterprise while others, like Simon Szreter*(2)*, would argue that public health, with its origins in the public health reforms of the late 19th Century, has historically been concerned with ethics. However, the development of public health ethics as a field of scholarship is a recent phenomenon unlike the more established field of bioethics.

Since its inception midway through the last century, the field of bioethics has focused on ethical issues pertaining to the practice of medicine and medical research. Consequently, bioethics as a discipline has focused almost exclusively on individualistic concerns, primarily the development of notions of patient autonomy. This is understandable, given the origins of bioethics in the Nuremberg Trials, the Tuskegee Syphilis study and patients' rights movements in the 1960s*(3)*. Indeed, Onora O'Neill has argued that bioethics has been "damagingly preoccupied" with not only the autonomy of individual patients but also with the requirements for justice within, but not between, states*(4)*. As a consequence, public health ethics has been largely neglected.

However, this is beginning to change, and an emerging literature is beginning to conceptualise the scope and central features of the field of public health ethics*(3, 5-9)*. Among other things, the advent of the new genetics, and threats of new global pandemics are drawing attention to the need for research into public health ethics. In Canada in particular, there have been a number of public health "crises" that have indicated a need for an articulated public health ethics. For example, in May 2000 in the town of Walkerton, Ontario, a waterborne e-coli outbreak resulting from inadequate health protection measures was responsible for seven deaths and the infection of almost half of the town's population. The recent SARS outbreak also highlighted the lack of preparation of public health authorities for major infectious disease threats. A major commission has recommended sweeping changes to the governance, legal structure, and training and practice of public health in Canada*(10)*. The use of quarantine, and other restrictive means of disease control in Canada and elsewhere for the control of SARS raised the issue of the appropriate scope and limitation of individual liberty by public health authorities for the control of disease. The variable means by which public health exercised its authority in response to SARS underscores the need for sustained international dialogue on the ethical aspects of disease control and their relation to ethical norms and human rights standards. There is also a growing acknowledgement of the need for action with respect to the enormous health inequities both within and between nations. What is clear from these cases is that the existing frameworks and tools developed by bioethicists are not easily adapted to deal with ethical issues in public health, nor is it appropriate to attempt to do so, given the individualistic focus of much of bioethics.

In order to address the need for research in public health ethics, a group at the University of Toronto organised an international symposium on Public Health Ethics in May 2002. The purpose of the international symposium was to bring together eminent scholars and public policy figures to discuss what research into public health ethics will be required in order to be able to deal with ethical issues arising from factors such as environmental disasters, new infectious disease epidemics (this was one year before SARS), and global biotechnological developments.

The central focus of this symposium was twofold:

1) To articulate and conceptualise the field of public health ethics as opposed to addressing specific issues arising from the practice of public health, i.e. it dealt with the ethics in public health, rather than the ethics of public health

2) To identify a research agenda for public health ethics that would be of use to scholars, policy-makers and the community.

The symposium was organized around four major themes that the organizing committee saw as characterizing the fundamental ethical domains in public health practice and policy:

- Risk and precaution
- Surveillance and regulation
- Individual rights and the common good
- Social justice/global health equity

The subsequent papers in this issue that are products of this symposium touch on all of these central themes. While the authors sometimes disagree, they lead us to a better understanding of the inherent tensions and problems that will need to be addressed further as public health ethics emerges as an important new field of study.

Overview of Symposium Proceedings

Jennings' article, "Frameworks for public health," is an appropriate introduction to the rest of the articles that were developed from the symposium. He argues for a better understanding of the ethical and political landscape in which public health controversies and social conflicts are played out, before attempting to develop new ethical discourses in public health ethics. He describes a framework that includes different types of applied ethical discourse, and argues that one type, namely critical ethics, should be prioritized.

It may be that understanding the "normative cultural and ideological context" from which public health has emerged, and in which it is practiced, will help us to understand why public health ethics differs from traditional bioethics. It also will help to show how deeply imbued with normative issues the practice of public health is, and how the role of public normative justification is central. While Jennings' article attempts to map the theoretical terrain of public health in the context of the United States, much of what he argues is applicable, with slight differences, to the industrialized West. As Benatar's paper will show, the challenges facing those in global public health have many of their origins in the ethical and political traditions of liberalism described by Jennings.

While he acknowledges that it is not possible to map ethical theories onto political theories, and vice-versa, Jennings' attempt to show how these two crucially important theoretical bodies influence the thinking of the other demonstrates how patterns of justification can be drawn each from the other. Ultimately, this is important, for while there may not be much fundamental disagreement over values and principles, the most effective means to formulate policy is a source of disagreement. Thus the issues of justice, justification and social legitimacy are central in public health, especially as they pertain to policy making. Jennings uses some interesting examples to illustrate this, such as risk reduction, and health promotion and disease prevention.

Jennings goes on to describe four different rhetorics or styles of ethical discourse found in public health. They are: professional ethics, advocacy ethics, applied ethics, and critical ethics. While he claims that advocacy ethics, in which social goals and reforms are championed, is the most lively area of public health ethics, Jennings argues that it is critical ethics where the most crucial work needs to be done. In critical ethics, larger social values and historical trends are brought to bear on the actual institutional arrangements and prevailing structures of public health, encouraging us to see it as a truly public or civic endeavor.

Of course, one of the most important aspects of civil society is its legal system. Gostin's article attempts to demonstrate the relationship between public health ethics, law and human rights. He then provides a framework for systematically evaluating public health policies that draws on each of these important and overlapping fields. In this way, he believes that the trade-off between public health and civil liberties can be reconciled.

Gostin begins by describing what constitutes public health, and then goes on to describe the field of public health ethics. He identifies ways that public health ethics can offer direction on 1) issues pertaining to the profession and practice of the profession; 2) the moral weight and value of the community's health and well being; 3) prevalent themes and dilemmas of public health and its practice; 4) the role of advocacy in public health.

Public health law is important to consider because it is a tool in public health that can influence norms for healthy behavior, identify and deal with health threats, and set and enforce certain standards. Gostin argues that the most important social debates concerning the public's health take place in legal fora, that is, legislatures, courts and administrative agencies. The language of law is also the language used in these debates, i.e., rights, duties and justice.

Not only is law a tool used to achieve health for populations, but it also regulates the "agents of behavioral change," for example, by improving safety standards for manufacturing. It also alters the physical environment by providing standards for builders and business to adhere to, as well as by providing protection to the natural environment.

Gostin argues that the notion of human rights has profoundly influenced the field of public health. He describes the interface of human rights and public health: public health policies can violate human rights; human rights violations can hurt the public's health; and, lastly, policies that promote both human rights and the public's health have positive outcomes for individuals and populations. Quite apart from its formal legal use, one of the key ways that the language of human rights is used is aspirational, or rhetorical.

One of the chief normative concerns in public health is the question of how society ought to decide when to limit individual and economic interests and freedom in order to protect the public's health. In his paper, Gostin offers up some key factors for consideration when determining whether interventions of this nature ought to be undertaken. They pertain to risk assessment, demonstrable effectiveness, economic cost, human rights burdens and fairness. Gostin argues that when thinking about each of these factors, examination of the principles and values emerging from public health ethics, law and human rights can be helpful and can provide justification for effective policies and practices.

Tradeoffs between individuals and public health permeate the field of public health ethics. Where Gostin offers some key factors for consideration when deciding when to make these tradeoffs, Chadwick questions whether we have ethical tools to really understand what we mean when we pit individual interests against those of the collective. Chadwick uses the example of the Human Genome Project and, more specifically, biobanking to raise questions about the adequacy of the dominant ethical frameworks used to address the notion of collective interests. She considers the individualistic approach to issues in biobanking, and then discusses other ethical concepts, such as solidarity and equity. In addition, she considers the normative issues of benefit sharing, public participation, priority setting and the establishment of a collective identity.

Chadwick argues that biobanks in particular are, or ought to be, precipitating new concern over group interests, as opposed to concern over issues arising from individualistic medical ethics-reliance on the individual choice model alone is likely to be inadequate. The Human Genome Project may necessitate new paradigms in ethics, whether or not we believe that there is a difference in kind between genetics and other kinds of medicine.

What Chadwick calls the "standard view" is the dominant bioethical framework that is based on autonomy and choice. Every ethical theory has a conceptualization of the individual moral agent and about individual choice, whether it be in relation to maximizing good, fulfilling duties, etc. In reference to genetics, then, ethics can help us understand what might be required to make informed choices, but ethics can also help us understand possible implications for personal identity. Chadwick argues that ethics can not only help us think about what is right and wrong when it comes to genetics, but that genetics can also change our view about what is ethically acceptable.

Insofar as genetic information pertains not only to the self, but to genetic relatives, it is not helpful to have an individualistic notion of choice because, she argues, "we make choices not only as individuals, but also as members of a number of different groups." This is important when it comes to looking at collective goods. She asks: What ethical resources should we be using in addressing the issues of genetics databases? Ought community interests take precedence over individualistic ones?

The principles of solidarity and equity are offered as different axioms from the individualistic ones considered earlier in the paper. She identifies democratic engagement as an issue that has recently become more prevalent, in part because biobanking, among other issues, forces us to consider what things could be considered common interests. One question that arises from this is whether public participation in decision-making can foster a sense of collective identity that is not merely an aggregation of individual interests or preferences. This leads her to conclude that shifting our ethical lens away from the individual and towards the community may be a necessary but insufficient means of identifying the "sources of collective identity that are at stake" when it comes to biobanking.

We need look no further than to Benatar's paper to see how impoverished our sense of collective identity is. He begins by showing empirical evidence for our lack of moral consideration for others and by demonstrating that progress and globalization have benefited only a small number of people. This, coupled with the emergence of new pandemics, leads him to conclude that we are either living in an amoral world at best, or a morally depraved one at worst. Benatar outlines the dominant values that have shaped our world, and attempts to show how a broader definition of public health is more consistent with a global ethic for health. His paper attempts to persuade us of the moral importance of extending moral considerability to those who lie beyond national and economic borders. One could say, following Jennings' lead, that Benatar's critical ethics gives rise to his plea for advocacy. Indeed, his paper concludes with some suggestions for how doctors can become better advocates for the public's health.

One of the crucial distinctions drawn in Benatar's paper is between what he calls 'upstream' and 'downstream' sources of health disparities. A broader definition of public health would include the social, political and economic determinants of health, and would allow for consideration of upstream, or root, causes in health inequities. Not only would the inclusion of these factors allow for the development of models of health that have more explanatory power, but they force us away from traditional bioethics' engrossment with the individual, human rights and interpersonal relationships. The deficiencies of human rights discourses and parochial perspectives in addressing global social injustice are clear, and potentially impede, the development of a global social contract. He argues for the expansion of the human rights discourse so that it includes social, economic, cultural and economic rights, as well as corresponding duties that obtain at the level of individuals and nations.

Central to Benatar's project is the promotion of particular values-the most obvious one being the common good. Solidarity is an important value as well. Self-interest, common interest and identity all play a part in how we conceive of solidarity. He argues that although solidarity may be a difficult value to define and a difficult state to achieve, this does not diminish its importance. Finally, he argues for greater attention to be paid to enlightened, long-term self-interest as a motivating factor for the development of a "global mindset in heath ethics." He argues this because he would not suggest that the rationale for this mindset be based solely on altruism.

This raises an interesting point. Altruism implies acting in a supererogatory manner, i.e. going beyond the call of duty. At the other end of the moral spectrum we find ethical egoism, of which enlightened self-interest is a form. Perhaps arguing for a global ethic, such as the one Benatar describes, could be done on deontological grounds, thereby relying neither on altruism nor upon the more base ethical egoism. For one important question, in terms of public health advocacy, is whether or not it is wise to advocate for the common good by appealing to people's sense of enlightened self-interest, despite the fact that it is surely the most pragmatic approach to advocacy. For if we have as our ultimate objective the expansion of people's realms of moral consideration so that they extend beyond their current bounds, then surely appealing to enlightened self-interest would not necessarily further this end-it could even undermine it in the long run. Benatar is right, however, to note that there has been a dearth of attention paid to the duties and responsibilities that correspond to human rights, thus making talk of respect for all persons in the context of community difficult.

Conclusion

Our symposium highlighted the fact that public health ethics is characterized by complexity and uncertainty. There is always a set of potential conflicts in public health and hence the need for balance between such things as collective and personal good, coercion and duty to care, scientific uncertainty and necessity for action.

Future scholarship and research is required, particularly on the conceptual and theoretical basis of public health ethics. Empirical case studies are required in order to evaluate the diversity of issues and practices specific to public health ethics. These should illuminate all dimensions of public health deliberation, local, national and global.

For public health ethics to mature as a discipline requires capacity-building with specific attention to curriculum development and funding for research and development. Currently, public health ethics is poorly represented on the course curricula of schools of public health, though this will change in the near future. A model curriculum has been developed in the United States*(11)* and the University of Toronto commenced a course in public health ethics in 2003. Finally, the use of moral imagination, and demonstration of courage in the need to change an inequitable global landscape should motivate public health ethics beyond a merely academic exercise.

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References

1. Beauchamp D. Public Health as Social Justice. *Inquiry* 1976; 13: 3-13.
2. Szreter S. The importance of social intervention in Britain's mortality decline. *Society for Social History of Medicine* 1988;1(1):1-41.
3. Beauchamp DE, Steinbock B, eds. *New ethics for the public's health*. New York: Oxford University Press; 1999.
4. O'Neill O. Public Health or Clinical Ethics: Thinking beyond Borders. *Ethics & International Affairs* 2002; 16 (2).
5. Callahan D, Jennings B. Ethics and Public Health: Forging a Strong Relationship. *AJPH* 2002;92 (2): 169-76.
6. Gostin L. Public Health, Ethics, and Human Rights: A Tribute to the Late John Mann. *Journal of Law, Medicine and Ethics* 2001; 29: 121-30.
7. Gostin L, ed. *Public Health Law and Ethics*. Berkeley: University of California Press; 2002.
8. Schabas R. Is Public Health Ethical? *CJPH* 2002; 93(2): 98-9.
9. Upshur R. Principles for the Justification of Public Health Intervention. *CJPH* 2002; 93 (2): 101-3.
10. National Advisory Committee on SARS and Public Health. *Renewal of Public Health in Canada: Her Majesty the Queen in Right of Canada* 2003; Report N°. 1210.
11. Association of Schools of Public Health. *Ethics and public health: model curriculum*; 2001-2003.

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FRAMEWORKS FOR ETHICS IN PUBLIC HEALTH

Bruce Jennings[*]

Abstract: This paper constructs a conceptual framework for the normative study of public health. It argues that to develop discussions of ethics in public health without paying attention to the broader theoretical and ideological context of public health controversies and social conflicts will be of limited value. In defining that context, the author distinguishes three main types of ethical theory-utilitarianism, contractarianism, and communitarianism; and several varieties of political theory –liberal welfarism, liberal egalitarianism, libertarian liberalism, deliberative democracy, civic republicanism, and cultural conservatism. The meanings and interconnections of these theory formations are discussed. Illustrations to particular public health programs and issues are given. The paper also distinguishes four different types of applied ethical discourse in public health-professional ethics, advocacy ethics, applied ethics, and critical ethics. Each of these modes of ethics is important, but the development of work in critical ethics is the most important priority within the normative study of public health at present.

Keywords: public health, ethics, liberalism, rights, communitarianism, utilitarianism, contractarianism, health promotion, public health surveillance

MARCOS CONCEPTUALES PARA LA ÉTICA EN SALUD PÚBLICA

Resumen: Este texto construye un marco conceptual para el estudio normativo de la salud pública. Argumenta que desarrollar discusiones sobre la ética en salud pública será de escasa utilidad si no se presta atención al contexto más amplio, teórico e ideológico, de las controversias en salud pública y a los conflictos sociales. En la definición de ese contexto, el autor distingue tres tipos principales de teorías éticas –utilitarianismo, contractarianismo y comunitarianismo– y diversas variantes de teoría política –liberalismo del bienestar, liberalismo igualitario, liberalismo libertario, democracia deliberativa, republicanismo cívico y conservatismo cultural–. Se discuten los significados e interconexiones de estas formaciones teóricas. Se ilustra su aplicación a programas y temas particulares de salud pública. El artículo también distingue cuatro tipos de discurso de ética aplicada en salud pública: ética profesional, ética de la abogacía, ética aplicada y ética crítica. Cada uno de ellos es importante, pero el desarrollo del trabajo en ética crítica constituye la prioridad más importante dentro del estudio normativo de la salud pública en la actualidad.

Palabras clave: Salud pública, ética, liberalismo, derechos, comunitarianismo, utilitarianismo, contractarianismo, promoción de la salud, vigilancia en salud pública

MARCOS CONCEPTUAIS PARA A ÉTICA EM SAÚDE PÚBLICA

Resumo: Este texto construi um marco conceitual para o estudo normativo da saúde pública. Argumenta que será de pouca utilidade alimentar discussões em torno da ética em saúde pública sem prestar atenção ao contexto mais amplo, teórico e ideológico, das controvérsias em saúde pública e aos conflitos sociais. O autor distingue três tipos principais de utilitarismo teórico ético: contratualismo, comunitarismo e vários tipos de políticas liberais teóricas de bemestarianismo; igualitarismo liberal; liberalismo libertário; democracia deliberativa, republicanismo cívico e convervativismo cultural. Discutem-se os significados e interconexões destas formulações teóricas. Apresentam-se programas e temas de saúde pública. Distinguem-se quatro tipos de discurso ético aplicado na ética de saúde pública profissional: defesa ética, ética aplicada e ética crítica. Cada um é importante, porém, neste momento, o desenvolvimento do trabalho em ética crítica constitui a prioridade mais importante no estudo normativo de saúde pública.

Palavras chave: Saúde pública, ética, liberalismo, direitos, comunitarianismo, utilitarismo, contratualismo, promoção da saúde, vigilância em saúde pública

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Introduction

In this essay I propose one conceptual framework to guide the development of normative and interpretive studies in public health. By "normative and interpretive studies," I mean to include inquiry into the ethical dimensions of public health policy and practice and the ethical principles or standards that should guide the conduct of public health practitioners. But I also mean something broader than ethics in public health: I mean the study of the normative cultural and ideological context within which issues of public value are framed, made to clash, and resolved.

Public health has emerged during the past two hundred years as a product of many historical forces: the maturation of the modern state; the industrial and post-industrial phases of capitalism; changing environmental, workplace, and life-style factors that affect the health of populations and individuals; the development of social systems highly urbanized and stratified by class, race, and ethnicity; the growth of medical scientific knowledge and the development of effective vaccines and other pharmaceuticals; and, finally, the growing body of observational and statistical knowledge, from epidemiology and other fields, of the nature of health risks and the distribution of disease and dysfunction on a population basis. These factors have created new kinds of public health threats and problems, and this body of knowledge has pointed to new kinds of interventions*(1)*.

The steady hallmark of the public health has been a focus on social and behavioral change. Social change, that is, in the direction of greater social and economic equality and greater access to the resources and conditions necessary for widespread health and the health of the least well off-sanitary living conditions, adequate medical care, and measures to limit risk and exposure to conditions that undermine health*(2)*. None of these issues is free from normative challenge or from the requirement of public normative justification. Here we cannot rely on an understanding of science and epidemiology alone. For these controversies are rarely settled solely the basis of the best available scientific understanding*(3)*. They involve the preexisting traditions, patterns, and conditions of normative argumentation and legitimation. Those preconditions of normative argument can be studied using the tools of history, philosophy, interpretive theory (hermeneutics), and social criticism*(4,5)*. So we have before us a domain of inquiry into the normative and interpretive context –the context of social value and meaning– that surrounds public health. It is this domain that I propose to explore and map in this paper.

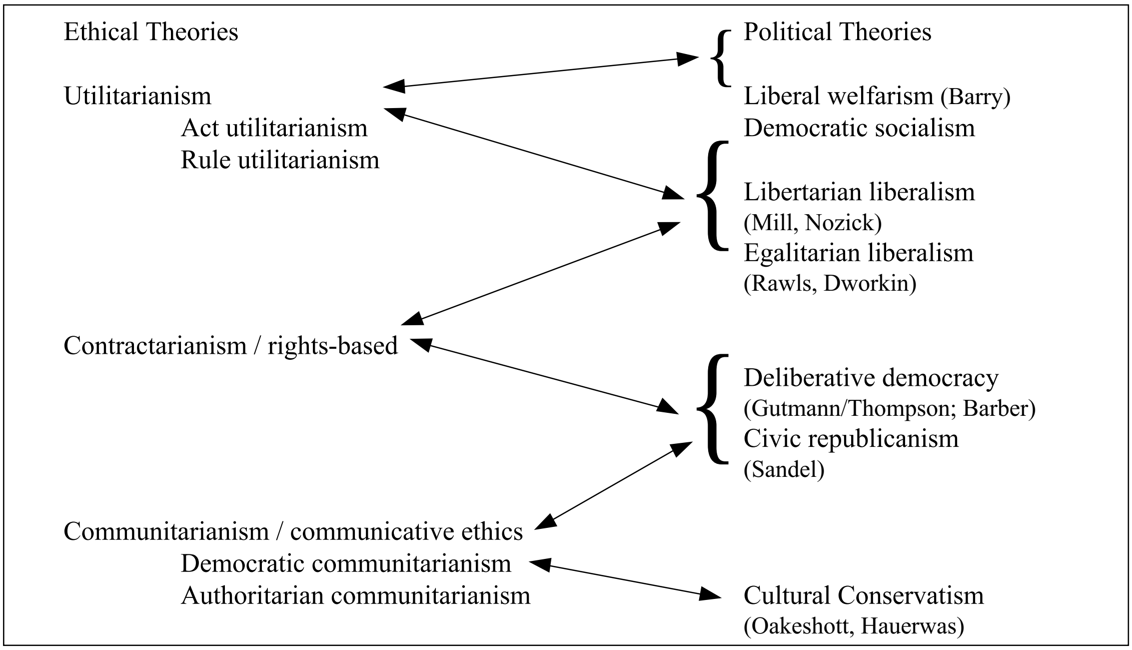
The Normative Grammar of Public Health

I begin with an attempt to map the prevailing array of ethical and political theories that interact and contest with one another in the discourse of political morality –justification and legitimation– in the United States. My description is self-consciously limited to political culture and discourse in the US at least as far as the terminology I employ is concerned. However, the basic concepts underlying the typology offered here is much more widely shared in the world today, although the configuration will differ in its nuances and details.

Figure 1 presents one scheme for classifying the main types of ethical and political theory that play a role in the normative argument within and about public health. This represents the universe of normative discourse with which those in public health should be familiar. A few caveats should be noted.

In the case of both ethical theory (moral philosophy) and political theory, the configurations I have chosen to highlight are

Figure 1. Aspects of Ethical and Political Theory in Public Health



not the only ones that could be mentioned by any means*(6)*. Moreover, I group together theoretical and philosophical orientations that, while having a certain family resemblance with one another, especially in contrast with other theoretical approaches, nonetheless have important internal differences. Partisans of any particular theory will no doubt object to such a grouping. Thus, I consider contractarian, neo-Kantian, and rights-based ethical theories together as one configuration, despite many important differences within and among them. For the purposes of this discussion, I believe we can gloss over these differences.

Even more simplistic is the attachment of any significant theorist with any of these types. Theorists destined for canonization in the Western political tradition, such as John Stuart Mill and John Rawls, create complex intellectual systems that draw from a variety of sources and traditions. These theorists show such originality in their deployment of key concepts that they defy any such simple characterization or "-ism". The same is true for each of the other important and original thinkers whose names I have attached to this figure*(7-16)*. (There are many others who could as well have been mentioned, for the literature in each of these theoretical orientations is voluminous). It is with many reservations that I have added names at all, and I have done so only to provide a rough orientation to those who may find my descriptive terminology unfamiliar.

There are three basic types of ethical theory at work in contemporary moral discourse and in discussions of ethical issues in public health. The first is utilitarianism, with its many standards of evaluation (pleasure, happiness, utility) and its varieties of form (whether it is applied to individual acts or to general rules or patterns of behavior; whether the evaluation uses averaged or weighted units)*(17)*. It is not surprising that utilitarianism should remain a significant aspect of public moral discourse. Its consequentialist orientation is appealing in a largely materialistic, empirically minded, and pragmatic cultural milieu. It seems to offer the most rigorous, even quantitative, approach to normative questions, and this comports well with fields such as economics, policy analysis, and public health which have roughly the same normative and epistemic biases. It offers something like a lingua franca among policy makers for the purposes of determining large scale policy or distributional issues*(11)*.

The second main cluster of ethical theories, contractarianism, has coexisted uneasily with utilitarianism since the late eighteenth century, and has been given a new invigoration in recent decades by the work of John Rawls. Rawls not only developed a new and quite sophisticated version of the contractarian theoretical apparatus, but also developed a powerful critique of contemporary utilitarianism by essentially showing that utilitarian accounts of justice were unable to take the differences among individuals, or the unique moral value of each individual, seriously*(10)*. In his later work, he has gone on to claim that some version of his type of theory reflects more cogently and accurately the actual moral beliefs of people in the Western countries, if not the global community*(18)*.

The keystone of this type of theory is that it grounds the justification of moral argument on the notion that any moral claim must be reasonably acceptable to a group of free and equal individuals deliberating on the basis of certain norms of reason and open discourse. Respect for the freedom and equal moral worth of each individual may be expressed in a slightly different way by an enumeration of fundamental political, social, and human rights that are shared by all persons; not on the basis of the (good) consequences of recognizing those rights, but on the basis of their intrinsic value and rightness*(19)*.

The third formation of ethical theories that must be taken into consideration are a disparate class of so-called “communitarian” orientations*(20)*. Communitarian ethics arose to some extent in reaction to what was perceived as the excessively individualistic character of contractarian ethics. Individuals seem to be free-standing and sui generis beings, without connection to others or society and without formation through the medium of a preexisting culture or tradition. Contractarians are critical of utilitarians for taking the individual to be little more than a utility maximizing strategic player in a social competition where the overall outcome –not the individual players– matter. In a similar vein, communitarians fault both the utilitarians and the contractarians for having an inadequate conception of the human person and for paying insufficient attention to the moral importance of the fabric that binds human beings together in a mutually beneficial, caring, and nurturing society. Communitarians have also been critical of an emphasis on the rights (claims, powers, and privileges of a person against society) of individuals without a corresponding emphasis on the responsibilities of individuals to the society or community to which they belong*(21,22)*.

It is not difficult to understand why communitarian ethics takes on both a kind of left-leaning egalitarian and participatory democratic turn and a more culturally conservative and authoritarian turn. One orientation strongly committed to social change and cultural transformation, feminist philosophy and the feminist movement, has been an important source of communitarian ethics. This shows how and why communitarianism can move in a progressive direction. Although persons are shaped by culture and relationships, they also shape them, and those cultural traditions, distributions of power, and relationships that are discriminatory and oppressive to certain types or classes of people should be transformed, not for the sake of greater individual liberation and autonomy in some abstract sense, but for the sake of better, more humanly self-fulfilling patterns of relationships and sharing of power*(23)*.

By the same token, an emphasis on the need of the individual for stability, order, and cultural roots, coupled with a sense of the limitations of human reason, either as a motivating factor in human conduct or as a faculty that can successfully design and guide deliberate social change, can take the communitarian orientation in a much more conservative and authoritarian direction. In this it has affinities with the conservative (aristocratic) heritage, with the civic republican tradition (given its emphasis on individual duty, virtue, and common morality), and with the worldview of religious orthodoxy and fundamentalism.

For its part, communicative ethics, growing largely out the tradition of German critical theory in the work of Jürgen Habermas and others, is perhaps more closely allied with contractarianism than other forms of communitarianism, and it can be quite formalistic and Kantian in character*(24)*. But several theorists of communicative ethics have turned away from theoretical constructs, such as the "original position" (Rawls) or the "ideal speech situation" (Habermas), and toward real world social discourse and deliberation, as the basic justifying grounds for ethical argument*(25)*.

Turning to political theory, it is not so easy to group various approaches into three clusters. The basic starting point for understanding American political theory is that most often both public argument and political conflict over ideology and policy have taken place within the parameters of the broad tradition of political and philosophical liberalism that Americans inherited from English revolutionary and Enlightenment thought. With rather short lived and localized exceptions, there has never developed a seriously authoritarian left-wing nor an authoritarian right-wing political theory in the United States. Thus the classification suggests a large range of variations on liberalism, with a left-communitarian-style emphasis on a more participatory form of democracy, on the one hand, and a right-communitarian-style cultural conservatism, on the other. These two forms of communitarianism, and not an old communist left nor a fascist right, make up what amounts to the main challenges to mainstream liberalism in America today.

Within the spectrum of liberalism broadly construed (including large portions of what is ordinarily called "conservativism" in the United States), we have variants that are close to being socialist and collectivist in nature, and these seem to me to grow mainly out of the utilitarian tradition. If one took a survey designed to get at something like these orientations among professionals in the field of public health, my hunch is that one would find large numbers occupying this area. What I am calling "egalitarian liberalism" is also of the left in that it favors the use of national state power to promote a more equal distribution of wealth and power in the society, a conception of justice that requires primary attention to the interests of the least advantaged, and the close regulation of corporate and private economic activity to mitigate deleterious environmental, social, and health effects. It draws theoretical justification from the individualistically oriented theorists of freedom, justice, equality and human rights that comprise the contractarian approach. Rounding out the liberal spectrum is libertarian liberalism, which favors maximum freedom of individual choice with a minimum of governmental power or coercion. Institutions that bring about social order and cooperation on the basis of unplanned and uncoordinated actions and choices of free individuals (e.g. the market model in theory) are preferred by libertarians over the achievement of social order and the public interest via governmental regulation and the exercise of the "police power" or the paternalistic authority of the state.

Liberalism of all types tends to presuppose an institutional framework of representative democracy, the rule of law, freedom of speech and political organization, and competitive elections. Liberalism and democracy were not always thought to be mutually compatible, but today they are joined at the hip at least in Western political thinking*(26)*. (That may be why a regime such as China, which seems to have pried apart economic liberalism from political democracy, embracing the former while rejecting the latter, presents us with something of an enigma). Perhaps the most theoretically innovative and interesting challenge to this liberal paradigm arises from forms of democratic theory that are not satisfied with current institutions of electoral politics and representative, interest group democracy. One such form, that is close to egalitarian liberalism in many ways, but which nonetheless demands a more direct, active role in both political argument and in civic and political life, is known as deliberative or discursive democracy*(27,28)*. It also has a great deal in common with left-communitarianism, as was noted above.

Another major type of political theory that rivals liberalism, and has long pedigree in the history of Western political theory, has come to be known as civic republicanism. With intellectual roots that can be traced back to classical political thought in ancient Greece and Rome, republicanism was rekindled during the Renaissance, by thinkers such as Machiavelli, and later transmitted to various English revolutionaries in the seventeenth century*(29)*. At that time, democracy was hardly mentioned, but establishing a republic was seen as the main alternative to hereditary and absolute monarchy, which had become the principal governmental form of the powerful nation states in the early modern period (France, Spain, England, Russia, the Holy Roman Empire). In American history republicanism was an important ideological foundation of the revolution and of the governing of the country during its first one hundred years*(14,30)*. It was not until the period of the industrial revolution in the late nineteenth century that more individualistic public philosophies –such as Lockean liberalism, libertarianism, natural rights theories and the more materialistic and economically oriented versions of utilitarianism– drove republicanism into abeyance. With its sense of the common good and its emphasis on public service and civic virtue, however, civic republicanism is proving to be a theoretical vocabulary of renewed vitality in recent years. It is a straightforward ally of communitarianism and deliberative democracy in many settings.

Finally, no schema of contemporary American political thought would be complete without mention of the kind of cultural conservatism that is so powerfully associated with the fundamentalist and religious revitalization movement now underway here*(31)*. Fortunately this movement has not taken on a guise of collectivism in the manner of national socialism or fascism, although its opposition to the power of government regulation and control seems to be waning during a presidential administration and a congressional majority that seems sympathetic. For the most part, however, this movement has embraced economic and political liberalism but oriented toward the goals of cultural and sexual conservatism and protestant Christian religious fundamentalism.

It is not possible to construct a one-on-one mapping of ethical theories with political theories. The lines drawn on Figure 1 are meant to indicate that there is a two-way pattern of influence between political and ethical thinking, and that each configuration of political theory can draw from several different sources within ethical theory. In *On Liberty*, for example, John Stuart Mill develops a position closely akin to libertarian liberalism on the basis of a utilitarian metatheory, while Robert Nozick grounds his libertarianism on rights-theory and contractarianism*(8,9)*.

Similarly, contractarianism provides the theoretical underpinnings for both egalitarian liberalism and some aspects of deliberative democracy. The main disagreement between these two camps would not be over fundamental values and principles, but over the most effective means to formulate policy and to build support for it in a process of democratic will formation (the democrats prefer actual deliberation over hypothetical deliberation). On the other hand, deliberative democrats and civic republicans (these terms have no relationship whatsoever to the American Democratic and Republican political parties) draw much in common from the insights of communitarianism about the moral and human importance of relationships of friendship and shared commitment, cultural tradition, and a sense of community. Yet they may differ considerably about the importance and the practicality of direct grassroots participation in deliberation and policymaking. The republican tradition has never insisted on direct democracy; indeed it is more characteristic of republicans to look toward governance by elites or experts, tempered perhaps by representative democracy and constitutional and other judicial protections. This is because the goal of civic republicanism is not active participation in shared decisionmaking per se (public citizenship), but rather the preservation of the public morality and a sense of duty and responsibility among private citizens whose behavioral support and restraint are necessary to achieve public goals and to realize the common good.

Normative Discourse in Public Health Practice

It is my hope that the preceding sketch, brief and oversimplified as it has been, nonetheless conveys a sense of the normative complexity of the semantic field within which public health policies and programs find themselves vying for parliamentary support, funding, and social legitimacy. This is not the place to elaborate on how various public health issues can be interpreted in light of the basic formations of ethical and political theory outlined above. Let me mention just a few areas where I believe one cannot understand the arguments that swirl around public health measures without sorting out the ideological and theoretical landscape as I have begun to do here.

One important area of normative controversy in public health is in health promotion and disease prevention. Such programs inevitably raise questions about the responsibility of individuals to live healthy lives; about the role of government in coercing health-related behavior or in developing educational programs; about the use of incentives, economic or otherwise, to promote good health; and about the relative importance for society of pursuing good health, particularly in a culture that prizes autonomy and does not always look fondly on government intervention.

A second area of public health controversy centers around the goal of risk reduction. Risks to the health of the public are many, and many methods are used to reduce or eliminate them. Almost everyone of them can pose one or more ethical problems. The concept of risk itself is seemingly impossible to define in value neutral terms and is inherently controversial. Even more ethically charged is the question of what level or degree of risk is socially acceptable, who should decide, and how should exposure to risk be distributed across the affected population. Routine public health practice involves a number of interventions and policies designed to prevent harm to individuals and to lower health risks within the population. These include various forms of public health surveillance –screening and testing– on different age groups, many of which are legally mandatory and paternalistic or are administered in a way that does not follow the requirements of informed consent. Epidemiological research may not always follow strict ethical protocols on the rights of human subjects, and the collection of health information may sometimes put the researcher in a position of having information that a specific individual might have an interest in knowing. The responsibilities of the public health researcher regarding individual notification and the protection of personal privacy and confidentiality are not yet clearly set out as a matter of consensus within the profession. Like the prevention of harm to others, individual privacy is a lightening rod for the conflicts and tensions between individual liberties and the common good that the main ethical and political theories of our time attempt to adjudicate and set in order.

Finally, there is the issue of structural and socioeconomic disparities in health status. Equitable access to decent health care and reduction in health status disparities have been long-sought goals in American society. What is the appropriate role for the public health community in seeking greater justice in health care, and how ought it to balance its fact-finding and educational role over against its historically strong advocacy mission. To what extent, if any, ought the field adopt a politically partisan posture?

Styles of Practical Ethical Discourse

To complete my analysis of normative inquiry in public health I turn from ethical theories to the available orientations and styles of practical or applied ethical analysis. As before, we need some rough typology or conceptual map to guide further research and interpretation in the normative study of public health. To borrow an analogy from linguistics, if ethical and political theories form the grammar (*la langue*) of normative discourse in public health, these styles or rhetorics of ethical discourse form its speech acts (*la parole*).

I want to distinguish four different styles of applied ethics: professional ethics, advocacy ethics, applied ethics, and critical ethics.

Professional ethics. The study of professional ethics tends to seek out the values and standards that have been developed by the practitioners and leaders of a given profession over a long period of time, and to identify those values that seem most salient and inherent in the profession itself. Applied to public health, this perspective entails identifying the central mission of the profession (e.g. protection and promotion of the health of all members of society) and building up a body of ethical principles and standards that would protect the trust and legitimacy that the profession should maintain. Like all professionals, public health officers exercise considerable power over the lives of others, and the way they use that power makes a substantial difference in the quality of those lives. The perspective of professional ethics would seek to express the virtues that practitioners ought to possess and the rules they ought to follow if they are to be permitted by society to exercise such power and authority.

A difficulty in using this approach in the arena of public health is the questionable, tenuous status of public health as a single, unified profession today. The power of this ethical approach usually comes from the fact that students and practitioners feel that they have taken on a special role-duty or "calling" when they enter the profession. This ethos and sensibility seem to be lacking in public health at the moment.

Advocacy ethics. If there is a characteristic ethical orientation within the field of public health today, it is probably less theoretical or academic than practical and adversarial. The ethical persuasion most lively in the field is a stance of advocacy for those social goals and reforms that public health professionals believe would enhance the general health and well-being, especially of those least well off in society. Such advocacy is in keeping with the natural priorities of those who devote their careers to improving public health. It has a strong orientation toward equality and social justice, for so much of the research and expertise in public health throughout its history has focused on showing how social deprivation, inequality, poverty, and powerlessness are directly linked to poor health and the burden of disease. In recent years a growing international movement in support of human rights has exerted an important influence in public health as well*(32)*. And it has moved public health ethics in its advocacy mode toward an agenda of social and welfare rights designed to provide resources and to empower individuals and groups, and not just to protect the so-called “negative” or political rights of the individual against intrusion or harm.

The problem raised by this perspective on ethics is the flip side of its passion and commitment. Precisely because it backs the professional service agenda of the field of public health, it has only a limited ability to provide a critical perspective on norms and orientations that are taken for granted in the field. As an ethical approach it aims more toward action than persuasion. It has little to calm and reassure those outside the field who may question the legitimacy of public health’s use of its governmental or social power. By definition an advocacy position is not primarily based on detached rational persuasion. To look beyond the advocacy ethics of public health we need to find an orientation no less critical of powerful interests, but one more committed to careful and inclusive deliberation; deliberation undertaken in an effort to set aside specific moral commitments and political agendas on behalf of gaining some broader perspective in the moral questions at issue.

Applied ethics. Another approach to public health ethics comes from the field that has emerged in recent years as “applied” or “practical” ethics. Bioethics is one area among others within this domain of ethics. The applied ethics perspective differs from the professional ethics perspective principally in that it adopts a point of view from outside the history and values of the profession. From this more general moral and social point of view, applied ethics seeks to devise general principles that can then be applied to real world examples of professional conduct or decisionmaking*(33)*. These principles and their application are designed to give professionals guidance and to give clients and the general public standards to use in assessing professional conduct. Thus in applied ethics there is a tendency to reason abstractly and to draw from general ethical theories, rather than from the folkways and knowledge base of the professions. The emphasis tends to be on professional conduct rather than on the virtues of professional character.

One difficulty in using the applied ethics approach is that it has been individualistic and client-rights oriented. It works most effectively, therefore, in what might be called client-centered as opposed to “public” professions*(34)*. For professions like public health the obligations and service pertain to a set of institutions, to a particular structure or arrangement of social relationships, and to the overlapping interests of large groups of people. When collective nouns, such as “the public”, “society”, “the community”, “children”, or “persons at risk for diabetes”, feature in the ethical obligations and principles of a given field, the applied ethics perspective has difficulty formulating ethical guidance that is philosophically coherent and practically useful. The same could be said when collective values (such as the common good or the public interest) are at the center of ethical controversies in the field, as they surely are – and must be– in public health.

Critical ethics. Finally, I would distinguish yet another possible perspective on ethics that could be directed toward the distinctive issues and problems of public health. For want of a better term, I call it “critical ethics*(35)*”. In many ways it attempts to combine the strengths of the other perspectives mentioned. Like professional ethics, it is historically informed and practically oriented toward the specific real world and real time problems of public health, but like applied ethics it brings larger social values and historical trends to bear in its understanding of the current situation of public health and the moral problems faced. These problems are not only the result of the behavior of certain disease organisms or of particular individuals. They are also the result of institutional arrangements and prevailing structures of cultural attitudes and social power. At one level, public health has always known this larger critique and has always stressed it; but of late, in its actual programmatic behavior, public health, like so much else in American culture, has neglected the project of institutional change and focused on the individual as the object of education, health promotion efforts, and life-style change*(36)*.

The perspective of critical ethics has much in common with the egalitarian and human rights oriented discourse of advocacy ethics in public health. One advantage critical ethics may have is that it calls upon the discussion of ethics and public health policy to be genuinely public or civic endeavors. Not the advocacy of a well-intentioned elite on behalf of needy clients, but the search for forums and programs of meaningful participation, open deliberation, and civic-problem solving and capacity building. Some of the best examples of public health practice, from this point of view, grow out of efforts to support communities in being places of mutual support, respect, and self-esteem, thereby reinforcing health promoting behaviors among their individual members*(37)*.

Conclusion

These different types of ethical analysis distinguish between the ethics ***of*** public health (how it frames and analyses the ethical problems it encounters), and the ethics ***within*** public health (how its practitioners understand their role, their values, and the criteria for judging the ethical perspective they bring to bear on their professional work). Many problems will require moving back and forth between the two levels. At the same time, there may well be a tension between the general values of society (e.g., its individualism) and the special values of public health (e.g., it population rather than individual orientation).

In the United States, we have traditionally been resistant to overall theories of the human good for individuals and the good of society. Yet a rich discourse on ethics and public health cannot be advanced without relating it to the background values of the general society, and the particular communities, in which it will be carried out. In Canada, for example, public health experts have much more consciously tried to relate public health and the sociopolitical values of Canadian society. It is one thing to say that public health rests on a communitarian foundation and quite another to determine how best to relate that foundation to our individualistic culture, particularly one historically hostile to government. The conflict, long endemic in our society, between rights to pursue self-interests and duties to sacrifice self-interest to the interests of others or the common good, does not make it easy to develop population-based health strategies that must, on occasion, pressure rather than persuade, require rather than invite. That seems easier for Canadians or for European countries with a stronger tradition of solidarity. But an effort to think the problem through requires a more open recognition of the tensions, which may be decreasing rather than increasing, both within the varieties of contemporary liberalism and between liberalism and its alternatives.

References

1. Rosen GA. *History of public health*. Baltimore: Johns Hopkins University Press; 1993.
2. Institute of Medicine. *The future of public health*. Washington DC: Academy Press; 1988.
3. Wildavsky A. *But is it true? A citizen's guide to environmental health and safety issues*. Cambridge, Mass.: Harvard University Press; 1995.
4. Pocock JGA. *Politics, language, and time*. New York: Atheneum; 1973.
5. Walzer M. *Interpretation and social criticism*. Cambridge, Mass.: Harvard University Press; 1987.
6. Singer P, ed. *A companion to ethics*. Oxford: Blackwell; 1991.
7. Barry B. *Political argument*. London: Routledge & Kegan Paul; 1965.
8. Mill JS. *On liberty*. Indianapolis: Bobbs-Merrell; 1971.
9. Nozick R. *Anarchy, state, and utopia*. New York: Basic Books; 1974.
10. Rawls J. *A theory of justice*. Revised edition. Cambridge, Mass: Harvard University Press; 1999.
11. Dworkin R. *Taking Rights Seriously*. Cambridge, Mass.: Harvard University Press; 1977.
12. Gutmann A, Thompson D. *Democracy and disagreement*. Cambridge, Mass: Harvard University Press; 1996.
13. Barber B. *Strong democracy*. Berkeley: University of California Press; 1986.
14. Sandel M. *Democracy and its discontents*. Cambridge, Mass: Harvard University Press; 1996.
15. Oakeshott M. *Rationalism in politics and other essays*. New and expanded ed. Indianapolis: Liberty Press; 1991.
16. Hauerwas S. *Truthfulness and tragedy*. South Bend, Ind.: University of Notre Dame Press; 1977.
17. Lyons D. *Forms and limits of utilitarianism*. Oxford: Oxford University Press; 1965.
18. Rawls J. *Political liberalism*. New York: Columbia University Press; 1993.
19. Feinberg J. The Nature and Value of Rights. In: Feinberg J, ed. *Rights, justice, and the bounds of liberty: essays in social philosophy.* Princeton: Princeton University Press; 1980: 143-58.

20. Etzioni A. *The spirit of community: rights, responsibilities, and the communitarian agenda*. New York: Crown Publishers; 1993.
21. Mulhall S, Swift A. *Liberals and communitarians*. 2d ed. Oxford: Blackwell; 1996.
22. Selznick P. *The moral commonwealth; social theory and the promise of community*. Berkeley: University of California Press; 1992
23. Walker MU. *Moral understandings; a feminist study in ethics*. New York: Routledge; 1998.
24. Habermas J. *Moral consciousness and communicative action*. Cambridge, Mass: MIT Press; 1990.
25. Benhabib S, Dallmayr F, eds. *The communicative ethics controversy*. Cambridge, Mass: MIT Press; 1990.
26. Macpherson CB. *The life and times of liberal democracy*. Oxford: Oxford University Press; 1977.
27. Dryzek J. *Deliberative democracy and beyond*. New York: Oxford University Press; 2000.
28. Macedo S, ed. *Deliberative politics*. New York: Oxford University Press; 1999.
29. Pocock JGA. *The machiavellian moment: Florentine political thought and the Atlantic republican tradition*. Princeton: Princeton University Press; 1975.
30. Bailyn B. The ideological origins of the American revolution. Cambridge, Mass: Harvard University Press; 1967.
31. Lakoff G. *Moral politics: what conservatives know that liberals don't*. Chicago: University of Chicago Press; 1996.
32. Mann JM, Gruskin, S, Grodin MA, Annas GJ, eds. *Health and human rights*. New York: Routledge; 1999.
33. Beauchamp T, Childress J. *Principles of biomedical ethics*. 5th ed. New York: Oxford University Press; 2001.
34. Jennings B, Callahan D, Wolf S. The professions: public interest and common good. *Hastings Center Report* February l987, Special Supplement; l7 (l): 3-l0.
35. Jennings, B. Bioethics and democracy. *Centennial Review* 1990; 34 (2): 207-25.
36. Bellah R, et al. *The good society*. New York: Vintage Books; 1992.
37. Putnam R. *Bowling alone*. New York: Simon and Schuster; 2000: 326-35.

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PUBLIC HEALTH ETHICS: TRADITION, PROFESSION, AND VALUES[*]

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Abstract: This article asks the difficult questions— what is public health? and what is public health ethics? The article also recognizes that even though public health and biomedical ethics overlap, they have distinct aspects. The article examines the unique population-based perspective of public health and how it can be distinguished from patient-centered biomedical ethics. Additionally, public health scholars and practitioners often use ethical analyses with other forms of reasoning, particularly law and human rights. The article, therefore, explores the relationship among public health ethics, public health law and human rights. The various meanings of each form of reasoning are discussed, as well as the similarities and differences among them. The article concludes with a proposal for reconciling the inherent tradeoffs between public health and civil liberties. Prior to exercising compulsory powers, public health officials should examine the risk to the public; the likelihood that the intervention will be effective; the opportunity costs; the burdens on human rights and the policy's fairness.

Key Words: Public health, ethics, public health law, human rights

ÉTICA DE LA SALUD PÚBLICA: TRADICIÓN, PROFESIÓN Y VALORES

Resumen: Este artículo analiza las difíciles preguntas ¿qué es salud pública? y ¿qué es ética de la salud pública? El artículo también reconoce que aunque la salud pública y la ética biomédica se superponen, abordan distintos aspectos. El artículo examina el enfoque único de la salud pública centrado en la población y cómo éste puede ser distinguido del enfoque de la ética biomédica, centrado en el paciente. Adicionalmente, los teóricos y practicantes de la salud pública frecuentemente utilizan el análisis ético con otras formas de razonamiento, particularmente el legal y el de derechos humanos. Por consiguiente, el artículo discute los diversos significados de cada razonamiento, como también las similitudes y diferencias entre ellos. El artículo concluye con una propuesta para reconciliar las tensiones inherentes entre la salud pública y las libertades individuales. Antes de ejercer poderes compulsorios, los oficiales de salud pública debieran examinar el riesgo para la población; la probabilidad de que la intervención será efectiva; los costos de oportunidad; los costos en términos de derechos humanos y la justicia de la política.

Palabras clave: Salud pública, ética, ley en salud pública, derechos humanos

ÉTICA DA SAÚDE PÚBLICA: TRADIÇÃO, PROFISSÃO E VALORES

Resumo: Esse artigo analisa as costões difíceis que é saúde pública? e que é ética da saúde pública? O artigo também reconhece que ainda que a saúde pública e a ética biomédica sobrepõem-se, eles abordam diferentes aspectos. O artigo examina o único enfoque à saúde pública centrada na população e como isto pode distinguir do enfoque ao ético biomédico, centrou no paciente. Além disso, os teóricos e profissionais da saúde pública utilizam com freqüência a análise ética com outras formas de raciocínio, em particular o legal e o dos direitos humanos. Em conseqüência, o artigo trata os diversos significados de cada raciocínio , assim como as de semelhanças e de diferenças entre eles. O artigo finaliza com uma proposta para conciliar as tensões inerentes entre a saúde pública e as liberdades individuais. Antes de exercer poderes obrigatórios, os funcionários de saúde pública devem examinar o risco para a população; a probabilidade de que a intervenção será eficaz; os custos de oportunidade; os custos em termos dos direitos humanos e a justiça da política.

Palavras chave: Saúde pública, ética, lei em saúde pública, direitos humanos

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What Is Public Health?

In thinking about the application of ethical thought to problems in public health, it is important first to understand what we mean by public health. How is the field defined and what is its content-mission, functions, and services? *(1,2)*. In truth, finding answers to these fundamental questions is not easy because the field of public health is highly eclectic and conflicted *(3,4)*.

Definitions of public health vary widely, ranging from the World Health Organization's*(5)*utopian conception of health as a "state of complete physical, mental, and social well-being" to a more concrete listing of public health practices. The definition offered by WHO is intended to convey the importance of health, which is more than the absence of illness or disease. Charles-Edward A. Winslow*(6, p.30)*, on the other hand, offers a concrete listing of public health practices. He defines public health as "the science and the art of preventing disease, prolonging life, and promoting physical health and efficiency through organized community efforts for the sanitation of the environment, the control of community infections, the education of the individual in principles of personal hygiene, [and] the organization of medical and nursing service for the early diagnosis and preventive treatment of disease."

The Institute of Medicine (IOM)*(7, p.19)*, in its seminal report *The Future of Public Health*, proposed one of the most influential contemporary definitions: "Public health is what we, as a society, do collectively to assure the conditions for people to be healthy." The IOM's definition can be appreciated by examining its constituent parts. The emphasis on cooperative and mutually shared obligation ("we, as a society") reinforces that collective entities (e.g., governments and communities) take responsibility for healthy populations. Individuals can do a great deal to safeguard their health, particularly if they have the economic means to do so. They can purchase housing, clothing, food, and medical care*(8)*. Each person can also behave in ways that promote health and safety by eating healthy foods, exercising, using safety equipment (e.g., seatbelts, motorcycle helmets, or smoke detectors), and by refraining from smoking, using illicit drugs, or drinking alcoholic beverages excessively. Yet there is a great deal that individuals cannot do to secure their health, and therefore these individuals need to organize, build together, and share resources. Acting alone, people cannot achieve environmental protection, hygiene and sanitation, clean air and surface water, uncontaminated food and drinking water, safe roads and products, and control of infectious disease. Each of these collective goods, and many more, are achievable only through organized and sustained community activities*(9)*.

Even the most organized and socially conscious society cannot guarantee complete physical and mental well-being. There will always be a certain amount of injury and disease in the population that is beyond the reach of individuals or government. The role of public health, therefore, is to "assure the *conditions* for people to be healthy." These conditions include a variety of educational, economic, social, and environmental factors that are necessary for good health.

Most definitions share the premise that the subject of public health is the health of populations –rather than the health of individuals– and that this goal is reached by a generally high level of health throughout society, rather than the best possible health for a few*(10)*. The field of public health is concerned with health promotion and disease prevention throughout society. Consequently, public health is interested in devising broad strategies to prevent or ameliorate injury and disease.

The traditional role of public health agencies is to identify risks or harms and intervene to prevent or reduce them. Discrete public health powers include testing, reporting, vaccination, treatment, partner notification, and quarantine. Public health authorities, however, are broadening their horizons. They are now interested in the equitable distribution of social and economic resources because social status, race, and wealth are important influences on the health of populations*(11,12)*. Similarly, the field is interested in "social capital" because social networks of family and friends, as well as associations with religious and civic organizations, are important factors in public health*(13,14)*. This inclusive direction for public health is gaining popularity; many governments seek reductions in health disparities and improved social cohesiveness.

The determinants of health include the physical environment, behavior, biology, and social environment. Using this vision, public health researchers and practitioners have ventured into areas of general social policy, ranging from city planning and safe housing*(15,16)* to violence, war and discrimination*(17)*. The expansive view of public health may well be justified by the importance of culture, poverty, and powerlessness on the health of populations. Social epidemiologists have found an association between these factors and increased morbidity and mortality*(18)*. As a group of prominent ethicists put it, "Justice is Good for Our Health"*(19)* because fair and compassionate societies tend to produce better health outcomes among their citizens.

What are Public Health Ethics?

If public health is what society does collectively to assure the conditions for healthy people, then what are public health ethics? Public health ethics may be defined as follows:

The principles and values that help guide actions among public health system actors, which are designed to promote health and prevent injury and disease in the population. The principal values of public health ethics include the salience of population health, safety, and welfare; fairness and equity in the distribution of services; and respect for the human rights of individuals and groups.

In thinking about this definition, it will be helpful to distinguish public health ethics from biomedical ethics. The field of biomedical ethics has richly informed practice and policy in medicine and health care. Biomedical ethics has often stressed the importance of individual interests of patients, notably the right to autonomy, privacy and liberty*(20)*. Ethicists, however, at least until recently, have given insufficient attention to the equally strong values of partnership, citizenship and community*(21)*. As members of a society in which we all share a common bond, we also have an obligation to protect and defend the community against threats to health, safety and security. There remains much work to do in public health ethics. Is the population-based perspective of public health different from the patient-centered perspective of medicine? Is a public health ethic merely the aggregation of individual interests in a population? What is the moral standing that should be attached to the common good? Under what circumstances should individual interests yield to achieve a collective benefit for the population?

Some scholars have thought about public health ethics in three overlapping ways*(22)*: professional ethics (the values that help public health professionals to act in virtuous ways); applied ethics (the values that help to illuminate hard problems in public health policy and practice); and advocacy ethics (the overarching value of population health and social justice).

Professional ethics are concerned with the ethical dimensions of professionalism and the moral trust that society bestows on public health professionals to act for the common welfare. This form of ethical discourse stresses the distinct history and traditions of the profession, seeking to create a culture of professionalism among public health students and practitioners. It instills in professionals a sense of public duty and trust. Professional ethics are role oriented, helping practitioners to act in virtuous ways as they undertake their functions. The Public Health Leadership Society in the United States, for example, has developed a Code of Public Health Ethics*(23)*. The Code's principles include the mandate for public health professionals to achieve the fundamental causes of disease; respect individual rights with respect for all cultures; encourage input from community members; empower disenfranchised people; enhance the physical and social environment; protect confidentiality; and assure professional competency. Many believe that a code of ethics, or at least a well-articulated values statement, could increase the status of the field and help clarify the distinctive ethical dilemmas faced by public health professionals. It is true that no single public health profession exists, but rather a variety of different disciplines –e.g., epidemiologists, nurses, sanitary engineers, and public health educators. Still, it is important to find a set of values that is relevant to all those engaging in population-based health.

Applied public health ethics are concerned not so much with the character of professionals as with the ethical dimensions of the public health enterprise itself. Here, scholars study the philosophical knowledge and analytic reasoning necessary for careful thinking and decision making in creating and implementing public health policy. This kind of applied ethics is situation or case-oriented, seeking to understand morally appropriate decisions in concrete cases. Scholars can helpfully apply general ethical theory and detached analytical reasoning to the societal debates common in public health. Applied public health ethics draws from the traditions of utilitarianism, which dictates that benefits are maximized and burdens minimized. Consequently, public health ethics stress the central importance of population health and safety as an overarching value. However, it will also be important to appropriately weigh individual rights in the calculation. The public health model should not assume that the appropriate mode of evaluating options is some form of inflexible cost-benefit test that appears to permit, or even require, that the most fundamental interests of individuals be sacrificed in order to produce the best overall outcome.

In addition to "professional" and "applied" ethics, it is possible to think of an "advocacy" ethic informed by the single overriding value of a healthy community. Under this rationale, public health authorities think they know what is ethically appropriate, and their function is to advocate for that social goal. This populist ethics serves the interests of populations, particularly the powerless and oppressed, and its methods are principally pragmatic and political. Public health professionals strive to convince the public and its representative political bodies that healthy populations, reduced inequalities, and social justice are the preferred societal responses. This argument is supported by a body of literature demonstrating a relationship between socio-economic status and healthy populations.

Public health ethics, therefore, can illuminate the field of public health in several ways. Ethics can offer guidance on (1) the meaning of public health professionalism and the ethical practice of the profession, (2) the moral weight and value of the community's health and well-being, (3) the recurring themes of the field and the dilemmas faced in everyday public health practice, and (4) the role of advocacy to achieve the goal of safer and healthier populations.

There needs to be a much more sustained, sophisticated discussion of ethics among students, practitioners and scholars in public health*(24)*. For example, ethics instruction in schools of public health is scarce and targeted primarily to biomedical ethics*(25)*. Further, few public health employers in the public and private sectors offer continuing education that includes ethical issues. Government and academic institutions should consider the value of including ethics in accreditation of schools, credentialing of professionals, and the promotion of public health research.

What is Public Health Law?

Public health law differs from ethics in that it is concerned with a body of rules of action prescribed by controlling authority and having binding legal force. Law is found in constitutions, which empower governments to act and set limits on their power; statutes, which are enacted by legislative bodies and control the actions of individuals and businesses; regulations, which have similar effects as statutes but are usually promulgated by the executive branch; and court cases, which interpret the constitution, statutes and regulations, often setting binding precedent*(9,26)*.

Law is a primary means with which government creates the conditions for people to lead healthier and safer lives. Law creates a mission for public health authorities, assigns their functions, and specifies the manner in which they may exercise their authority. Law is a tool in public health work which is used to influence norms for healthy behavior, identify and respond to health threats, and set and enforce health and safety standards. The most important social debates about public health take place in legal fora –legislatures, courts, and administrative agencies– and in the law's language of rights, duties and justice.

Public health power is the natural authority of sovereign governments to regulate private interests for the public good. The state possesses a power and a duty to protect, preserve and promote the health, safety, morals, and general welfare of the people. To achieve these communal benefits, the state retains the power to restrict, within constitutional limits, private interests. For example, surveillance or data collection affects privacy; compulsory vaccination or treatment affects bodily integrity; and isolation or quarantine affects liberty. Similarly, public health powers can affect economic interests such as the freedom of contract and the use of property (e.g., licensing and inspection requirements).

Law can be an effective tool to achieve the goal of improved health for the population. Statutes, regulations, and litigation, like other public health prevention strategies, intervene at a variety of levels, each designed to secure safer and healthier populations. First, government interventions are aimed at *individual* behavior through education (e.g., health communication campaigns), incentives (e.g., taxing and spending powers), or deterrence (e.g., civil and criminal penalties for risky behaviors). The WHO Framework Tobacco Convention, for example, urges countries to adopt laws to reduce tobacco use*(27)*. These include health information designed to inform people about the hazards of smoking; regulation of tobacco advertising and promotions targeted to children, women, or minorities; higher taxes to discourage cigarette purchases; and restraints on export of tobacco products.

Second, law regulates the *agents of behavioral change* by requiring safer product design through regulation and tort litigation. The law has done a great deal to make products safer for public use. Governments regulate directly by requiring safety standards for manufacturing. For example, regulations often specify that automobiles have seatbelts and passive restraints and children's toys are safe. The law also allows for indirect regulation through the tort system. For example, individuals may sue manufacturers of inherently dangerous products such as cigarettes and firearms. Both these forms of regulation –direct regulation and tort litigation– have improved design in consumer products.

Finally, law alters the physical (e.g., city planning and housing codes), natural (e.g., clean air and water), and business (e.g., inspections and licenses) *environments*. The environment in which people live is critical to their health. Government can help make the physical, or built, environment more healthful by controlling toxic exposures such as lead paint, radon, and pests*(28)*. The state can plan cities to encourage exercise (e.g., development of green spaces) and good nutrition (e.g., making available fresh meat and vegetables rather than fast foods). Government can similarly make the natural environment more healthful by regulating air and water quality. The air we breathe, the water we drink, and the pollutants emitted into the environment are powerfully associated with healthy, or unhealthy, living conditions. Finally, government can make the business environment more healthful by requiring safer places to work at and safer corporate practices. Businesses expose their workers to a range of hazards and working conditions. They also have major health impacts on their surrounding communities. It is therefore critically important that the business community takes seriously its obligations toward workers and the neighborhoods in which they operate*(14)*.

What is the Role of Human Rights in Public Health?

In recent years, human rights have profoundly influenced the field of public health. Historians may reasonably inquire why a body of international law dating back to the mid-twentieth century would suddenly become part of the public health discourse. The emphasis on individual rights and liberties that became fashionable in the AIDS pandemic later in the century provides a partial explanation. Civil libertarians turned to the language of human rights to defend persons living with HIV/AIDS from stigma and discrimination*(29)*.

Scholars and practitioners came to see human rights as essential tools in the work of public health. They reasoned that persons who fear government coercion or private discrimination would not come forward for testing, treatment, and partner notification. Individuals who lacked social status and economic power, moreover, would be more vulnerable to infection. Women, for example, may understand that unprotected sex or needle sharing transmits HIV infection, and they may even have the means of protection available (e.g., condoms and sterile injection equipment). But if these women remain powerless in abusive relationships or economically dependent on their partners, they cannot resist unwanted sex or needle sharing, which places them at risk.

The interface between human rights and public health can be described by the following three relationships*(30)*. First, public health policies can violate human rights. The use of compulsory public health powers can interfere with autonomy, bodily integrity, privacy, and liberty. Second, human rights violations can harm public health. The use of torture or inhuman and degrading conditions can harm individuals and populations. Third, policies promoting both human rights and public health result in positive, mutually reinforcing outcomes for persons and for society. There often exists a synergistic relationship between health and human rights, so that one supports the other.

The language of human rights is used in different, but overlapping, ways. Some use human rights language to mean a set of entitlements under international law, while others use human rights for its aspirational, or rhetorical, qualities. Depending on the way in which human rights are used, the field can have features that are quite similar to law or ethics.

Legal scholars use human rights to refer to a body of international law that originated in response to the egregious affronts to peace and human dignity committed during World War II. The main source of human rights law within the United Nations system is the International Bill of Human Rights comprising the United Nations Charter, the Universal Declaration of Human Rights, and two International Covenants of Human Rights. Human rights are also protected under regional systems, including those in American, European, and African countries. In Latin America, for example, the Pan-American Health Organization protects and promotes the health of Latin Americans using several tools, including the OAS Declaration of the Rights and Duties of Man and the Additional Protocol on Human Rights in the Area of Economic, Social, and Cultural Rights, or Protocol of San Salvador*(31)*.

Human rights are often divided between those that protect civil and political rights on the one hand and economic, social, and cultural rights on the other. Civil and political entitlements include the right to life, liberty, and security of person; the prohibition of slavery, torture, and cruel, inhuman, or degrading treatment; freedom from arbitrary interference with privacy, family, or home; and freedom of conscience, religion, expression and association. Economic, social and cultural rights include the right to social security, education and work, as well as the right to share in scientific advancement and its benefits.

The right to health is rooted in the economic, social and cultural rights found in numerous international documents. Article 25 of the Universal Declaration of Human Rights acknowledges the right to health as a component of “a standard of living adequate for the health and well-being of [a person and that person’s] family,…including medical care and necessary social services, and the right to security in the event of…sickness.” The International Covenant on Economic, Social and Cultural Rights (art. 12) adopts a broad concept of health as a human right, declaring “the right of everyone to the highest attainable standard of physical and mental health.” States must make efforts to fully realize this right including “the creation of conditions which assure all medical services and medical attention in case of sickness.” (art. 12(2)). Regional instruments provide more detailed right to health provisions that specifically outline the States’ obligations. The European Social Charter conceives of a right to health that encompasses public health and health care. The descriptive and expansive conception of the right to health advanced by the European Social Charter is mirrored in the Inter-American System’s Protocol of San Salvador, which in addition to calling for “enjoyment of the highest level of physical, mental and social well-being” includes six specific areas within the right to health, including “satisfaction of the health needs of the highest risk groups…” (Article 10). The African Charter on Human and Peoples’ Rights (Article 16) contains “the right to enjoy the best attainable state of physical and mental health” requiring the State to “take necessary measure to protect the health of their people and to ensure that they receive medical attention when they are sick.”

The right to health is also found in many national constitutions. The Pan American Health Organization examined the right to health in the constitutions of many Latin American countries. Some, including Bolivia, Chile, and Paraguay, enumerate a right to health explicitly in their constitutions*(31)*. Kinney*(32)* similarly found right to health provisions in numerous national constitutions. The constitutional right to health can be significant in the public health context, forcing governments to pay attention to the needs of the population. For example, the Constitutional Court of South Africa found that the government's refusal to provide antiretroviral medication for pregnant women infected with HIV violated the country's constitution[1].

The language of human rights is often used for its aspirational, or rhetorical, qualities. When "rights" language is invoked, it is intended to convey the fundamental importance of the claim. It expresses the idea that government should adhere to certain standards, or provide certain services, because it is right and just to do so. Human rights as a symbol commands reverence and respect. Used in this aspirational sense, human rights need not be supported by text, precedent, or reasoning; they are self-evident and government's responsibility simply is to conform.

Although human rights are supported by a body of international law and express an inspiring idea about personal dignity, they are often criticized for imprecision and lack of enforceability. Civil and political rights are perhaps the most precisely defined and carefully studied, but international agencies often fail to rigorously defend these rights in the real world. Economic, social and cultural rights are thought to be vague and unenforceable. For example, the conceptualization of health as a human right, and not simply a moral claim, suggests that states possess binding obligations to respect, defend and promote that entitlement. Considerable disagreement, however, exists as to whether "health" is a meaningful, identifiable, operational and enforceable right, or whether it is merely aspirational or rhetorical.

To achieve the goal of greater clarity and enforceability, the United Nations Committee on Economic, Social, and Cultural Rights issued *General Comment No. 14: The Right to the Highest Attainable Standard of Health* (2000). General Comment 14 conceives of a right to health that is extensive, fundamental, and "indispensable for the exercise of other human rights." Thus, the right to health encompasses public health and health care, as well as other conditions that are necessary determinants for people to live health lives, including adequate nutrition, housing, uncontaminated drinking water, sanitation, safe workplaces, and a healthy environment. The right to health also contains both "freedoms and entitlements." The freedoms are protections essentially drawn from the context of civil and political rights: the right to have control over one's health and body, sexual and reproductive freedom, and freedom from interference, including the right to be free from torture and from medical treatment or experimentation without consent. The entitlements, by comparison, include an affirmative right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health. The General Comment considers the right to health in terms of broad norms, state obligations, violations, and implementation standards.

As scholars, practitioners and advocates explore more deeply the meaning of the right to health, it will be helpful to suggest several concrete elements, including the right to: essential

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[1] Minister of Health and Others v. Treatment Action Campaign and Others, CCT 08/02, decided April 4, 2002 http://www.concourt.gov.za/date2002.html

health services; affordable, quality health care; equality of access to health services; conditions needed to protect and preserve health (e.g., clean water, housing, sanitation); freedom from serious environmental threats; occupational health; minimally adequate education; and enhanced health protection for vulnerable populations.

Tradeoffs Between the Collective Good and Individual Rights

Public health law, ethics, and human rights often require careful balancing between individual interests in personal (e.g., autonomy, privacy, and liberty) and economic (e.g., contracts and property) freedoms on the one hand and collective interests in health safety and security on the other. Certainly, freedom and security can be mutually reinforcing. Affording individuals their rights can result in greater overall well-being by empowering people to safeguard their own health and safety. For example, if people do not fear loss of privacy or liberty, they are more likely to seek medical and public health services. Coercive powers can literally "drive epidemics underground."

Sometimes policy makers must make hard tradeoffs between individual and collective interests and, in these circumstances, they need to be guided by ethical values and attentive to legal procedures and norms, as well as human rights. Public health laws and our courts have traditionally balanced the common good with individual civil liberties. As Justice John Marshall Harlan wrote in the seminal United States Supreme Court case of *Jacobson v. Massachusetts*, 197 U.S. 11 (1905), "the whole people covenants with each citizen, and each citizen with the whole people, that all shall be governed by certain laws for the 'common good.'" Jacobson was a case that concerned compulsory vaccination, but the difficult tradeoffs between public and private interests can extend to many areas of public health concern ranging from infectious disease control powers (e.g., testing and screening, partner notification, and quarantine) to control of businesses (e.g., inspections and nuisance abatements) and the professions (e.g., licensing).

How should society determine whether to intervene to protect the public's health and safety when doing so will diminish a personal or economic interest? There is no sure way to know when interventions are necessary and appropriate, but here are some of the factors that need to be taken into consideration*(26)*:

Step One: Demonstrate Risk. Risk is a complex idea that involves several dimensions. First, what is the nature of the risk? Risks arise from numerous sources including physical, chemical, organic, environmental and behavioral. Second, what is the duration of the risk? Risks may be imminent, distant, acute or chronic. Third, what is the probability that the risk will actually occur? Risks may be either highly likely or remote. Finally, what is the severity of harm should the risk materialize? Harms can be catastrophic or relatively trivial if they do occur. They may affect individuals or populations, current or future generations, or people or the things that people value (e.g., plants, animals, or the environment).

Step Two: Demonstrate the Intervention's Effectiveness. The intervention should be reasonable likely to reduce the risk. Public health is primarily about prevention so one important measure is whether the intervention is reasonably like to work. This is a "means-ends" inquiry, which seeks to understand if the public health intervention will lead to effective risk reduction.

Step Three: Assess the Economic Cost. The intervention should not only be capable of reducing the risk, but it should do so at a reasonable cost. Policy makers, therefore, should discover the costs to the regulatory agency and the subject of the regulation. Wherever possible, policy makers should prefer strategies that are least expensive and most effective. The reason is that government only has limited resources. If it spends money wastefully on an intervention, it will not have those resources available for another, potentially more effective, intervention. Thus, cost-ineffective measures have "lost opportunity" costs.

The criterion to prefer cost-effective measures does not mean that society must wait until there is unassailable scientific evidence before it can intervene. Some advocates have argued for the adoption of a "precautionary principle." The precautionary principle is not consistently defined but it means that public health authorities may act to prevent future harms to people and the environment even in the absence of conclusive proof that the harm is real or that the intervention will be effective.

Step Four: Assess the Burdens on Human Rights. Sometimes even cost-effective policies should not be undertaken if they disproportionately burden human rights. Policy makers, therefore, should think about the invasiveness of the intervention, the frequency and scope of the infringement, and the duration of the infringement. Human rights do not always trump public health, but they certainly need to be weighed carefully.

Step Five: Assess the Fairness of the Intervention. Policies should be formed and implemented in just ways. Thus, there should be a fair distribution of benefits and burdens. Ethicists examine fairness in a variety of different ways, but they often focus on need and risk. Benefits or public health services should often be distributed based on need. That is, those who have the greatest need should have some claim to the benefit or service. On the other hand, regulatory burdens should often be distributed on the basis of risks posed. That is, those who pose the greatest risks to the public or the environment should bear the costs and burdens of regulation. There are certainly other ways to evaluate the just allocation of benefits and burdens (e.g., principles of the most efficient distribution), but need and risk are two likely criteria.

In summary, a public health intervention can be evaluated using several criteria: (i) the nature, probability and severity of the risk; (ii) the likelihood that it will be effective in meeting its objectives; (iii) the economic costs entailed, including opportunity costs; (iv) the burdens on human rights, and (v) the fairness, including a just allocation of benefits and burdens.

Conclusion

The field of public health is highly complex. What is the meaning of pivotally important abstract concepts that are common in public health: population, community, risk, harm, and benefit? How should society decide when it is necessary and appropriate to intervene to protect the public's health? Are factors such as risk, effectiveness, cost, burdens and fairness the best ways to evaluate public health interventions? How does the population perspective differ from the individual perspective? To what extent should social justice be an animating value in public health? Scholars and practitioners use various forms of reasoning in analyzing these problems, notably ethics, law, and human rights. Each form of reasoning has its own benefits and disadvantages. While each form of reasoning is distinct, all the forms overlap in important ways. One thing is certainly clear, there are no "correct" answers in public health. However, careful examination of principles and values taken from each of these fields can clarify thinking and, ultimately, lead to more effective and just policies and practices in public health.

References

1. Turnock BJ. *Public Health: What it is and how it works.* Gaithersburg, MD: Aspen Publishers; 2001.
2. Novick LF, Mays GP, eds. *Public health administration: principles for population-based management.* Gaithersburg, MD: Aspen Publishers; 2001.
3. Beaglehole R, Bonita R. *Public Health at the Crossroads: Achievements and prospects.* Cambridge, UK; New York, NY, USA: Cambridge University Press; 1997.
4. Fielding JE. Public Health in the Twentieth Century: Advances and Challenges. *Annual Review of Public Health* 1999; 20: xiii-xxx.
5. *Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference*, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.
6. Winslow CA. The Untilled Fields of Public Health. *Science* 1920; 20-30.
7. Institute of Medicine. *The Future of Public Health.* Washington, DC: National Academy Press; 1988.
8. McKinlay JB, McKinlay SM. The Questionable Contribution of Medical Measures to the Decline of Mortality in the United States in the Twentieth Century. *Milbank Quarterly* 1977; 55: 405-29.
9. Gostin LO. *Public Health Law: Power, Duty, Restraint.* Berkeley and New York: University of California Press and Milbank Memorial Fund; 2000.
10. Gostin LO. Public Health, Ethics, and Human Rights: A Tribute to the Late Jonathan Mann. *Journal of Law, Medicine, and Ethics* 2001; 29: 121-30.
11. Marmot M, Wilkinson RG eds. *Social determinants of health.* Oxford, UK; New York, NY, USA: Oxford University Press, 1999.
12. Syme SL. Social and Economic Disparities in Health: Thoughts about Intervention. *Milbank Quarterly* 1998; 76: 493-505.
13. Cattell V. Poor People, Poor Places, and Poor Health: The Mediating Role of Social Networks and Social Capital. *Social Science and Medicine* 2001; 52: 1501-16.
14. Smedley BD, Stith AY, Nelson AR, eds. *Unequal treatment: confronting racial and ethnic disparities in health care.* Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, Board on Health Sciences Policy, Institute of Medicine. Washington DC: National Academies Press; 2003.
15. Hancock T. Healthy Communities Must Also Be Sustainable Communities. *Public Health Reports* 2000; 115:151-6.
16. Maantay J. Zoning, Equity, and Public Health. *American Journal of Public Health* 2001; 91: 1033-41.
17. Breakey WR. It's Time for the Public Health Community to Declare War on Homelessness. *American Journal of Public Health* 1997; 87: 153-5.
18. Berkman LF, Kawachi I, eds. *Social Epidemiology.* Oxford, UK; New York, NY, USA: Oxford University Press; 2000.

19. Daniels N, Kennedy B, Kawachi I. Justice is Good for Our Health. *Boston Review* 2000; February/ March: 6-15.

20. Kass NE. An Ethics Framework for Public Health. *American Journal of Public Health* 2001; 91:1776-82.

21. Beauchamp DE, Steinbock B, eds. *New Ethics for the Public's Health*. New York: Oxford University Press; 1999.

22. Callahan D, Jennings B. Ethics and Public Health: Forging a Strong Relationship. *American Journal of Public Health* 2002; 92:169-76.

23. Thomas JC, Sage M, Dillenberg J, Guillory VJ. A Code of Ethics for Public Health. *American Journal of Public Health* 2002; 92:1057-9.

24. Childress JF, Faden RR, Gaare RD, Gostin LO, et al. Public Health Ethics: Mapping the Terrain. *The Journal of Law, Medicine, & Ethics* 2002; 30(2): 170-81.

25. Coughlin S, Katz WH, Mattison DR. Ethics Instruction at Schools of Public Health in the United States. *American Journal of Public Health* 2000; 90: 768-70.

26. Gostin LO, ed. *Public Health Law and Ethics: A Reader.* Berkeley and New York: University of California Press and Milbank Memorial Fund; 2002.

27. World Health Organization. *Framework Convention on Tobacco Control.* [Website] Available in http://www.who.int/tobacco/fctc/en/ Visited August 25, 2003.

28. Perdue W, Stone L, Gostin LO. The Built Environment and Its Relationship to the Public's Health: The Legal Framework. *American Journal of Public Health* 2003; 93:9.

29. Gostin LO. *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations.* Raleigh: University of North Carolina Press; 2004.

30. Mann JM, Gostin LO, Gruskin S, et al. Health and Human Rights. *Journal of Health and Human Rights* 1994; 1: 6-23.

31. Fuenzalida-Puelma HL, Connor SS, eds. *The Right to Health in the Americas: A Comparative Constitutional Study*. Washington DC: Pan American Health Organization; 1989.

32. Kinney, ED. The International Human Right to Health: What Does This Mean for Our Nation and World? *Indiana Law Review* 2001; 34: 1457-75.

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PUBLIC HEALTH AND SOCIAL JUSTICE
Toward ethical sustainability in healthcare and research

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Abstract: This paper puts forward the notion of ethical sustainability as the manifestation of moral values in public health policy. The most relevant of these values is that of justice, which is interpreted as fairness and qualified according to the type of society: Gemeinschaft, where social relations are ends in themselves, and Gesellschaft, where social relations are means to individual ends. Bioethics, as the dialogical construction of the moral universe and the support of moral imagination, is depicted both as a discourse and as a tool for improving the commonwealth.

Key words: Bioethics, public health, social justice, ethical sustainability

SALUD PÚBLICA Y JUSTICIA SOCIAL
Hacia una sustentabilidad ética en atención de salud e investigación

Resumen: Este artículo desarrolla la noción de sustentabilidad ética como manifestación de valores morales en las políticas de salud pública. El más relevante de tales valores es el de la justicia, interpretada como equidad y cualificada según el tipo de sociedad: *Gemeinschaft*, en la cual las relaciones sociales son fines en sí mismos, y *Gesellschaft*, en la cual las relaciones sociales son medios para fines individuales. La bioética, como construcción dialógica del universo moral y sustento de la imaginación moral, se presenta como discurso y como una herramienta para mejorar el bien común.

Palabras clave: Bioética, salud pública, justicia social, sustentabilidad ética

SAÚDE PÚBLICA E JUSTIÇA SOCIAL
Para a sustentabilidade ética no cuidado à saúde e na pesquisa

Resumo: Este artigo desenvolve a noção de sustentabilidade ética como manifestação de valores morais nas políticas de saúde pública. O mais relevante de tais valores é o da justiça, interpretada como equidade e qualificada segundo o tipo de sociedade. Gemeinschaft, em que as relações sociais são fins em si mesmos, e Gesellschaft, em que as relações sociais são meios para afins individuais. A bioética, como construção dialógica do universo moral e sustento da imaginação moral, apresenta-se tanto como discurso, bem como uma ferramenta para melhorar o bem comum.

Palavras chave: Bioética, saúde pública, justiça social, sustentabilidade ética

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Health as a multilayered construct

A basic source of ethical conflict and tension exists between individual needs or desires and the public good. Theories about priorities and ways of resolving this conflict are central to any discussion on health and healthcare.

Political liberals tend to promote a rights model of health care. According to this model, there is an individual right to health and a corresponding right to equal access to health care. Communitarians tend to view sickness and death as shared threats to human life, a basic condition of human existence requiring a shared response. Solidarity as a basic value is treated differently in the context of these two theoretical positions. In the first, it is a convenience calculation ("every good egoist is an altruist"), in the second it constitutes a precondition for collective life ("the good of society is superior to the good of individuals").

Health is typically a "layered", complex, construct. At the *microlevel*, that is, at the level of biochemical and physiological processes "within" biological organisms, it is difficult to define, with no meaning distinct from statistical normalcy, and susceptible of intervention for correcting values which fall outside a normal range. At the *macrolevel*, health is the aggregate of societal effects that promote or maintain well-being of individuals but at the same time promote, enhance or improve social capital, the web of creative relations between people. It is at the *intermediate level*, the level of individual health, where medical action, death and suffering take place. The level of the person is endowed with meaning and constitutes the privileged locus of moral action. Medicine has been concerned mostly with this intermediate level at the risk of neglecting the "common space" of societal health. At some point in the history of the health sciences, and influenced by the nascent disciplines of the social sciences, some authors spoke about "sick societies"*(1)*. This soon proved to be a metaphorical way of referring to states of distress of individuals in groups. Society, as such, cannot become ill in the sense that an organism gets ill, unless the metaphor equating society with the body is pushed too far, as Rudolph Virchow did when he compared medicine to politics and cells to individual human beings.

That health cannot be defined below the level of the individual organism and is difficult to ascertain at the societal level supports the contention that equating health with good occurs only at the human level. It is, in fact, an evaluative act, not a neutral or natural determination. In 1941, Henri Sigerist wrote that "a healthy individual is a man who is well balanced bodily and mentally, and well adjusted to his physical and social environment... Health, therefore, is not simply the absence of disease; it is something positive, a joyful attitude towards life, and a cheerful acceptance of the responsibilities that life puts upon the individual"*(2)*. Undoubtedly, this position influenced the definition adopted by the First World Assembly of WHO and the drafters of that definition stated that health is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"*(3,4)*. Good is no natural category, however, in the sense that molecules or cells are, and evaluative acts can be performed on an indefinite number of life domains, such as the spiritual, which can also be considered part of the definition of health. Thus, individual health as a value is more an ideal (or "virtue", *areté*, excellence) to aspire to, rather than a description of a state or a factual determination. More a quality of life than a scientific object of study, health has become difficult to measure and indicators are difficult to develop.

Bioethics and public health

This difficulty in definition and operationalization of the health construct is evident in the field of public health. Its disciplinary independency started with descriptive sciences, such as epidemiology, whose task soon was expanded to providing help in decision-making processes and as a useful device for making recommendations on how to improve people's lives. It also became apparent that *quality of life*, a more inclusive concept than health itself and scientifically more neutral, could be related either to individual health aspects or to the contexts (physical, social and symbolic) in which persons live. Public health may be said to reflect this contextual aspects of health and the realm of interventions at the macro level. As an interventional strategy, public health refers to those activities performed by the organized social body to attain and maintain the culturally appropriate level of functioning of its members and of the group.

Bioethics in the sphere of public health expands the dialogical participation of moral actors to the health consequences of interventions at the contextual level, that is the web of relations and interactions between human bodies, be they physical or abstract and symbolic. Whereas autonomy, beneficence and non-maleficence are principles with evident application at the intermediate level of the health construct (the level of individual persons), justice is undoubtedly the principle most relevant to planning and intervention at the macro, societal or public level.

The Kantian categorical imperative implies that the maxim by which a person directs his/her life should be generalizable to society as a whole. In this sense, a just action is an action which assures continuity and wellness of society and not only of a few members in it. It is a prospective value, its existence provides the foundation for social life.

As the discussion below shows, there is both a formal and a material aspect to justice and there exist many forms in which the principle or value is expressed in societies. Goal-based, duty-based and rights-based considerations for the fulfillment of this value or principle are useful for devising (or "inventing") those rules which will lend presence to justice in human affairs, modulated by cultural imprint and traditions. In any context, it may be observed that individual moral agents reach a *reflective equilibrium* between their own personal experiences (cases of consciousness), the principles explicitly supported by people and those mores, traditions and customs which implicitly modulate moral action.

It may be said that the principles of autonomy, beneficence, non-maleficence and justice, among others, can be discerned in all known societies. The precise architecture of their relations is, nevertheless, different in different societies. This is similar to the principle of isomerism in chemistry, where compounds which are similar in general formulae may be different in structure.

Justice and society

Justice is a property of social systems, in much the same way as truth is a property of systems of thought (Rawls). The definition of group and social system is not, however, a simple one.

It has proven useful to distinguish, with the sociologist Tönnies, between *Gemeinshaft* and *Gesellschaft*. The first is based on face-to-face contacts and comprises small groups. The essential aspect is that social relations between persons are ends in themselves. In the second type of social organization, typical of larger societies with differentiation by work and classes of individuals, human relations are mostly means to accomplish personal or social goals. It might be said that *Gemeinschaft* is a group geared towards human relations and *Gesellschaft* is a group oriented towards impersonal social tasks. This type of society, characteristic of Western industrialized nations, was made responsible for alienation and other social ills and concentrated the criticism from the social reformers who founded the discourse of the social sciences in the XIXth and XXth century.

Justice is a property of both types of social systems. Justice may be said to imply the fair distribution of good in society. The type of justice most appropriate for *Gemeinschaft* is commutative or retributive justice, the essence of which is the exact retribution of what is given. Primitive forms of legal systems indicate that penalties are proportional to, if not equal to, offences. Contracts are based on trust and reciprocal agreement in exact proportion of what is exchanged. Common morality, or morality in the narrow sense, is closely associated with custom and tradition.

The form of justice most appropriate for *Gesellschaft* is distributive justice. The commutative form does not disappear. It finds expression in many different areas, such as penal and contractual law. In healthcare the question is how can society provide equal opportunities to its members and how fair the distribution of social goods can be. Health as such cannot be reduced to a commodity that can be sold, bought or exchanged, but healthcare and its associated services are subject to market principles as any other service.

Health, as rightly pointed out by many, is a personal construction not reducible to medical interventions, and depends on social, personal, spiritual and economic factors. In this regard, it is useful to remember that development and maintenance of healthcare systems require acknowledging a “clash of rationalities”. A rationality is a set of principles for administering and expanding a technology (technologies like the productive ones, the semiotic ones, power technologies and technologies of the self are part of the operation of healthcare systems) and it exhibits a tendency to monopolize the whole system of thought (technocratic turn of modern societies). Economic rationality, for instance, is based on the notion of scarcity and aims at maximizing efficiency and efficacy in the use of resources. Therapeutic rationality, on the other hand, is oriented towards alleviating or ameliorating deficits. Scientific rationality is aimed at renovating disciplines and producing generalizable knowledge.

The technocratic turn of modern societies has led to a unilateral development of privileged forms of rationality which become monopoles. The notion of sustainability, for instance, is associated mostly with economic rationality. However, there are also other forms of sustainability, each associated with a different rationality. We tend to speak of “ethical sustainability” to refer to a form of social behavior appropriate for the challenges of moral wisdom.

In relation to healthcare and justice, irrespective of the form this principle adopts in a particular society (it is always a formal, not a material principle, and has to be filled with content in a given tradition), the larger the society the greater the need for “moral imagination” from its members. Moral imagination, in large and impersonal societies, replaces face-to-face contacts and immediate consequences of actions with anticipation of effects and empathic understanding of the motives people have for behaving the way they do. Moral imagination is also the ability for inventing moral rules, which constitute the “practical translation” of values and principles into everyday practice. Values and principles are *universals of meaning*, practical rules are concrete instances.

Towards bioethical sustainability

Daniel Callahan has forcefully put forward the notion of a sustainable medicine*(5)*. The idea of sustainability is borrowed from the economic sciences and implies the renovation and affordability of decisions in the future. His reflections deal with the requisites the social institution of medicine should have for being able to meet the goals society ascribes to it. He suggests that indefinite progress, unending technological innovation, and the perpetual search for perfection militate against universal coverage, equity of access, and affordability. Even in economic terms, his analysis seems –or may be interpreted as– conflicting with the main trends of Western medicine. We need, Callahan says, a steady-state medicine, a sustainable social practice that perhaps will not be the best possible in technological terms but will be attainable, reasonable, and affordable. His is a plea for sobriety and self restraint. He emphasizes the fact that technology-driven medicine has been obsessed with means and that a fresh look at this institution should examine its goals. In a groundbreaking project entitled precisely "The goals of medicine", a number of scholars from different countries examined what the perennial goals of social practices may be and how badly needed a reflection on them was in times of reform. From that analysis, several propositions can be formulated for the future of healthcare and several suggestions for further research at the interface between philosophical analysis and empirical social research.

Ethical sustainability as a concept is deeply rooted in a profound consideration of justice in all its forms. The challenge ahead lies in recapturing those positive aspects of small societies (*Gemeinschaft*) in a reformulated *Gesellschaft* that has learnt to appreciate that progress without humanity is no progress at all. It may appear as a truism but experience shows that social systems built around technology and its mores tend to free themselves from external restraints and become autonomous. The problems they create are of a kind which technology itself cannot address, even less solve.

The reason why we should explore the relation between technology and health is that technology is one of the forces behind contemporary political power, the market, and the idea of indefinite progress. Up to now, the technological divide (in its form of digital divide, or of economic prosperity) is clearly a factor in the increasing inequity of access to life opportunities and to healthcare which plagues Latin American countries and other regions of the world. The more money is invested in high tech medicine, the deeper the difference between the "have" and the "have not", the more evident the spiraling of injustice which, in naive hands, may lead to antiscience or antitechnology movements. Globalization has come to mean power of those who possess technoscience and, along with respect, it commands distrust and antagonism.

A technology-driven progress is not in itself dangerous or even negative. It is the uses of technology which should be viewed against a deep reflection on justice and equity. Goal-based considerations may suggest that we should not stop research and science, for some day their benefits will be accessible to all. This has not proved to be true up to now. Duty-based considerations imply that those who have should share with those who do not have. Every good egoist, the saying goes, should be an altruist. However, blind quest for profit may obliterate any good use of technology based on duty considerations. And finally, rights-based considerations, although appealing to those who try to defend them, are usually less compelling for rights than "centripetal factors" are. They are located in persons but do not emanate from persons, since they have to be recognized by others to be fully effective.

Duties, on the contrary, radiate from the person and are his/her sole responsibility. An unfulfilled duty engenders guilt. A right not respected produces anger and shame. As the historical record shows, only by the force of law and convention can rights be ascertained and made respectable.

Violations of human rights occur everywhere and at all times. This implies that rights need a two-tied system, their presence and the "good will" to respect them, whereas an accepted duty is a force in itself for the person who recognizes it as personal.

References

1. Halliday J. *Psychosocial Medicine. A Study of the Sick Society.* New York: Norton; 1948.
2. Sigerist HE. *Medicine and Human Welfare*. New Haven: Yale University Press; 1941.
3. World Health Organization. *Constitution*. Geneva: WHO; 1948.
4. Chatterji S, Ustün BL, Sadana R, et al. *The conceptual basis for measuring and reporting on health.* Global Programme on Evidence for Health Policy. Discussion Paper No. 45. Geneva: WHO; 2002.
5. Callahan D. *False Hopes.* New York: Simon & Schuster; 1998.

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PUBLIC HEALTH AND PUBLIC HEALTH ETHICS[*]

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Abstract: Spectacular achievements in the health of individuals have not been matched by equivalent improvement in the health of whole populations. Indeed it is against the background of deterioration in levels of population health in some parts of the world and the emergence and re-emergence of infectious diseases in association with powerful globalizing forces that there has been a recrudescence of interest in 'Public Health'. Here attention is drawn to the dominant values that have shaped our world, to the differences between broad and narrow definitions of public health, to some values that need to be promoted, and to an ethic of public health that considers both human rights and human needs.

Key Words: Public health, medical ethics, rights, needs, duties, values, solidarity, epidemics, global health

SALUD PÚBLICA Y ÉTICA EN SALUD PÚBLICA

Resumen: Los espectaculares logros alcanzados por la salud de los individuos no han sido equiparados por una mejoría equivalente de la salud de las poblaciones en su conjunto. Justamente, ha habido un aumento del interés por la "Salud Pública" debido al deterioro del nivel de la salud de la población en algunas partes del mundo y a la emergencia y re-emergencia de enfermedades infecciosas asociadas con poderosas fuerzas globalizadoras. Aquí se llama la atención hacia los valores dominantes que han moldeado nuestro mundo, hacia las diferencias entre definiciones amplias y/o restrictivas de la salud pública, hacia algunos valores que deben ser promovidos y hacia una ética de la salud pública que considere tanto los derechos como las necesidades humanas.

Palabras clave: Salud pública, ética médica, derechos, necesidades, deberes, valores, solidaridad, epidemia, salud global

SAÚDE PÚBLICA E ÉTICA EM SAÚDE PÚBLICA

Resumo: Os avanços espetaculares alcançados pela saúde pública individual não foram acompanhados por uma melhoria equivalente da saúde das populações. Em algumas partes do mundo aumentou o interesse pela "saúde pública" devido ao deterioração do nível de saúde da população e a emergência e re-emergência das enfermidades infeciosas com poderosas forças globalizantes. Chama-se atenção para os valores dominantes que moldaram nossos mundo, em relação às diferenças entre definições amplas ou restritivas de saúde pública, para alguns valores que devem ser promovidos e para uma ética de saúde pública que leve em conta tanto os direitos como as necessidades humanas.

Palavras-chave: Saúde pública, ética médica, direitos, necessidades, deveres, valores, solidariedade, epidemia, saúde global

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[*] Based on a Summary presentation at the end of a two day symposium on Public Health Ethics at the University of Toronto in May 2002.

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Introduction

Spectacular achievements in the health of individuals as a result of the application of many major biomedical advances are the hallmark of medicine at the beginning of the 21st century. New medical breakthroughs –both preventive and therapeutic in nature– are promised by the eventual clinical application of the revolution in molecular and cell biology and in genetics. Despite these advances and their potential, it is noteworthy that there has been much less striking improvement in the health of whole populations. Indeed, in some parts of the world the health and life expectancy of billions of people have deteriorated in recent decades, especially since the re-emergence of infectious diseases in multi-drug resistant forms (for example tuberculosis and malaria), and the emergence of many new infectious diseases, of which HIV/AIDS has been the most catastrophic.

At the end of the 20th century patterns of diseases and of longevity differ markedly across the world. Of the approximately 52 million people who die each year 17.5 million die of infectious and parasitic diseases (16 million of these - many in their youth - in the developing world), 10 million die of diseases of the circulatory system (4.5 million of these in the developing world) and 6 million die of malignant diseases (3.5 million of these in the developing world)*(1)*. Among the poorest quintile of people in the world 55% die of communicable diseases, as compared with 5% of the richest. The WHO estimated that in 1998, 11 million children and young adults died of six infectious diseases that could have been prevented at the cost of $20 per life saved. Poor countries bear over 80 % of the global burden of disease in disability adjusted life years (DALYs). This burden is likely to increase as the epidemiological transition progresses, with added disability and suffering from non-communicable diseases such as vascular disease, malignant neoplasms (especially of the lung associated with smoking), neuro-psychiatric disease, accidents and trauma.

Life expectancy at birth ranges from well over 70 years in highly industrialized countries to below 50 years in many poor countries. Wide disparities in life expectancy are also observed between rich and poor in rich countries. In sub-Saharan Africa gains in longevity achieved during the first half of the 20th century are rapidly being reversed by the HIV/AIDS pandemic.

Globalization and new threats to public health

Globalization is a complex and ambiguous concept with social and ecological manifestations that reflect a long, interwoven economic and political history in which peoples, economies, cultures and political processes have been subject to international influences. The pace of globalization has escalated during the past 40 years under the influence of advances in information and transport technology, decreasing barriers and homogenization of activities through the imposition of a set of ideas that accord higher priority to market transactions than to other human values and activities. Positive, and widely appreciated manifestations of progress associated with globalization include advances in science and technology; increased life-expectancy; enhanced economic growth; greater freedom and prosperity for many; improvements in the speed and cost of communications and transport; and popularization of the concept of human rights. About 20% of the world's population have benefited maximally from such progress.

Negative effects of globalization include widening economic disparities between rich and poor (within and between nations) and increases in both absolute and relative poverty. In addition to progressive widening of the economic division between nations, and growing external control over the economies of small countries through the 'debt trade' and markets that are increasingly global, other powerful global forces radically are disrupting the lives of many*(2)*. These include new patterns of war and ethnic conflict, illicit trade in arms, money, drugs and people, toxic waste dumping, sexual exploitation and child labor and animal abuse on a wide scale. The trajectory of progress has thus excluded a large proportion of the world population from the benefits of globalization because the process fragments and divides as much as it unifies*(3)*.

It is against this background of rapid and profound change, contributing to the creation of new ecological niches and to adaptive evolution of microbes, emergence of new infectious diseases and the recrudescence of multi-drug resistant tuberculosis and malaria that the resurgence of interest in Public Health is so relevant. The recent SARS epidemic is a further reminder that the whole world is threatened by the ongoing potential for emergence of new, rapidly spreading infectious diseases.

If we contemplate the meaning of these developments it is not difficult to conclude that at the least we live in an amoral world. A harsher diagnosis is that our world, in which some live short miserable lives while luxuries for the few are favored over essentials for the majority, economic slavery is tolerated and sustained, gross abuses of basic human rights are ignored and threats to long-term self-interest are discounted, is morally depraved. We would surely also conclude that an economic system that generates vast wealth but increases poverty is unstable, that the risks of political and other terrorism are growing, and that the emergence of new infectious diseases and other biological threats together with environmental degradation are wake-up calls for new ways of thinking about our world and ourselves*(4,5)*.

In this article I begin by outlining the dominant values that have shaped our world. Against this background I then address an evolving understanding of what we mean by public health by drawing attention to differences between broad and narrow definitions and to the fact that public health is 'at the crossroads'*(6)* The discussion proceeds with a description of public health ethics and its implications, a review of values that need to be promoted and some consideration of human rights and needs approaches to public health. I shall conclude by asking what prospects there are of making progress in public and population health.

Dominant Values

Understanding the dominant values driving behavior in the modern world can assist our understanding of how our polarized world has developed. Firstly, there is great faith in the belief that many of the problems we face will be ameliorated though scientific progress. For example, the solution to the specter of millions of starving and sick people in the world is seen in the development and use of genetically engineered crops and in the application of new genetic technology through vaccines and novel treatment*(7)*, (although the threats as well as the promises of biotechnology have been recognized*(8)*) This emphasis on acquiring new knowledge distracts us from applying knowledge we already have. In relation to the above example the focus could profitably be broadened to include improved means of distributing the excess food produced in the world (much of which is wasted), and making essential drugs and health care more widely accessible.

This shortcoming is amplified by a second idea in which much faith is placed: namely that economic growth is the answer to poverty. Sadly not enough attention is given to how massive economic growth in recent decades has failed to alleviate poverty in the absence of fair reward for work and greater justice in the redistribution of resources towards those in most need.

A third 'belief' that aggravates this situation is the exclusive focus on 'human rights' as a modern civilizing moral agenda. While the human rights approach has great potential this is much diminished by a narrow focus on uninhibited individual freedom with little sincere attention paid to the whole range of human rights as an indivisible whole, as described in the Universal Declaration of Human Rights *(9,10)*.

Finally, the disproportionate belief in the pursuit of short-term self-interest, fostered by market fundamentalism, emphasizes production of goods for consumption by individuals while long-term interests and the production of public goods are undervalued.

What is Public Health?

The 'crossroads' in public health described by Beaglehole and Bonita*(6)* 'lead in two directions: a broad direction, addressing the sociocultural foundations of health, and a narrow direction, focusing on more proximal risk factors'*(11)*. The modern biomedical approach to medicine, described as a model that 'uncouples the etiology of disease from its social roots', has spawned a narrow definition of public health with its practitioners focusing on statistics, epidemiology and measurable risk factors. As a result public health has become increasingly divorced from practice, and public health workers have become 'tame counters of events' rather than professionals 'doing' anything to improve public health*(12)*.

Because of the shortcomings of such a focus a broad definition is currently advocated. The Institute of Medicine's definition is 'What we as a society do collectively to assure the conditions for people to be healthy*(13)*'. Public health in the United Kingdom is defined as 'the science and art of preventing disease, prolonging life and promoting health through organized efforts of society*(14)*'. The report 'Healthy People 2010'*(15)* describes four constructs: a healthy body, high-quality personal relationships, sense of purpose in life, and self-regard/resilience. Further it is argued that a broad definition is necessary 'because public health cannot be separated from its broad socioeconomic context,' and public health professionals cannot silently witness such egregious social injustices as poverty, discrimination, inequality and violence*(11)*. Clearly it is necessary to acknowledge that now, more than ever, addressing upstream causes of widening disparities is essential in confronting public health issues. 'Compared with the narrow perspective of public health, the broad perspective has intellectual merit because it identifies the fundamental causes of many public health problems, providing more complete and parsimonious explanatory models'*(12)*.

Medical Ethics and Public Health Ethics

The traditional concept of medical ethics is centered on standards of professional competence and conduct broadly outlined by formal codes of practice to which individual medical practitioners and medical organizations claim allegiance*(16)*. Training in medical ethics has, until recent decades, relied almost exclusively on apprenticeship. Its practice was dependent on the conscience of individual practitioners and on exhortation through professional associations and various codes. Role modeling served to pass professional norms from one generation to the next. Although the emphasis was on medical etiquette, two major principles of medical morality were also propagated: '*to do good and no harm to others*' and '*to respect human life and the dignity of the individual.*'

These, combined with compassion and confidentiality, have formed the basis for the desired relationship of trust between patient and doctor and the investiture of authority in medical doctors by society. Ethics was considered largely from the perspective of the duties of physicians.

The focus of much of the bioethics discourse over recent decades, driven by the dominant value placed on individualism and autonomy in the USA, has been on reshaping the nature of the health professional-patient relationship. Narrowing the power gap in decision-making has empowered patients to over-ride dominating medical decisions made from within what has been pejoratively labeled paternalistic medicine. An approach based on autonomy allows for a wide range of patient perspectives, and has been widely advocated and adopted especially in the Western world.

The understandable focus on ethical issues at the interpersonal level has undoubtedly eclipsed ethical issues that need to be addressed in dealing with public health issues. Widening disparities in health, the HIV pandemic and possibilities for improving health that are opening through new genetic biotechnology remind us of the limitations of such an approach and the need to extend our perspective beyond individual health to include the health of whole populations. In a globalising world, perhaps best described as a de-territorialising world, in which boundaries are becoming blurred and the lives of geographically disparate people are more intimately interconnected than ever before, it is necessary to re-evaluate traditional ideas of what it means to be an ethical professional*(17)*.

We have suggested that achieving improvements in human life and health globally will require a broader moral agenda that includes, but goes beyond, interpersonal ethics and civil and political rights. Extension of the ethics discourse beyond the doctor-patient relationship should include considerations of order and fairness within institutions that serve the communities in which individuals are socially embedded and in which medical practice is '*constructed*' *(4,18)* The responsibility of physicians here must be viewed more broadly to include concern for equitable access to health care, for improved public health and for the allocation of scarce resources in ways that promote the common good. This calls for an understanding of what the public good is and for a balance between individual rights and the common good –both of which pose the intellectual and social challenges of how to strike a balance between the rights (and needs) of individuals and the common good of societies*(19)*.

In a world in which individual health is increasingly linked to population health, both within countries and between countries, there is thus a need to develop a scholarly and coherent account of Public Health Ethics. A start has been made and eloquent arguments have been offered in favor of a language of public health that "speaks to the reciprocity and interdependence that characterize community"*(20)*. A broad outline of the terrain of public health has also been offered 'without suggesting that there is a consensus about the methods and content of public health ethics'*(21)*. The latter account, however, is not designed to be a universal public health ethic but rather a focus on public health ethics in the particular setting of the United States. In my view it is vital to understand that in a globalizing world public health ethics should extend well beyond parochial considerations to include considerations of global social justice and the nature of the 'social contract' within a broader interdependent global society struggling to achieve sustainable development. How these considerations and the conflicts of interest that accompany them will impact on the physician/patient relationship will also need attention as the ethics discourse is broadened to encompass the ethics of public health and of professional responsibilities to society. While the focus on individual rights is vital and necessary for the well being of individual persons, such a focus is not sufficient for the achievement of improved public health*(22)*.

The American Public Health Association's Public Health Code of Ethics, describing 12 Principles of ethical practice of public health, is supported by an explanation of the values and beliefs underlying the code and notes on the individual ethical principles*(23)*. Several ethical principles have been proposed for the discourse on public health –especially in relation to constraints that may have to be imposed on individual liberties to prevent the spread of infectious diseases*(21,24)*. The 'effectiveness principle' requires demonstration of the effectiveness of a measure in improving public health if other moral considerations are to be infringed. The 'necessity principle' requires that there is no other method that would conflict with other moral considerations. The 'proportionality principle' calls for a positive balance between benefits and adverse effects. The 'harm principle' states that the only justification for restricting the liberty of an individual or group is to prevent harm to others. The 'least restrictive means principle' requires that less coercive means (for example, education, facilitation and discussion) must first be tried before it can be justified to use the full force of state authority. The 'reciprocity principle' requires that the state should assist individuals to meet their public responsibilities through support and compensation for time and income lost in the process of so doing. The 'transparency principle' refers to the decision-making process, requiring that it be as clear and accountable as possible and free of political interference. The importance of these principles became apparent in dealing with the SARS epidemic in Toronto recently[1].

Achieving an improved balance between the needs and rights of individuals on the one hand, and the requirements for advancing public health on the other, will require a shift in mindset away from strong individualism towards respect for individuals within the context of a sense of duty towards the community. Essential steps will include: firstly, acquiring deeper insight into the upstream causal factors influencing public health; secondly acknowledging the need for a new balance between individual and population health; thirdly, developing the political will to undertake ambitious projects (for example, seeking ways of reducing poverty and dependency and of increasing access to health care); and, finally, placing high value on the longer term economic and social justice required for meaningful and sustainable progress.

The dilemmas regarding public health ethics will be greatest for those societies that are intolerant of any infringement of individual liberties in the name of the common good. The challenge for societies more oriented towards the common good is to avoid excessive infringements of individual rights in the pursuit of public health goals. Realistically a middle ground will have to be forged, because the choice is not between polar extremes but rather about achieving an optimal balance between competing goods*(25)*.

Making Progress - expanding the discourse on ethics and human rights as a first step

Morality is about right and wrong in relationships. Ethics is the branch of philosophy that examines the basis for right and wrong or good and bad. Morality and ethics are usually

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[1] Singer PA, Benatar SR, Bernstein M, et al. Ethics and SARS: learning lessons from the Toronto experience. *British Medical Journal* 2003; (in press)

considered between individual persons –interpersonal ethics– or within groups such as families and religious groups. We have proposed that the discourse about relationships should be extended to relations within institutions (institutional or public health ethics) and between nations (ethics of international relations). Similarly the discourse on human rights needs to be extended beyond civil and political rights to include social, economic and cultural rights as well as environmental rights and the right not to be exploited at the level of international relations. The process of extending the bioethics discourse will require promotion of several crucial values*(18)*.

Values to Promote

Concern for the common good

Constructing new and acceptable ways of achieving economic redistribution is the key to resolving many global problems*(26)*. Widespread appreciation is needed for the likelihood that further widening of disparities in wealth and health, beyond the already grotesque differences that currently characterize our world, is a guaranteed recipe for disaster. If the privileged care progressively less for the lives of those whom they consign to living under inhumane conditions, the lives of the privileged will become meaningless and inhuman to the underprivileged masses. This global trap, in which neither rich nor poor care if millions of the other group should die, is the precursor to conflict and loss of life on a grand scale. If rational self-interest plays any role in human life, it should not be difficult to agree that such conflict must be avoided.

Achieving widespread access to such public goods as education, basic subsistence needs and work requires collective action, including financing, to make sure they are produced, and good governance to ensure their optimum distribution and use. The current international system is very effective at stimulating the production of private goods (e.g., the role of WTO in promoting international trade) but not at the production of public goods –for example education for all children, equitable access to health care and the realization of labor rights and human rights*(19,26,27)*.

While economic equality is an impossible goal, narrowing the current gap is surely well within our grasp. Fair trade rules, debt relief, various forms of taxation, such as the Tobin tax on currency trades across borders (that could generate US$100-300 billion per year) and environmental taxes, have been suggested as ways of facilitating the development of the solidarity required for peaceful co-existence in a complex world*(5,27)*. It should also be acknowledged that greater value needs to be placed on such non-economic aspects of life as a sense of personal worth and dignity.

Belief in and promotion of all human rights (and duties)

"Human rights", as a secular concept for promoting human dignity, has the potential to transcend religions, national borders and cultures. In recent decades the human rights movement has flourished and more countries seem to be accepting universal human rights as a "civilizational" standard*(28)*. Although human rights are widely accepted in the rhetorical sense, much argument continues about the nature and extent of rights. Since the early 1990s a complex debate has also emerged regarding the Western bias and origins of human rights. The extension of human rights from the West to the rest of the world, while superficially successful, must still be considered as largely 'unfinished business*(29)*'.

Today many countries consider access to basic health care as a basic human right that nation states should be committed to providing for their citizens. Some form of socialized and equitable health care is provided in all western European nations and in Canada. Regrettably the example of medical care (as a marketable commodity - albeit with considerable state assistance for the poor and the aged) set by one the wealthiest nations in the world (with damaging effects on that society that are increasingly being acknowledged in the USA*(30)*) has been followed by many developing countries. Such privatization of medical care, aided and abetted by structural adjustment programs promoted by the IMF and the World Bank, has adversely affected health in many poor countries. Acknowledging the need for, and the right to, universal access to a basic health care package and achieving this goal pose challenges for the future. The WHO's renewal strategy for health-for-all places emphasis on equity, solidarity and appropriate technical, political and economic strategies that could promote health and sustainable health care systems as central requirements for development*(31)*.

The application of human rights must extend beyond civil and political rights to include social, cultural and economic rights and their close integration with the reciprocal responsibilities required to ensure that rights are honoured and basic needs are met. Just as the concept of 'political citizenship' requires non-discriminatory enfranchisement of all, so the concept of 'social citizenship' requires access to the basic requirements for survival and potential flourishing –a requirement of modern democracy. Considerations of group rights to protect minorities add another layer of complexity*(32)*. Protecting minorities is more than an extension of human rights and is an essential component of the quest for international peace and security. Much remains to be achieved if human rights are to become an integral aspect of global politics and law*(33)*.

The different perspectives from which rights are discussed include consideration of rights as entitlements under law, rights as ethical standards and rights as aspirational ideals. Medical ethics is also addressed from a range of perspectives –including, but not limited to, deontological ethics, consequentialist ethics, casuistry, virtue ethics and caring. Medical ethics and human rights are linked indirectly and directly. Indirect links are evident from the concerns of health care professionals to improve the health and lives of individuals and of society, and to treat all patients with equal respect. Direct links include recent declarations to respect human rights and an increasing discourse about rights within bioethics. Human rights proponents and bioethicists share values regarding human dignity. However, these two sets of activities use different discourses and methods and have different implications. The scope of medical ethics or bioethics is more comprehensive than the human rights discourse, embracing concepts of duties and virtue, empathy, compassion and communication skills that cannot be dealt with through a rights approach. However, rights are powerful and have a specific role in medicine. For example the special role of health care professions in witnessing and responding to abuses of human rights provides the opportunity and the responsibility to act on these*(34)*.

There are several ways in which health care professionals can protect or promote human rights: Firstly, by *promoting commitment to high ideals in medicine* through exhortation and other means of sustaining idealistic aspirations. Secondly, by promoting greater knowledge and understanding of the content of ethics and human rights through *education*. Thirdly, by implementing *due process* through international statutes and international law. Fourthly, by developing *strategies* to enlist assistance from national and international Medical Associations. Finally by operationalizing ideals through the *actions* of Human Rights Commissions and other Non-Governmental Organizations such as Amnesty International.

Sense of solidarity with others

Solidarity is a complex concept the nature of which, its justifications and implications are all contested depending on how self-interest, the common interest and identity are conceived and balanced*(35)*. However, the term seems to have special relevance in a dangerously polarized world. Developing a global state of mind about major global health problems is arguably the most crucial element in the evolution of global health ethics. Given the plurality of deeply held perspectives solidarity will also be difficult to achieve –as illustrated by the struggle to develop global alliances on the environment, nuclear deterrence, debt relief for highly impoverished countries, on the tobacco trade and on universal access to basic drugs. Its importance, however, is not diminished by such difficulty.

Long-term self-interest

While advocating for both the desirability and the necessity to develop a global mindset in health ethics, we do not suggest that this should be based solely on altruism. In addition there should be greater attention to enlightened long-term self-interest*(18)*. In the past, the achievement of security has depended on striving for *competitive* advantage and on building fortresses for protection. With the progress of nuclear and other weapons of mass destruction it becomes evident that this approach is inadequate and could destroy all life on the planet. As all of our lives become increasingly dependent on environmental preservation and on the improved living conditions that could reduce the emergence of new infectious diseases, security will become increasingly dependent on *co-operation* within a mindset that allows us to see ourselves as intricately linked to the lives and well being of others globally.[2] There may be no clearer example of self-interest, mutual interdependence and the need for co-operation than in facing the threat posed by the HIV/AIDS pandemic. Politicians are coming to recognize this, as illustrated by former President Clinton's declaration that HIV is a national security threat to the USA and the agreement at the 1999 meeting of Commonwealth Heads of Government that HIV/AIDS is a global emergency.

From rights to needs and a broader moral agenda for public health

Inadequate attention has been paid to the fact that rights and duties are intimately connected - the conceptual logic of rights entails corresponding duties. Thus duty bearers need to be identified to ensure the realization of rights. If all claim rights but none are willing to bear duties, rights will not be satisfied. Our ability to enjoy rights is thus determined by our willingness to accept our responsibilities. The recently proposed Declaration of Universal Duties could further strengthen the rights approach*(36)*. A focus on duties would expose the responsibility of developed nations not to act in ways that may abrogate the rights of people in developing countries. It could also promote recognition of the role developing countries themselves play in causing and perpetuating the misery of their peoples.

Both the Universal Declaration of Human Duties, recently offered as a supplement to the UDHR, and a detailed formulation of how rights and responsibilities (which are indeed inextricably related), can be reintegrated*(37)*, illus-

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[2] Much greater attention will also be required to the ways in which we use and abuse animals – creatures whose lives are more closely intertwined with ours than is currently appreciated

trate how the power of human rights language could be enhanced. Of concern is that political discourse is impoverished by a human rights discourse in the US, which "far more than in other liberal democracies, is characterized by hyper-individualism, exaggerated absoluteness, and silence with respect to personal, civic, and collective responsibilities*(37)*." The reintegration of rights and responsibilities offers three advantages: (i) moving the human rights debate in the direction of who has to do what if these rights are to be realized, (ii) more focused and specific discussions of questions of priority among rights and other important social goals, and (iii) discussions of the inadequacies of the contemporary international political and economic order*(38)*. A shift is required from an excessively liberal human rights paradigm to a social model of human rights that links benefits and entitlements with the acceptance of a series of responsibilities - the starting point for such rights being the principle of respect for all persons in the context of community*(37)*.

While the necessity of the highly commendable rights approach should be acknowledged, it would be wrong to imagine that it is a sufficient moral agenda for the achievement of greater social justice. While rights language is effective in meeting some needs, and is thus a necessary component of the moral vocabulary, it cannot meet all. The language of needs is another essential means of pursuing progress towards achieving decent societies*(39)*. '[It] provides a moral discourse for health promotion and the common good and would be conducive to *'a moral economy of interdependence'* that goes beyond the individualistic oriented 'political economy,' takes account of the inherently 'political nature of need,' 'situates the definition and adjudication of needs in the common life of the community, and incorporates notions of reciprocity that go beyond the dichotomy of dependence and independence. A theory of human need provides the justifying framework for such an approach*(40)*.

Conclusions

The world is changing rapidly, with new threats arising to human health at both individual and population levels, and new ideas are needed to make moral and social progress. While new ideas take time to impact there is now a glimmer of hope that advancement towards improved global health is possible. For example, the recent report from the US Council of Foreign Relations and the Milbank Memorial Fund acknowledges the relationships between health and social capital, political stability, the economy and war*(41)*.This could facilitate deeper commitment by the USA and other nations to the moral and strategic importance of improving global health. The work of the Commission on Macroeconomics and Health*(42)* and the inauguration of a Global Health Fund*(43)* also reveal a deeper understanding of the importance of global health and an acknowledgement of the responsibility of developed nations to address this constructively. A recently proposed method of promoting a market in global public goods draws attention to how international institutions could promote the production of global public goods by steering a middle path to development between the goals of avid pro-globalization advocates and aggressive anti-globalization groups*(44)*.

However, these are very modest beginnings and much more is required to build a moral global community*(26)*. Public health is a complex notion. Justice and social justice are also complex notions. While there is no satisfactory theory of social justice that could improve public health, injustice is easy to recognize and much progress could be made through new scholarly approaches and the application of common sense conceptions of what could be done to reduce injustice. While achieving justice may be impossible, it is feasible to reduce injustice if we focus on global injustice and develop a public health ethics discourse capable of reshaping how we think and act*(18)*.

While it may seem daunting to individual physicians to consider that they could make any impact on global problems of such magnitude several suggestions can be made. First, we should acknowledge our obligation to know about the impact of global forces on health. Second, we should become more introspective about our privileged lives. Third, we should appreciate that our personal skills, developed on the basis of labor and investment by previous generations, represent social capital and involve social obligations for us. Fourth, we should become a force in coupling excellent treatment of individual patients to national programs that improve public health within nations. Finally, we need to locate our activities within the global context described above and promote new ways of thinking about local and international activities that have the potential to improve well-being and health at the global level. If physicians, scholars and other influential persons (individually and collectively) were to accept these responsibilities there would at least be some hope of moving beyond the present impasse towards healthier and better lives for all.

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References

1. Murray CJL, Lopez AD, eds. *The global burden of disease*. Cambridge MA: Harvard University Press; 1996.

2. Friman HR, Andreas P, eds. *Illicit global economy and state power*. New York: Rowan and Littlefield; 1999.

3. Held D, McGrew D. The great globalization debate: an introduction. In: Held D, McGrew A, eds. *The global transformation reader*. Cambridge UK: Polity Press; 2000: 1-45.

4. Benatar SR. Millennial challenges for medicine and modernity. *Journal of the Royal College of Physicians of London* 1998; 32: 160-5.

5. Benatar SR. The coming catastrophe in international health: an analogy with lung cancer. *International Journal* 2001; LV1(4): 611-31.

6. Beaglehole R, Bonita R. *Public health at the Crossroads. Achievements and Prospects*. New York: Cambridge University Press; 1997.

7. Singer PA, Daar AS. Harnessing genomics and biotechnology to improve global health equity. *Science* 2001; 294: 87-9.

8. Clark N, Stokes K, Mugabe J. Biotechnology and development: threats and promises for the 21st century. *Futures* 2002; 34: 785-905.

9. Universal Declaration of Human Rights. *British Medical Journal* 1997; 315: 1455-6.

10. Benatar SR. Human Rights in the Biotechnology Era. BioMed Central 2002 [Website] Available in http://www.biomedcentral.com/1472-698X/2/3 Access in November 7, 2003.

11. Meyer IH, Schwartz S. Social issues as public health: promise and peril. *American Journal of Public Health* 2000; 90: 1189-91.
12. Fee E, Brown TM. The Past and Future of Public Health Practice. *American Journal of Public Health* 2000; 90: 691-2.
13. Institute of Medicine. *The Future of Public Health*. Washington DC: *National Academy Press*; 1988.
14. School of Public Health and Related Research [Website] Available in http://www.shef.ac.ul/publich/research/ethics Access in November 7, 2003.
15. *Health people 2010: Conference Edition.* Washington DC: US Department of Health and Human Services; 2000.
16. *Ethical Codes and Declarations relevant to the health professions*. London: Amnesty International; 2000.
17. Benatar SR. The meaning of professionalism in medicine. *South African Medical Journal* 1997; 87: 427-31.
18. Benatar SR, Daar AS, Singer PA. Global health ethics: the rationale for mutual caring. *International Affairs* 2003: 79; 107-38.
19. Kaul I, Grunberg I, Stern MA, eds. *Global Public Goods: International Cooperation in the 21st Century*. New York: Oxford University Press (published for The United Nations Development Programme (UNDP)); 1999.
20. Robertson A. Critical reflections on the politics of need: implications for public health. *Social Science and Medicine* 1998: 47; 1419-30.
21. Childress J, Faden R, Kahn J, et al. Public Health Ethics: Mapping the Terrain. *Journal of Law, Medicine and Ethics* 2002; 30: 170-8.
22. Buchanan D. *An ethic for health promotion*. New York: Oxford University Press; 2001.
23. American Public Health Association. [Website] Available in http://www.apha.org/codeofethics/ethics.htm Access in November 17, 2003.
24. Upshur REG. Principles for the justification of public health intervention. *Canadian Journal of Public Health* 2002; 93: 101-3.
25. Benatar SR. Bioethics: Power and Injustice: Iab Presidential Address. *Bioethics* 2003; 17: 387.
26. Royal Danish Ministry for Foreign Affairs. *Building a global community: globalization and the common good*. Copenhagen: RDMFA; 2000.
27. Fact sheet on Tobin taxes. [Website] Available in http://www.ceedweb.org/iirp/factsheet.htm Access November 17, 2003.
28. Donnelly J. Human rights: a new standard of civilization? *International Relations* 1998; 74: 1-24.
29. Falk R. *Predatory globalization: a critique*. Cambridge: Polity Press; 1999.
30. Institute of Medicine of the National Academies. *Hidden Costs, Values Lost: Uninsurance in America.* Washington DC: National Academy Press; 2003.

31. World Health Organization. *Renewing the health-for-all strategy: elaboration of a policy for equity, solidarity and health*. Geneva: WHO; 1995.

32. Felice WF. *Taking suffering seriously: the importance of collective human rights*. New York: State University of New York Press; 1996.

33. Falk R. *Human rights horizons: the pursuit of justice in a globalizing world*. New York: Routledge; 2000.

34. British Medical Association. *The Medical Profession and Human Rights; Handbook for a changing agenda*. London & New York: Zed Books; 2001.

35. Khushf G. Solidarity as a moral and political concept: beyond the libertarian/communitarian impasse. In: Bayertz K, ed. *Solidarity.* London: Kluwer Academic Publishers; 1999.

36. *Trieste Declaration of Universal Duties*. Trieste: Trieste University Press; 1997.

37. Chapman AR. Reintegrating Rights and Responsibilities. In: Hunter KW, Mack TC, eds. *International Rights and Responsibilities for the Future*. Westport, Connecticut: Praeger; 1996: 3-28.

38. Nickel JW. How human rights generate duties to protect and provide. *Human Rights Quarterly* February 15, 1993: 77-86.

39. Ignatieff M. *The needs of strangers*. New York: Viking Penguin; 1984.

40. Doyal L, Gough I. *A theory of human need*. London: MacMillan; 1991.

41. Kassalow JS. *Why health is important to US foreign policy*. New York: Council on Foreign Relations / Milbank Memorial Fund; 2001.

42. World Health Organization. *Macroeconomics and health: investing in health for economic development. Report of the Commission on macroeconomics and health*. Geneva: WHO; 2001.

43. Tan DHS, Upshur REG, Ford N. Global plagues and the global fund: challenges in the fight against HIV, TB and malaria. BioMedCentral 2003. [Website] Available in http://www.biomedcentral.com/1472-698X/3/2 Access October 1, 2003.

44. Soros G. *On globalization.* New York: Public Affairs; 2002.

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GENOMICS, PUBLIC HEALTH AND IDENTITY

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Abstract: This paper questions the utility of the ethical principles that are usually invoked to deal with genomic issues, particularly genetic databases. Concepts such as solidarity, benefit sharing, equity, public participation, and collective identity are discussed. The author argues that genetic banks are precipitating new concern over group interest, as opposed to concern over issues arising from individualistic medical ethics. Genomics era needs new paradigms in ethics. An individualistic approach based on choice and autonomy is not useful, because we make choices not only as individuals but also as members of different groups. The doctrine of informed consent evolved in different historical conditions from the ones we face in the era of genomics. This is complicated by the global context of genetic research, in addition to powerful commercial interests. This suggests that it is not sufficient to move from an individual-centred ethic approach to a more community-centred one; an approach of renegotiating the relationship between individual and community. We need also to be clear about what the interests at stake are, which may mean reconceiving the terms ‘individual’ and ‘community’ in this context and the ways in which their interests are affected, identifying the sources of collective identity that are at stake.

Keywords: Genomics, ethics, biobanks, collective identity, individual interests, collective interests, community

GENÓMICA, SALUD PÚBLICA E IDENTIDAD

Resumen: Este artículo cuestiona la utilidad de los principios éticos que son generalmente aludidos para abordar problemas de genómica, particularmente los de bancos de datos genéticos. Conceptos como solidaridad, compartir los beneficios, equidad, participación pública e identidad colectiva son discutidos. La autora sugiere que los bancos de datos genéticos están generando nuevas preocupaciones sobre los intereses del grupo, preocupaciones opuestas a los temas de una ética médica individualista. La era de la genómica necesita nuevos paradigmas éticos. Un enfoque individualista basado en la elección y la autonomía no es útil, puesto que tomamos decisiones no sólo como individuos sino también como miembros de diferentes grupos. La doctrina del consentimiento informado surgió en condiciones históricas diferentes de las que enfrentamos en la era de la genómica. Esto se complica por el contexto global de la investigación genómica y la presencia de poderosos intereses comerciales. Ello sugiere que no es suficiente moverse desde un enfoque centrado en el individuo a un enfoque más centrado en la comunidad; uno de renegociación de la relación entre individuo y comunidad. Necesitamos también tener claro cuáles son los intereses en riesgo, lo que puede significar redefinir los términos “individuo” y “comunidad” en este contexto y los modos en que sus intereses pueden ser afectados, identificando las fuentes de identidad colectiva que están en riesgo.

Palabras clave: Genómica, ética, bancos de datos genéticos, identidad colectiva, intereses individuales, intereses colectivos, comunidad

GENOMICA, SAUDE PÚBLICA E IDENTIDADE

Resumo: Esse artigo questíona a utilidade dos princípios éticos que se aludem geralmente para abordar problemas do genoma, em particular os de bases de dados genéticas. Conceitos tão a solidariedade, a dividir os benefícios, a equidade, a participação pública, e a identidade coletiva pública tratam. O autora sugire que as bases de dados genéticas estão gerando novas inquietudes pelos juros do grupo, inquietudes opostas aos temas de uma ética médica individualista. A era da genômica necessita de novos paradigmas éticos. Um enfoque individualista baseado na a eleição e a autonomia não é útil, porque nós tomamos decisões não apenas como indivíduos como também como membros de diferentes grupos. A doutrina do consentimento fundamentado surgiu em diferentes condições históricas das quais nós olhamos na era da genômica. Isto se complica mais pelo contexto global da pesquisa genômica e da presença de juros comerciais potentes. Isto indica que não é suficiente de mover de um enfoque estado centrado no indivíduo a um enfoque mais centrado na comunidade; um de renegociação da relação entre individuo e a comunidade. Nós necessitamos estar também seguros o qual são os juros em risco, que pode significar redefinindo os terminos do “indivíduo” e a “comunidade” nesse contexto e as modalidades nestes seus juros podem ser afetados, identificando as fontes de identidade coletiva que estão em risco.

Palavras chave: Genômica, ética, bases de dados genéticas, identidade coletiva, juros individuais, juros do coletivo, comunidade

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Introduction

The growth of a public health agenda in genomics has raised anew the debate about genetic exceptionalism. In the field of ethics, while in clinical genetics individualism has prevailed, proposals for population biobanks have invoked principles of solidarity and benefit-sharing; concepts of gift and global public goods. What is needed, however, is attention to notions of identity in both contexts, individual and collective.

Science (6 June 2003) carried a story about a proposal to establish an African-American population biobank. The aim is to collect DNA samples from 25,000 volunteers over five years to "help disentangle genetics from socio-economic and other environmental factors in understanding disease among African Americans". It is also hoped that it will change attitudes among this group, who has been distrustful of medical research since the scandal of the Tuskegee syphilis studies. As the *Science* article points out, the role of race and ethnicity in thinking about medical ethics and policy is controversial because the genetic differences between individuals within a 'race' are greater than differences between ethnic groups. This reinforces the view that differential incidence of diseases between groups may be strongly influenced by socio-economic factors such as discrimination. Nevertheless such biobanks will, it is envisaged, facilitate the acquisition of more soundly based information on the respective inputs of genes and environment.

While health inequalities between different groups have long been an issue in medical ethics, I want to suggest that the move to population biobanks puts group interests, rather than individualistic medical ethics, more prominently on the agenda. The question is whether we have the theoretical resources to deal with this. Ironically, as we move in this direction, the purported benefits of genetic research are increasingly framed in terms of individual benefits, as in the clams for the future of individualised prescribing arising out of pharmacogenetics and nutrigenomics. The following quotation is illustrative of an approach which sees genetic possibilities as a mechanism of individual empowerment:

> While rapid progress continues, there is much you can do now for yourself and your loved ones. Know your family history, be cognizant of your ethnic origin, determine your genetic susceptibilities, opt for necessary gene tests, take preventive actions, establish appropriate surveillance, and seek pre-emptive treatment where applicable. In this way, you can exercise control over your genetic destiny, secure your health, and –in more ways than you yet realize– save your life (Milunsky, 2001, xv).

I want to suggest that we need to think again about individualism: in particular, reliance on the individual choice model alone is likely to prove insufficient. And yet social science research, in the UK at least, has suggested that people are becoming increasingly individualistic in their thinking[1].

The more that we understand about the human genome, the greater the possibilities for developing tests, of different kinds, that can be offered to individuals. Discussion initially focused on cases such as establishing that an individual has a disorder traceable to a single gene, such as Huntington's. If an individual tests positive for the Huntington's gene he or she is virtually certain to develop the disorder in middle life.

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[1] Research by Paul Whiteley for the ESRC Democracy and Participation programme, reported on BBC Radio 4 Today programme 24 September 2003

Not all genetic tests are of this kind however. Others would enable two would-be parents to establish whether they were both carriers of a recessive gene that would give them a one-in-four chance of having an affected child. Again, there are tests that establish, not whether an individual has one of the genetic disorders as such, but whether he or she has a genetic make-up that would put him or her at higher than average **risk** of developing one of the common diseases, such as breast cancer, or heart disease.

Into this frame we now have to put the development of new types of test. We are all familiar with going to the doctor and receiving a prescription for medication. It is envisaged that, in the light of advances in genetics, the practice of medicine as we know it may in future be quite different. Among the types of genetic test that are likely to become available in the next few years is a 'medicine response test'. The point of this will be to test individuals for information regarding their likely response to drugs in the light of their particular genetic profile. Pharmacogenetics is the term used to describe the use of genetic information to show how variations in patients' DNA may affect drug responsiveness and susceptibility to side effects. Pharmacogenetics will enable us to identify who will be likely to benefit and who harmed. If we could establish this in advance, the argument goes, doctors could prescribe more safely and effectively – prescribing would become more tailored to the individual than it is now. The whole practice of medicine could become much more 'geneticised' by this development in what is called pharmacogenetics. It is not clear, however, how this would work – would doctors test the patient at the time of prescription or would information about everyone's genetic make-up be kept on a database that could be accessed by physicians or perhaps by pharmacists? Or would we have our own 'smart cards'?

In addition to developments in pharmacogenomics, there is increasing interest in analogous possibilities in nutrigenomics (Müller and Kersten, 2003). As society goes further down the path of grappling with the issues of the postgenome era, the relationship between genetics and diet is becoming increasingly central. The UK Department of Health White Paper, *Our Inheritance, Our Future* (2003) states that:

> …the way external factors and genes interact to cause disease or protect us from disease will be better understood. This information will allow people with certain genetic profiles to avoid foods, chemicals or environmental factors, such as smoking, which are particularly risky for them (DoH, 2003.)

Here the issues of nutrigenomics arise: the application of genomics in nutrition research, enabling associations to be made between specific nutrients and genetic factors, e.g. the way in which foods or food ingredients influence gene expression; and the study of individual differences at the genetic level influencing response to diet.

Ethics and the individual

There have long been arguments that there is something special about genetics which makes the presumptions that have operated in medical ethics inappropriate. This idea about specialness is known as **genetic exceptionalism.** Genetic exceptionalism holds that there is a difference in kind between genetics and other areas of medicine, because, for example, genetic information is predictive, not specific to time, and shared between blood relatives. There is a weight of argument, however, against genetic exceptionalism that points to other areas of medicine that share, at least to some extent, some of these features: there are non-genetic tests that are predictive; a person's HIV status is relevant not only to him or herself.

Pharmacogenetics and nutrigenomics, however, raise anew the thesis of 'genetic exceptionalism'. What we might call pharmacogenetic exceptionalism suggests that pharmacogenetics will change the practice of medicine more than ever by producing 'personal pills' and challenging expectations of professional roles. Similar considerations apply with regard to nutrigenomics and the possibilities of individualised dietary advice. We have to consider suggestions of new paradigms in medicine and nutrition, following from the new scientific paradigms arising out of the Human Genome Project, and possibly new paradigms in ethics.

I think it is fair to say that in the context of clinical genetics and health service delivery, the prevailing ethical framework, what I call the 'standard view', has been individualistic, being based on the autonomy and choice of the individual.

- Individuals and couples undergoing genetic tests, particularly in the reproductive context, should have access to **non-directive** genetic counselling.
- Population screening should only be carried out where there is scope for action for the individuals who test positive.
- Individuals, on this model, have both a right to know and a right not to know genetic information about themselves, and
- should be given the opportunity for informed consent to donating a DNA sample.

It is also important, however, to have regard to constructions of individual identity in these contexts.

Autonomy and identity

We live in an era in which information, and individual choice, is, in general, prized. The argument for this can be supported from more than one kind of ethical perspectives, involving the notion of individual autonomy. Every ethical theory presupposes a particular understanding of the individual agent. From a utilitarian point of view, the individual agent is regarded as a utility maximizer – he or she will, if rational, act to promote their interests. Individual autonomy, on this perspective, consists in choosing what one sees as good, on the basis of what one wants. Each individual agent is helped in maximising his or her own utility by having the relevant information to take into account, e.g. about their future health risks, or predisposition to side effects from particular drugs, and this also arguably facilitates the utility of the larger group. It is in general in the best interests of society that individuals should make informed decisions about their own future good. Although in particular cases it may seem that the best consequences can be achieved by keeping people in ignorance, nevertheless we have seen several well publicised instances in the media of cases where a great deal of anger has been caused by people being denied information -in medical settings, in particular. So facilitating individual choice by making information available can be supported on the grounds that it tends to lead to the best overall consequences.

From another point of view, individual autonomy does not consist in pursuing one's interests as defined by one's desires or one's individual conception of the good. On the contrary, it consists in making a **responsible** choice, **as** a rational moral agent. It could be argued that there is a **duty** to be well-informed in order to fulfil one's duty to oneself and others. It is not that having the information will maximise one's utility: the question is whether a choice not to know a piece of genetic information is right. Consider the example of the option to know whether one had a genetic predisposition which made one much more likely to suffer from lung cancer if one smoked. Could a choice **not** to know this be supported - choosing not to know a piece of information that could be instrumental in preventing premature death? In the past few years, however, there **have** been more frequent arguments that there is a right **not** to know genetic information about ourselves (Chadwick et al., 1997). Although, as we have seen, there are considerations that favour making information available to individuals so that they can make informed choices about what is in their best interests, there is a difference between making information available and forcing it upon people if they do not want it. On the utilitarian version of autonomy, different utility maximisers might take different views, according to their own preferences and attitudes to risk. It is a commonplace that people differ in this respect. We make a distinction between those we call 'risk lovers' and those we call' risk averse'. Even if it **is** the case that there might be arguments for knowing genetic information that is potentially life-saving, however, the amount of genetic information that is covered by this criterion is a relatively small proportion.

Let us look at an example. There has been considerable debate over the question of whether there is a 'homosexuality gene', although it is now generally recognised that to speak in this way, of a 'gene for' a condition or characteristic, is very misleading. Genetic influences, where they exist, are likely to be very complex, not direct causal chains between one gene and one characteristic. That being said, let us suppose that it did become possible to have access to some information about genetic influences on one's sexual orientation. Here I want to turn to considerations of autonomy and identity. Today we recognise the important role that sexuality can play in an individual's identity. Establishing and protecting one's identity as an individual human is a wider if not a richer notion than the notion of moral agent. The right to preserve one's self-image has itself been advanced as an argument for a right not to know certain genetic information. Peter Widmer, for example, has argued that "I am not obliged to agree…to receive information … which could lead me to modify my picture of myself in an undesirable manner" (Widmer, 1994). Although there may be problems arising from self-deception in some cases where an individual's self-image is too far divorced from reality, we might think that there are reasons for understanding autonomy here in a different sense, in terms of making decisions about one's life as a whole, about what kind of person to be overall, rather than what to do in particular situations – for example, instead of thinking in terms of whether or not to take test x or not, the question would be: do I *want to be the sort of person* who takes every test available, or would I prefer to take things as they come? As the genetic 'revolution' advances, the latter choice may become reduced in some contexts. It may be the case that it will come to be regarded as negligent and contrary to medical ethics, for example, for doctors to prescribe medication without relevant genetic information, whether or not we want to know it ourselves. It is, then, not only the case that ethics can help us to think about what is acceptable in genetics, but advances in genetics can change our view about what is ethically acceptable.

Genes can also be associated with our conceptions of our own identity in a deeper sense. Whereas in the past it may have been the norm to think of one's identity in terms of one's soul, it is becoming more common to speak of one's identity as connected in some sense with the genes (Nelkin and Lindee, 1995). This to some extent explains the widespread revulsion towards reproductive cloning, and the objection expressed by many people to the deliberate creation of a being with an identical genome to another. It has to be said, however, that it can also explain some of the attraction of reproductive cloning to those who support it. People who have lost a loved one, for example, may think that it is possible to bring them back in some sense by creating a genetic 'replica' by cloning. This kind of thinking has been encouraged by stories that some scientists working on the Human Genome Project have claimed that an individual's identity could be encapsulated in a disk containing all their genetic information. Some have used 'reductionist' language suggesting that we can all, ultimately, be reduced to or explained by our DNA sequences, so that to know a person's genes is to know all there is to know about them. Others, however, suggest that this kind of thinking is a mistake. Human beings are much more than their genes: our environment and experiences play a part in creating who we are, so to try to recreate a lost loved one, even if reproductive cloning of humans were both practicable and permissible, would on this view result in disappointment.

Nevertheless, even if our identity as human beings cannot be completely reduced to our genes, it may well be true that our genes play a large part in influencing how we think about our selves, in more ways than the issue of how we take decisions about our future health. If it becomes possible to establish links between genetic factors and behavioural characteristics, as is envisaged by some, we may find ourselves as individuals given access to information about our tendency to be happy or sad, prone to take risks or cautious, and so on. It is not just how we think of our own future development as individuals, however, that is open to being affected by developments in genetics: there are also relational issues to consider. Knowledge about who our genetic relatives are, for example, has always been seen as important and it can be traumatic for those who either know nothing of their genetic parentage or find out that it is quite different from what they imagined, because we partly construct our identity in relation to others. We make choices not only **as** individuals, but also **as** members of a number of different groups. This will be very important in relation to biobanks.

Partly because of the need for research for the purposes of pharmacogenetics, we are now witnessing the setting up of large population databases, which will facilitate research of different kinds: association studies to establish links between genetic profiles and common disease; and association studies to establish response to drug toxicity, for example.

Let us consider a scenario in which a pharmaceutical company is undertaking a clinical trial to establish the safety and efficacy of a new product and, at the same time, to track the drug response against the genetic profiles of the participants. The participants are asked to give a separate consent to the traditional and the genetic aspects of the trial. What is different about the consent issues in the one case from the consent issues in the genetic aspects? Clinical trials in this area may have features that distinguish them from traditional clinical trials: first, it should be possible for clinical trials to become more targeted towards specific groups. For present purposes, however, the salient point is that they are likely to involve storage of DNA samples as responses to drugs are tracked over time, and this raises questions about the feasibility of informed consent. Another key change from the considerations outlined above concerns feedback: the focus of debate shifts from discussing an individual's choice or responsibility to know or not know genetic information, towards the issue of whether organisations involved in establishing databases have a duty to give feedback. In the course of the debates about genetic exceptionalism, generally concerns have been voiced about the possibility of genuine informed consent in genetics generally (Chadwick, 2001), for a number of reasons, but in the case of long term storage of DNA samples the issues become particularly complex because of the difficulty of making sense of 'consenting' to potential, but presently unforeseeable, uses of one's samples at some point in the future. The issue of predictability and storage is key here.

Beyond the issues for individuals, patients could be stratified according to genetic risk factors, as they are presently classified by other risk factors such as high blood pressure. In this connection the possible implications for particular population groups should be considered, in the light of possible differences between ethnic groups as regards, for example, slow or rapid rate of metabolising a drug. Given the complexity of these issues in relation to research databases for pharmacogenetic purposes, population wide biobanks, such as the proposed African-American one, for research and service delivery purposes are likely to be even more complicated, and bodies, such as the WHO, are recognising [in their draft report on genetic databases] that

> The justification for a database is more likely to be grounded in communal value, and less on individual gain … it leads to the question whether the individual can remain of paramount importance in this context
>
> And again:
>
> The achievement of optimal advances in the name of the collective good may require a reconsideration of the respective claims so as to achieve an appropriate balance between individual and collective interests, including those of ethnic minorities, from a multi-cultural perspective (WHO, 2001).

The question arises, then, as to what ethical resources we should be using in addressing the issues of genetic databases. The WHO appears to be suggesting a shift away from the paramountcy of the individual in favour of community interests.

The HUGO Ethics Committee in its Statement on Benefit-Sharing in 2000 (HUGO, 2000) addressed the issue of sharing the benefits of genetic research. On the one hand, some advocate that pharmaceutical companies who benefit from genomic research should make some return to the communities and families who have made increased revenues possible. On the other hand, those who oppose benefit-sharing may suggest that people who contribute samples for research have not themselves done anything to make their sample valuable, that their samples become valuable by virtue of the work done by scientists. Also, a practical problem in sharing benefits is that many years could elapse between the original research and the development of a marketable drug. And efforts to distribute benefits may be seen as an attempt to buy people off. Recognising these difficulties, the HUGO Ethics Committee (2000) recommended that benefit-sharing should not be understood only in financial terms –'returns' can be of different kinds, e.g. starting with a 'thank you – but that companies should consider investing between 1 and 3% of their net profits in health care infrastructure or other humanitarian endeavours.

While benefit-sharing is based on a principle of equity, according to the principle of **solidarity**, one could have a duty to facilitate research progress that could be crucial to the health of others, by, for example, making a 'gift' of one's sample. Turning to principles of solidarity and equity is a quite different approach from the individualistic one we considered earlier - the individual's right to decide whether to participate or refuse to participate in genetic research. It has been suggested that the post-genomic era might be the right time to rethink informed consent and the right to withdraw from or refuse to participate in research, provided that appropriate mechanisms regulating access to and use of the information are in place (Chadwick and Berg, 2001). As has been suggested above, there might, in fact, be risk to the individual *qua* member of a group, but this point strengthens the argument that the issues cannot be resolved by individual informed consent.

Partly because there are collective, rather than individual, interests to consider, public participation has moved higher up the agenda. There might be a number of objectives in public participation activities, consideration of which is beyond the scope of this discussion. I intend to consider, for present purposes, the objective of developing a communitarian consensus. Hub Zwart contrasts the liberal perspective –which has tended to emphasize not only personal autonomy but also a right to choose to have health care interventions– with the communitarian perspective which, according to Zwart, should aim at developing a consensus on the goals of medicine. From this point of view:

> the moral agent should not be viewed in an atomistic way, but rather as situated in a moral community from which he derives his moral identity, his substantial moral convictions and his sense of direction. (Zwart, 1993, 53-4)

Zwart developed this argument in relation to priority setting in medicine, but it is also relevant to biobanks. Community consensus is not the same as a majority vote, which could be prejudicial to the interests of minority groups. It is dependent on a "normative, deontological framework defining the meaning of community interests" (ten Have, 1993, 45).

It might be objected, however, that in a pluralistic, post-modern society, a communitarian consensus of this kind is not possible; that the notion of community is not available (Poole, 1991), or that the effectiveness of the community-oriented criterion relies on its power to exclude - to silence some voices (van Willigenburg, 1993). Len Doyal has argued:

> any local, community-based, small-scale form of need satisfaction can foster 'insider' conceptions of human need and inhibit the growth of generalisable notions based on a wider collective identity ... The dream of a community politics which could unite different groups ... cannot be realised in the absence of precisely such a cross-cultural and cross-group source of identity as human need. (Doyal, 1991, 308-9).

It remains to be seen, therefore, whether democratic engagement can elucidate the required sources of collective identity to inform the debates about population based genomic research involving biobanks, a collective identity which goes beyond the majoritarian expression of individual preferences based on individual identity.

Conclusion

At the very least the situation we face in thinking about the appropriate ethical framework for genetic databases is one of increasing complexity. The thinking behind the doctrine of informed consent evolved in a very different situation from the one we face in the era of genomics. It is a context complicated by the global context of genetic research in addition to powerful commercial interests at stake. This suggests that it is not sufficient to take the approach of moving from an individual-centred ethic to a more community-centred approach; an approach of renegotiating the relationship between individual and community. This might be a necessary step, but we need also to be clear about what the interests at stake are, which may mean reconceiving the very terms 'individual' and 'community' in this context and the ways in which their interests are affected, identifying the sources of collective identity that are at stake.

It is not quite the picture that Milunsky (2001) envisages, then, of the individual taking increasing control. I spoke about the individual choosing as a utility maximizer, as responsible agent, and as choosing what sort of person they want to be. Even exercising control over my identity, however, has to be done with an eye to the context. I have to choose not what sort of person I want to be in isolation, but with an eye to my membership of different groups. What **is** the case is that every individual has to consider what the benefits are – what does it mean to call databases global public goods – in what sense are the **global**, what is meant by **public**, and what is meant by **good** – are they really goods in which we all can share? The individualistic model that has prevailed so long has been a reaction to discredited eugenic policies, which arose from another type of 'public good' thinking which was inherently discriminatory.

In so far as there are new paradigms in ethical thinking in this context, this is the key focus – whether a new public good argument, that avoids these historic difficulties, can be made out.

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Bibliography

Chadwick R, et al, eds. *The Right to Know and the Right not to Know.* Aldershot: Avebury; 1997.

Chadwick R. Informed consent in genetic research. In: Doyal L, Tobias J, eds. *Informed Consent in Medical Research*. London: BMJ Books; 2001: 203-10.

Chadwick R, Berg K. Solidarity and equity: new ethical frameworks for genetic databases. *Nature Reviews Genetics* 2001; 2: 318-21.

Department of Health. *Our inheritance, our future: realising the potential of genetics in the NHS*. London: Department of Health; 2003.

Doyal L, Gough I. *A theory of human need.* London: Macmillan; 1991.

ten Have H. Choosing core services in the Netherlands. *Health Care Analysis* 1993; 1: 43-7.

Human Genome Organization (HUGO) *Ethics Committee. Statement on Benefit-Sharing*. London: HUGO; 2000.

Milunsky A. *Your Genetic Destiny: Know Your Genes, Secure Your Health, Save Your Life*. Cambridge Mass: Perseus; 2001.

Müller M, Kersten S. Nutrigenomics: goals and strategies. *Nature Reviews Genetics* 2003; 4 (4): 315-22.

Nelkin D, Lindee S.M. *The DNA Mystique: the Gene as Cultural Icon*. New York: W.H. Freeman; 1995.

Poole R. *Morality and Modernity*. London: Routledge; 1991.

Thorsteinsdôttir H, et al. Genoomics - a global public good? *The Lancet* 2003; 361 (9361): 891-2.

Van Willigenburg T. Communitarian illusions, or why the Dutch proposal for setting priorities in health care must fail. *Health Care Analysis* 1993; 1: 49-52.

Widmer P. Human rights issues in research on medical genetics. In: *Ethics and Human Genetics*. Strasbourg: Council of Europe; 1994: 175-188.

World Health Organization. *Genetic Databases: Assessing the Benefits and the Impact on Human & Patient Rights.* Report for Consultation 2001.

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LAS MUERTAS DE JUÁREZ. BIOÉTICA, GÉNERO, PODER E INJUSTICIA[*]

Jorge Alberto Álvarez Díaz[**]

Resumen: Más de 300 mujeres muertas... la historia está llena de injusticias. En ocasiones, las víctimas, sus descendientes u organizaciones han reclamado por la injusticia realizada. Este trabajo intenta ser un reclamo por la injusticia vivida por más de 300 mujeres, muchas de ellas víctimas de violación y homicidio, en Ciudad Juárez, Chihuahua, México. En la década pasada (1993-2003) más de 300 mujeres han desaparecido; muchas se han encontrado posteriormente violadas, mutiladas y asesinadas. Recordando el principialismo, el énfasis se hace en una reflexión posmodernista de la bioética, el género, el poder y la injusticia. Se hace un análisis de la violencia como un problema de salud pública, con un énfasis especial en la salud sexual y la violencia en contra del género femenino. Se comenta la relación entre violación y homicidio contra mujeres. Finalmente, un comentario sobre el escalofriante caso de "las muertas de Juárez". Analizando los datos epidemiológicos sobre violación y homicidio en México, es particularmente importante recalcar que los casos de Juárez no son "típicos", son realmente diferentes.

Palabras clave: Muertas de Juárez, bioética, género, poder, injusticia

DEAD WOMEN OF JUAREZ. BIOETHICS, GENDER, POWER, AND INJUSTICE

Abstract: More than 300 dead women ... the history is plenty of injustices. Sometimes, the victims, their descendents or organizations, have claimed by the injustice done. This work tries to be a claim for the more than 300 women victims of rape and homicide, in Ciudad Juarez, Chihuahua, Mexico. More than three hundred women have disappeared over the last decade (1993-2003); many of them were later found raped, mutilated and murdered. Remembering the principlism, the emphasis is done with a postmodern reflection about bioethics, power, gender and injustice. An analysis of the violence is done like a public health problem, with a special emphasis in the sexual health and the violence against the feminine gender. A comment about the relationship between rape and homicide against women is done. Finally, a comment about a spine-chilling Mexican case, "the dead women of Juarez", is included. Analyzing epidemiological data about rape and homicide in Mexico, it is particularly important to point out that the Juarez's cases are not "typical"; they are really different.

Key Words: Dead women of Juarez, bioethics, gender, power, injustice

AS MORTAS DE JUÁREZ. BIOÉTICA, GÊNERO, PODER E INJUSTIÇA

Resumo: Mais de 300 mulheres mortas... a história está cheia de injustiças. Por vezes, as vítimas, seus descendentes ou organizações protestaram pela injustiça ocorrida. Este trabalho procura ser um clamor pela injustiça vivida por mais de 300 mulheres, muitas delas vítimas de estupro e homicídio, na Cidade Juárez, Chihuahua, México. Na década passada (1993-2003), mais de 300 mulheres desapareceram; muitas foram encontradas posteriormente como vítimas de estupro, mutiladas e assassinadas. Lembrando o principialismo, a ênfase é feita numa reflexão pós-moderna da bioética, o gênero, o poder e a injustiça. Analisa-se a violência como um problema de saúde pública, com uma ênfase especial na saúde sexual e na violência contra o gênero feminino. Comenta-se a relação entre estupro e homicídio contra as mulheres. Finalmente, um comentário sobre o terrível caso das "mulheres de Juárez". Analisando os dados epidemiológicos sobre estupro e homicídio no México, é particularmente importante realçar que os casos de Juárez não são "típicos, são realmente diferentes.

Palavras chave: Mortas de Juárez, bioética, gênero, poder, injustiça

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Las Muertas de Juárez: "Mientras Dormíamos", las "Voces sin Eco"

"Las muertas de Juárez" es la frase utilizada por los medios masivos de comunicación para hacer referencia a casos de "feminicidio" vividos en Ciudad Juárez, México. "Mientras dormíamos" es el nombre del *performance* que Lorena Wolffer ha presentado en diferentes ciudades del mundo para narrar los hechos sobre "las muertas". La frase remite a dos interpretaciones: primera, que los hechos han ocurrido, en su mayoría probablemente, durante la noche; segunda, que las mujeres siguen desapareciendo ante los ojos de una sociedad que manifiesta (en palabras de Wolffer) una "somnolencia generalizada, en la cual un crimen de esta magnitud, que nos atañe a todos, ha pasado impune".

El crimen se refiere a que, en la última década (1993-2003), cientos de mujeres han desaparecido sin saber más de ellas, a menos que los raptores, luego de violarlas y mutilarlas en muchas de las ocasiones, decidan abandonar el cuerpo en algún suburbio de la ciudad... por lo menos 300 cadáveres se han encontrado con huellas de violación, mutiladas o quemadas. Este patrón victimológico uniforme se rompe y, actualmente, se puede hablar claramente de "feminicidio". Ya no es un tipo único: cualquier mujer puede ser otra víctima.

Y mientras dormíamos, las "voces sin eco". Nombre de una organización no gubernamental de la localidad, que también nos puede remitir a dos interpretaciones: al inicio la mayoría formaba parte de grupos marginados socioeconómicamente dentro de la ciudad, por lo que una desaparecida más no tenía peso... y hace referencia, a la vez, a que la gran mayoría de las desapariciones y asesinatos contra mujeres en Ciudad Juárez no han sido resueltos.

¿Cuáles son los hechos? Muy difíciles de evaluar en forma objetiva o "científica" debido a múltiples factores. Mientras que la versión oficial menciona, aproximadamente, 200 mujeres, en organizaciones no gubernamentales se habla hasta de 500. La cifra oficial habla de 198 asesinatos de 1993 a 1999 (2.3 asesinatos por mes); un estudio analiza a 162 víctimas, con los datos que tuvo disponibles la autora... mujer*(1)*. Ella misma acota que "no se permite el acceso a los expedientes de las mujeres asesinadas para corroborar el número exacto de mujeres asesinadas, la violencia con que fueron asesinadas y si realmente los asesinos están convictos".

Se trata de un fenómeno único, favorecido por un entorno socioeconómico propicio, conformado por impunidad, violencia de género en un mundo patriarcal misógino, con ineficiencia policíaca, indiferencia, desigualdad, prejuicio, ignorancia, narcotráfico e intereses políticos. Este entorno se da en Ciudad Juárez, en el estado de Chihuahua, al norte de México. Ciudad fronteriza que colinda con El Paso, Texas, USA, y es importante punto estratégico de cruce internacional. Con una población de 1.3 millones (según el Instituto Nacional de Estadística, Geografía e Informática, INEGI, 2000), la tasa de crímenes en la última década es única en el mundo: 2.3 x 10 000 habitantes.

Históricamente, el punto de partida para el desarrollo de situaciones sociodemográficas especiales en esta ciudad fronteriza se podría ubicar en la década de los setenta, cuando se intensifica la migración hacia Ciudad Juárez. Esto contribuye a un espectacular crecimiento de la población en asentamientos irregulares, predominantemente hacia los suburbios.

El segundo hecho histórico correspondería al crecimiento sin precedentes de la industria maquiladora en los años ochenta, con la creación de miles de empleos, sobre todo para mujeres, ocasionando un incremento de la población femenina.

El tercer factor aparecería en la historia hacia los años noventa: la industria automotriz atrae una migración mayoritariamente masculina, seguida de más asentamientos irregulares, el fortalecimiento del narcotráfico y el comercio de armas. Entre 1995 y 1998 el número de trabajadores en maquiladoras aumenta de 150 a 230 mil. Crece el machismo y la misoginia en una ciudad donde se da un fenómeno muy peculiar: la fuerza de trabajo femenina es superior a la masculina, las mujeres tienen más oportunidades de trabajar y producir, contando con mejores trabajos y salarios que los hombres.

Lo anterior explicaría el perfil predominante en la mayoría de las asesinadas al inicio del fenómeno: no son originarias de Juárez, son recién llegadas, habitan los asentamientos irregulares, son empleadas de la industria manufacturera ("maquiladora") y presentan edades y características físicas parecidas. Sin embargo, no es así para el 100% de los casos y, dentro de esta generalización, se cae en una visión reduccionista del fenómeno del "feminicidio", diluyéndose los casos de mujeres que no tienen estas características. Por otro lado, estereotipar a las mujeres asesinadas en una tipología única evita que la sociedad tome la seriedad y la responsabilidad adecuadas frente a los casos de violencia contra la mujer.

Otra asociación importante para el desarrollo de estos hechos es consumo de drogas y violencia. La violencia tiene dos vertientes en Juárez. La primera se deriva del tráfico de drogas; muy obvio para quienes habitan la ciudad, donde se escenifica desde hace algunos años una verdadera guerra por su control, con innumerables muertes y desapariciones.

La segunda, del consumo de drogas. La última encuesta nacional sobre adicciones permite hacer una comparación. El promedio nacional de consumidores de drogas es de 5.30% de la población entre 12 y 65 años; en Juárez es del 9.2%. Por género, el 16.68% de los hombres aceptaron haber consumido drogas, contra el 2.79% de las mujeres. El promedio de consumo de marihuana en el ámbito nacional es de 4.7% de la población; en Juárez es de 8.42%. Para cocaína, el promedio nacional es de 1.45%; en Juárez, de 3.07%. Esto significa, además, que de cada tres consumidores de marihuana hay uno de cocaína. Un promedio muy alto, comprensible cuando se descubre que en las zonas suburbanas de la ciudad hay decenas de los llamados "picaderos", lugares donde se inyecta o vende droga de ínfima calidad por precios que, a veces, no superan el dólar por dosis.

Este panorama nos muestra un espacio en el cual la mujer tiene más y mejor trabajo que el hombre, alejándola del consumo de drogas (contrario a lo que sostuvieron en el pasado autoridades locales, que atribuyeron las muertes a la vida "licenciosa" de las jóvenes asesinadas, como si ello fuera excusa para crímenes tan terribles). A la vez, el arraigo y los lazos familiares, como consecuencia de la migración, son muy débiles. Los hombres, con menores posibilidades de trabajo, se han ido involucrando cada vez más en el ámbito del narcotráfico y consumen con regularidad una cantidad mucho mayor de drogas que las mujeres. Se escenifica una guerra de narcotraficantes con sus secuelas de armas, violencia y desprecio por la vida. En ese escenario, el asesinato de mujeres se ha convertido en una realidad casi cotidiana.

Bioética

Para la Asociación Internacional de Bioética, ésta puede definirse como "el estudio de los temas éticos, sociales y jurídicos que surgen en la atención sanitaria y las ciencias biológicas". Una circunstancia que amerita el raciocinio bioético es el tema de la violencia. Es necesaria la reflexión acerca de la violencia desde el punto de vista bioético, porque produce disminución de la calidad de vida, enfermedad, discapacidad y muerte.

Diego Gracia ha defendido la tesis de que la salud puede definirse como “la posesión o apropiación por parte del hombre de su propio cuerpo*(2)*”. Si salud es posesión o apropiación del cuerpo, enfermedad sería la desposesión o desapropiación del propio cuerpo. El grado máximo de desposesión o desapropiación, evidentemente, es la muerte*(3)*. En su propuesta hay dos niveles de apropiación del cuerpo.

En un primer nivel está una ética de mínimos que incluye la corrección del acto moral. Involucra los principios de no-maleficencia y justicia. Desde el principio de no maleficencia, la ausencia de desposesión correspondería a la no lesión del cuerpo de las personas por parte de otro cuerpo. Desde el principio de justicia, la ausencia de expropiación correspondería a la no discriminación y la no segregación social de un cuerpo. En este primer nivel, el cuerpo debe estar protegido públicamente y ser igual para todos; de ahí que proporcionarlo sea obligación del Estado, cuyo papel es meramente positivo. Con esta visión, todo acto maleficente o injusto lleva a la desposesión y expropiación del cuerpo.

En un segundo nivel está una ética de máximos que incluye la bondad del acto moral. Involucra los principios de autonomía y beneficencia. Este segundo nivel de posesión y apropiación del cuerpo dependerá del sistema de valores de cada persona, de su ideal personal de vida y de sus proyectos de perfección y felicidad. Por ello, esta posesión y apropiación tiene un carácter fundamentalmente privado, no dependiendo de la sociedad, sino de uno mismo. Desde el principio de autonomía se daría la posesión, siendo cada persona quien se propone sus objetivos de vida, utilizando el cuerpo para obtenerlos. Desde el principio de beneficencia, se daría la apropiación, siempre de lo beneficioso para cada uno, de acuerdo con su concreto e intransferible proyecto de vida. En este segundo nivel, la intervención del Estado es distinta ya que su función primordial no es la promoción de valores. El papel del Estado es meramente negativo, al no impedir que los individuos lleven a cabo libremente sus proyectos de vida y sus ideales de perfección y felicidad, que debieran ser totalmente personales.

Además de la obligación bioética a nivel individual de apropiarse cada quien de su propio cuerpo de forma autónoma y beneficentemente, de acuerdo con el ideal de perfección y felicidad de cada uno, se tiene la obligación bioética específica de no actuar maleficentemente ni injustamente sobre el propio cuerpo ni sobre otro. Aquí la normativa debe ser igual para todos. Aunque cada individuo es dueño del propio cuerpo, se tienen los límites impuestos por los principios de no maleficencia y justicia con otros cuerpos, y que, además, el Estado puede y debe obligarnos a respetar y cumplir.

Con este fundamento principialista podríamos decir que el Estado tiene la responsabilidad, desde el principio de justicia y con respeto a la autonomía, de brindar la protección que necesitan los cuerpos en la sociedad.

Recientemente se ha incrementado una crítica contra el principialismo como modo de razonar en bioética, basado en la filosofía, considerándolo predominantemente racionalista y absoluto*(4)*.

Una propuesta de un acercamiento posmoderno cambia el uso filosófico y racionalista del principio de autonomía e instaura, en su lugar, un marco de reflexión bioética basado en las nociones sociológicas de poder, subjetividad y discurso. El intento es ensanchar la conceptualización acerca del método central en bioética, desde su localización actual en el campo de la filosofía moral, para incluir nociones sociológicas importantes. Este modelo muestra que las ideas posmodernas de discurso y poder constituyen una alternativa a la reflexión bioética. Reflexión que mueve el centro, desde la posición más filosóficamente tradicional de teorizar a través de la aplicación de principios racionales, hacia la creación de nuevas opciones.

Género

El género corresponde al conjunto de determinantes socioculturales e históricos que se establecen para las categorías de feminidad y masculinidad (a diferencia del sexo, que es el conjunto de características biológicas heredadas que colocan al individuo en algún punto de un continuo que tiene en los extremos a individuos reproductivamente complementarios*(5)*). Tradicionalmente se impone la feminidad a la mujer y la masculinidad al hombre.

La Declaración Universal de los Derechos Humanos fue adoptada el 10 de diciembre de 1948; la Primera Conferencia sobre la Mujer se llevó a cabo en 1975 (en México); el decenio 1975-1985 fue declarado por la ONU como La Década de la Mujer; el 18 de diciembre de 1979 fue adoptada la Convención sobre la Eliminación de todas las formas de Discriminación contra la Mujer; en 1980 se celebró la Segunda Conferencia Mundial sobre la Mujer (Copenhague); en 1990 se celebró la Tercera Conferencia Mundial sobre la Mujer (Nairobi); el 20 de diciembre de 1993 se redactó el documento Declaración sobre la Eliminación de la Violencia contra la Mujer; en ese mismo año la ONU declaró que la violencia contra las mujeres supone una violación a los Derechos Humanos; el 9 de junio de 1994 fue suscrita la Comisión Interamericana para Prevenir, Sancionar y Erradicar la Violencia contra la Mujer; la última Conferencia Mundial sobre la Mujer tuvo lugar en 1995 en Beijing. Evidentemente, la firma de un documento o su aceptación, no garantiza su aplicación.

El párrafo segundo del artículo 4º de la Constitución Política de los Estados Unidos Mexicanos afirma: “El varón y la mujer son iguales ante la ley”. Sin embargo vemos que, en la práctica, la mujer sigue siendo objeto de discriminación. La perspectiva de género implica una visión ética sobre el desarrollo y la democracia como contenidos de vida para enfrentar la inequidad, la desigualdad y la injusticia. Todas las personas viven inmersas en relaciones de poder marcadas por su género. Los hombres como género tienen asegurado el dominio en el mundo y las mujeres como género tienen asegurado el cautiverio*(6)*. Los poderes intergenéricos e intragenéricos están articulados entre sí y forman el complejo orden político en el mundo patriarcal*(7)*. La propuesta de género feminista implica una redistribución de los poderes sociales, la transformación de los mecanismos de creación y la reproducción de esos poderes.

El Servicio de Asistencia a Víctimas de Agresiones Sexuales, en Argentina, afirma que: “nacer mujer significa nacer en situación de riesgo”. La situación sería similar para Latinoamérica. Esta situación de riesgo se hace evidente con la susceptibilidad de ser víctima de violencia en general, y violencia sexual en lo particular. Se ha propuesto que la violencia sexual en contra de las mujeres posee su fundamento en los valores que sustentan la sociedad patriarcal y que se relacionan directamente con la sexualidad culturalmente aprendida. El cuerpo de las mujeres está para satisfacer los deseos sexuales de los varones; si la mujer se resiste a ello, la forzarán; si aún resiste, la amenazarán con dañarla o darle muerte. Por lo tanto, la violencia sexual se fundamentaría en las relaciones de poder, en las cuales uno tiene el poder sobre otro que, en este caso, es otra*(8)*. Tal vez por ello el Tribunal Mundial de Viena (1993) dice que "el ser mujer puede volverse cuestión de vida o muerte".

Y en la cuestión de la muerte, el "feminicidio" es la categoría que debe ser discutida para los casos de Juárez. El término se debe a dos feministas, Russell y Radford*(9)*, y corresponde al "asesinato misógino de mujeres por ser mujeres". La práctica del "feminicidio" es un producto del sistema cultural patriarcal y, de acuerdo con Cameron y Frazer, estos "actos antisociales no siempre son actos asociales: éstos, frecuentemente, están apuntalados por las significaciones sociales existentes."

Poder

El patriarcado es una toma del poder por parte de los hombres en la que no queda muy claro si el determinante es económico (apropiación del excedente y de su productor, la mujer) o cognoscitivo (conocimiento del varón del papel que desempeña en la generación de los hijos). La forma de esclavitud de la mujer es el matrimonio monogámico; la primera oposición de clases es la del género femenino con el masculino. En este sistema de dominación de género, las mujeres permanecen, genéricamente, bajo la autoridad, a su vez genérica, de los hombres; el sistema dispone de sus propios elementos políticos, económicos, ideológicos y simbólicos de legitimación*(10)*.

Asimismo, los conceptos de violencia y poder parecen inseparables. El riesgo de violencia se intensifica cuando la comunidad confronta desventajas sociales, como niveles bajos de educación y altos de pobreza, desempleo, fragmentación familiar y abuso de alcohol. Esto es común en áreas marginadas, comunes en países en vías de desarrollo*(11,12)*.

Además, las culturas que presentan un sistema de dominación de género contribuyen a la desigualdad, tanto social como sexual, de las mujeres y niños, quienes son más vulnerables a la victimización sexual*(13)*.

La violencia de género tiene una forma concreta (de lo masculino contra lo femenino, con independencia de quienes lo representen) y está ligada al poder diferencial de los géneros.

Sin embargo, no está claro cómo es la estructura patriarcal en cualquier contexto particular ni cómo variaciones en la forma y grado del patriarcado pueden afectar la violencia.

¿Tiene el género influencia en la violencia a través del aprendizaje social? La investigación que apoya como predictiva de violencia a la conexión entre estructura genérica y variables de aprendizaje social es incompleta, compleja y controvertida. La forma en la cual el género tiene su influencia sobre la violencia, es un área para mayor investigación*(14)*.

A pesar de todo lo anterior, y aunque la condición de la mujer en el mundo occidental ha mejorado enormemente en los últimos años, la revolución que hará a mujeres y hombres realmente iguales no ha ocurrido todavía. Se debate sobre un movimiento feminista sin la categoría de género, lo que parece novedoso, pero muy difícil de llevarse de la teoría a la práctica*(15)*.

El caso de las muertas de Juárez ha sido analizado desde la perspectiva de género, y se le destaca como un "problema real social (...) Las mujeres, como objeto de violencia por parte de los hombres, la sufren desde su identidad genérica y su posición en el sistema de clases sociales*(16)*".

No debe llamar la atención, ante el hecho sin precedentes de las más de 300 muertes de mujeres en Juárez, que exista ya una profusa hemerografía y bibliografía al respecto; pero sí la llama que haya publicaciones científicas serias que no mencionen siquiera la posibilidad de que se dé la combinación violación y homicidio*(17)*. La violación es la materialización última de la demostración violenta de la supremacía del poder de lo masculino sobre lo femenino.

Los estudios indican que los violadores aparentan ser personas ordinarias, sin rasgos que permitan identificarlos y, en la mayoría de los casos, se trata de conocidos, amigos o familiares de la víctima*(18)*. Estos datos coinciden con estudios realizados en México, tanto con víctimas de violación*(19)* como con victimarios*(20)*. Sin embargo, en México se cuenta con poca experiencia respecto al estudio de los violadores, ya que la mayoría de las veces no se denuncian, y cuando se hace, se castiga al agresor recluyéndolo en cárceles sin recibir tratamiento. En nuestro país la población de presos psiquiátricos es de 1 802 y aproximadamente el 10% corresponde a agresores sexuales (perfil general del agresor sexual con padecimiento mental a nivel nacional, 1997*(21)*).

Por otro lado, podemos considerar al homicidio como la materialización última de la violencia. En México, la tasa de homicidios aumentó de 1979 a 1992, de 17.5 a 19.1/100 000 hab. (3/100 000 en el estado de Yucatán, hasta 57/100 000 en el estado de Guerrero). En 1996, México tuvo la mayor tasa en Latinoamérica. En las mujeres, el riesgo de morir a manos de su pareja o de un familiar es más elevado que en el hombre, y la mayoría de las muertes femeninas suceden en el hogar*(22)*.

¿Cómo relacionar la violación con el homicidio? Desde perspectivas criminológicas se ha observado que el homicidio es, a veces, expresión de una sexualidad socialmente disfuncional, ya que sólo a través de él consiguen el orgasmo algunos individuos. Habría, entonces, que distinguir este homicidio del perpetrado durante la violación, y que está dirigido a vencer la resistencia de la víctima o a impedir llamar la atención*(23,24)*.

Desde perspectivas sexológicas se sabe que la mayoría de las violaciones son realizadas por sujetos normofílicos. Sin embargo, puede existir una relación entre violación y homicidio en pacientes con parafilias. Las parafilias son formas de conducta erótica en las cuales se consigue la excitación sexual mediante la imaginación o actos sexuales inusuales o extravagantes, que son necesarios, reiterados y a veces excluyentes, para conseguir excitación y orgasmo, siendo de carácter compulsivo. Frecuentemente, la experiencia del deseo erótico parafílico, o de su actuación, es precedida de angustia y culpabilidad. Dos tipos de parafilias que podrían corresponder a estos cuadros, de acuerdo con la clasificación de John Money, son las depredadoras (cuando, en la relación sexual, el objeto sexual es robado o tomado por la fuerza) y las sacrificial/expiatorias (cuando, en la relación sexual, uno o ambos sujetos debe ser castigado, pudiendo llegar hasta la muerte*(25)*).

La biastofilia (o raptofilia) es una parafilia depredadora, en la cual el deseo sexual y la facilidad para conseguir un orgasmo dependen del ataque sexual sorpresivo y sin consentimiento de la víctima aterrorizada por parte de un extraño. La principal fuente de excitación sexual es el miedo, sorpresa y resistencia de la víctima*(26)*.

La erotofonofilia es una parafilia sacrificial/expiatoria en la cual el deseo sexual y la facilidad para conseguir un orgasmo dependen de la muerte de la víctima durante la relación sexual*(26)*.

Otra consideración que podemos hacer es la del delincuente sexual serial. El examen psiquiátrico ha mostrado en estos casos que un 80 a 90 % no presentan signos de alienación mental franca, es decir, jurídicamente son imputables. Sujetos normofílicos que, por alguna razón, llegaron a cometer el acto delictivo. Solo el 10 al 20% está compuesto por individuos que presentan graves problemas de personalidad, con características psicopáticas enajenantes, es decir, jurídicamente inimputables. Aquí, al tocar el terreno del ámbito jurídico, se debe distinguir entre el parafílico y el delincuente sexual.

La combinación violación y homicidio ha sido escasamente estudiada. Se ha abordado desde estudios de sexología forense. Un reporte de investigación analiza 41 casos de mujeres victimizadas de esta forma, en Florida, USA. La edad promedio de las víctimas fue de 42 años, con una distribución bimodal. Las víctimas más jóvenes (promediando 31 años) fueron encontradas más frecuentemente en canales o terrenos baldíos, mientras que las víctimas mayores (promediando 51 años) fueron encontradas más frecuentemente en sus propias casas. La muerte, comúnmente, se produjo por asfixia mecánica y fue muy raro el uso de armas de fuego. El promedio de la incidencia de este tipo de eventos se calcula en 0.14/100 000 habitantes donde se realizó el estudio, no ocurriendo cambios de 1959 a 1983. Con ello, los autores concluyen que la muerte como resultado de un ataque sexual es, distintivamente, inusual*(27)*.

El caso de las muertas de Juárez ha sido ya analizado por una autora feminista quien aporta la posibilidad de una tipología en los asesinatos, distinguiendo sexuales (pudiendo ser algunos de tipo serial), sexistas, por narcotráfico y por adicción*(16)*. El asesinato de mujeres a manos de hombres es relativamente común en un mundo patriarcal, pero el tomar características seriales hace especial la condición.

Injusticia

La historia de la humanidad está llena de injusticias. La gente ha sido humillada, desposeída, explotada, esclavizada, torturada y asesinada; y, prácticamente, ninguna reparación se ha intentado hacer por ellos o sus descendiente*(28)*.

La petición por la reparación de injusticias históricas puede realizarse en tres categorías principales: a petición de individuos quienes fueron víctimas de una injusticia cometida muchos años antes, por la demanda de miembros de comunidades que han padecido la injusticia y por el reclamo hecho por descendientes de las víctimas de injusticia.

Epílogo

No conocemos los mecanismos exactos por los cuales las diferencias de poder intergenéricas e intragenéricas tienen su influencia sobre la violencia en general, y la violación en particular. Las características que se saben comunes para las víctimas y victimarios de violación no son las que coinciden con los casos de Juárez. Además, la asociación violación y homicidio ha sido poco analizada. Los datos que hay en la literatura no son concluyentes y, en medio de esta problemática con respecto a la disponibilidad de información y falta de investigación, siguen apareciendo cadáveres de mujeres.

Este ensayo intenta ser una forma de petición por la reparación de la injusticia del multicitado "feminicidio", realizada por un miembro de la comunidad que ha padecido la injusticia, un mexicano nacido y avecindado en Ciudad Juárez, quien además es padre de una hija... mujer... ¿cuál será su destino viviendo un doble riesgo: ser mujer, y vivir en Ciudad Juárez?

Referencias

1. Monárrez Fragoso JE. La cultura del feminicidio en Ciudad Juárez: 1993-1999. *Frontera Norte* 2000; 12 (23): 87-117.
2. Gracia D. *Bioética clínica.* Bogotá: El Búho; 1998.
3. Gracia D. *Introducción a la Bioética*. Bogotá: El Búho; 1991.
4. McGrath P. Autonomy, Discourse and Power: A Postmodern Reflection on Principlism and Bioethics. *Journal of Medicine and Philosophy* 1998; 23 (5): 516-32.
5. Álvarez Díaz JA. Corporalidad y sexualidad. Aportaciones desde la esterilidad. *Archivos Hispanoamericanos de Sexología* 2002; 8 (1): 73-112.
6. Lagarde M. *Género y feminismo. Desarrollo humano y democracia*. México: Horas; 1997.
7. Lagarde M. La regulación social del género: el género como filtro de poder. En: Pérez-Fernández CJ, ed. *Antología de la sexualidad humana.* Tomo I. México: Porrúa; 1998: 389-425.
8. Fernández-Mena F. Violencia sexual: el silencio cómplice. *Archivos Hispanoamericanos de Sexología* 1997; 3 (2): 183-7.
9. Radford J, Russell D. *Feminicide. The politics of Women Killing.* New York: Twayne Publishers; 1992.
10. Valcárcel A. *Sexo y filosofía. Sobre "mujer" y "poder"*. Madrid: Anthropos; 1994.
11. Calahan CM, Rivara FP. Urban high school youth and handguns: A school-based survey. *JAMA* 1992; 267: 3038-42.
12. Koop CE, Lundberg GD. Violence in America: A public health emergency. Time to bite the bullet back. (Editorial) *JAMA* 1992; 267: 3075-6.
13. Finkelhor D. *Abuso sexual al menor.* México: Pax-México; 1992.
14. Morash MA. Consideration of gender in relation to Social Structure: A General Theory of Crime and Deviance. *Theoretical Criminology* 1999; 3 (4): 451-62.
15. Lorber J. Using gender to undo gender. A feminist degendering movement. *Feminist theory* 2000; 1 (1): 79-95.
16. Monárrez Fragoso J. Feminicidio sexual serial en Ciudad Juárez: 1993 -2001. *Debate Feminista* 2001; 25.
17. Rangel A, Maillard-Ferrer MA, Cariño-Preciado EM, Solís-García GM. La violación de mujeres en México. En: Galeana P, ed. *La condición de la mujer mexicana.* Tomo II. México: UNAM-Gobierno del estado de Puebla; 1995: 115-24.
18. Burnan MA, Stein SA, Golding JM. Sexual assault and mental disorders in a community population. *Journal of Consulting and Clinical Psychology* 1988; 56: 6843-50.
19. De la Garza-Aguilar J. Díaz-Michel E. Elementos para el estudio de la violación sexual. *Salud Pública de México* 1997; 39: 539-45.

20. Lomelí-García MI, García-Torres BE. Delincuentes sexuales que llegan a un CERESO y su tipificación. *Revista de la Facultad de Medicina UNAM* 2000; 43 (6): 220-25.

21. Rodríguez-Carranza R. Una aproximación al estudio de los agresores sexuales. *Salud Sexual* 1999; 1 (2): 19-24.

22. Híjar-Medina M, López-López MV, Blanco-Muñoz J. La violencia y sus repercusiones en la salud; reflexiones teóricas y magnitud del problema en México. *Salud Pública de México* 1997; 39: 565-72.

23. Marchiori H. *Psicología criminal*. México: Porrúa; 1989.

24. Marchiori H. *Criminología. La víctima del delito.* México: Porrúa; 1998.

25. Rubio-Aurioles E, Velasco-Téllez AC. Las parafilias. En: Pérez-Fernández CJ, ed. *Antología de la sexualidad humana.* Tomo III. México: Porrúa; 1998.

26. Money J. Forensic Sexology: Paraphilic serial rape (biastophilia) and lust murder (erotophonophilia). *American Journal of Psychotherapy* 1990; 44 (1): 26-36.

27. Deming JE, Mittleman RE, Wetli CV. Forensic science of fatal sexual assaults on women. *Journal of Forensic Sciences* 1983; 28 (3): 572-76.

28. Thompson J. Historical Injustice and Reparation: Justifying Claims of Descendants. *Ethics* 2001; 112: 114-35.

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ALGUNAS OBSERVACIONES SOBRE EL ESTADO ACTUAL DE LA BIOÉTICA EN ARGENTINA

Delia Outomuro[*]

Resumen: Este trabajo propone como tesis que la bioética en la Argentina corre el riesgo de operar como *institución*, en el sentido antropológico del término, y que, como tal, lejos de contribuir a la cristalización de la racionalidad emancipatoria, cumple la función de legitimar el *statu quo*. En la bioética argentina coexisten las etapas emotiva, reconstructiva y de consolidación disciplinaria, con todos los peligros inherentes a cada una de ellas. El legalismo y la juridización de los conflictos éticos, el fundamentalismo, el charlatanismo, la expertocracia y el snobismo desvirtúan su cometido de convivencia democrática.

Finalmente, se postula que la bioética debe promover la realización de la comunidad ideal de comunicación y que, por lo tanto, el carácter pluralista, transdisciplinario y procedimental debe prevalecer en este discurso como condición *sine qua non* para la articulación de los intereses emancipatorios de las personas.

Palabras clave: Bioética, peligros, institución, *statu quo*, pluralismo, emancipación

SOME OBSERVATIONS ON THE CURRENT STATE OF BIOETHICS IN ARGENTINA

Abstract: This paper proposes as thesis that in Argentina bioethics runs the risk of operating as an institution in the anthropological sense this term and that, as such, far from contributing to the crystallisation of the emancipatory rationality, it performs the function of legitimating the *statu quo*. In Argentina, the three bioethic stages (the emotive, the reconstructive and the consolidation stage) coexist, with all the inherent dangers to each one of them. The legalism and the lawfulness of the ethical conflicts, the fundamentalism, the cheaters, the expert-cracy and the snobbism adulterate its real purpose of democratic coexistence.

Finally, it is postulated that bioethics should promote the realisation of the ideal community of communication and that, therefore, the pluralistic, transdisciplinary and procedural character should prevail in this speech like a *sine qua non* condition for the articulation of people's emancipatory interests.

Key words: Bioethic, dangers, institution, *statu quo*, pluralism, emancipation

ALGUMAS OBSERVAÇÕES SOBRE O ESTADO ATUAL DA BIOÉTICA NA ARGENTINA

Resumo: Este trabalho apresenta a tese de que a bioética na Argentina corre o risco de funcionar como instituição, no sentido antropológico do termo, e como tal, longe de contribuir para a cristalização da racionalidade emancipadora, cumpre a função de legitimar o estatus quo. Na bioética Argentina coexistem as etapas emotivas, reconstrutiva e de consolidação disciplinar com todos os perigos inerentes à cada uma delas. O legalismo e o jurisdicismo dos conflitos éticos, o fundamentalismo, o charlatanismo, a espertocracia e o esnobismo desvirtuam a convivência democrática.

Finalmente, postula-se que a bioética deve promover a realização da comunidade ideal de comunicação e que, portanto, o caráter pluralista, transdisciplinar e prodecural deve prevalecer no discurso como condição sine Qua non para a articulação dos interesses emancipatórios das pessoas.

Palavras chave: Bioética, perigos, instituição, status quo, pluralismo, emancipação

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Introducción

Poco tiempo ha transcurrido desde que Van Rensselaer Potter introdujera el neologismo "bioética" al titular su libro *Bioethics: Bridge to the future*, publicado en 1971. En estos algo más de treinta años, lo denotado por tal significante se ha impuesto como disciplina, es decir, en términos de Roland Barthes, como discurso enseñable. De hecho, existe una comunidad de hablantes que comparte (?) el lenguaje bioético, que constituye los objetos de estudio, que cree en ellos y que cuenta con seguidores y discípulos*(1)*. Se trata de un discurso que es también un producto, en la medida en que, con él, se identifican comisiones nacionales, comités, cursos, centros de investigación y revistas*(2-4)*. La máxima expresión como producto se evidencia en su principal *textbook*, me refiero al clásico libro *Principles of Biomedical Ethics*, que Beauchamp y Childress publicaran en 1979.

No obstante, si observamos detenidamente a la comunidad de hablantes que dice compartir el discurso bioético, podemos sorprendernos al ver que, en realidad, no todos hablan el mismo idioma ni comparten los mismos productos y, ni siquiera, se proponen los mismos objetivos. En lenguaje kuhniano, la bioética pareciera estar en un estadio pre-paradigmático.

El carácter polisémico del término bioética, manifestado a través de las múltiples definiciones que encontramos, no es un hecho menor. Esta multiplicidad de acepciones deja espacio para una vaguedad –e incluso, en algunos casos, ambigüedad– que permite la inclusión de actores, discursos y temáticas que, en mi opinión, conspiran contra el verdadero propósito de la bioética. La ética es parte inevitable de la bioética y la ética es, inevitablemente, filosofía. Y si algo hemos de pedir a la filosofía, es que contribuya a la racionalidad emancipatoria. Nada más lejos de la filosofía que mantener las cosas tal como están[1].

Propongo como tesis que la bioética, fenómeno reciente de nuestra cultura occidental judeocristiana, corre el riesgo de operar como *institución*, en el sentido antropológico del término, y que, como tal, lejos de contribuir a la cristalización de la racionalidad emancipatoria, cumple la función de legitimar el *statu quo*.

Reconozco la audacia de esta afirmación y, por ello, limitaré el análisis al estado actual de la bioética en Argentina, aunque es posible que muchas de sus notas distintivas sean extensibles al resto de América Latina y, tal vez, a la bioética en general. No obstante, esta última afirmación requeriría una tarea de fundamentación que excede mi actual propósito.

Para llevar a cabo este objetivo comenzaré recordando el concepto antropológico de institución desde la perspectiva funcionalista y funcional-estructuralista. Luego iré mostrando algunas características que el discurso bioético ha adquirido en mi país y que, como dije, lo pueden hacer funcional a la estructura social vigente, desnaturalizando su verdadero cometido. Finalmente, intentaré mostrar que el carácter democrático, pluralista, transdisciplinario y procedimental debiera prevalecer en este discurso como condición *sine qua non* para la articulación de los intereses emancipatorios de las personas.

Cultura e instituciones: su función

El concepto de cultura ha variado a lo largo del tiempo. No se trata de un concepto estático sino de un constructo. Las ideas dominantes en cada momento lo condicionan y, de esta manera, iluministas, evolucionistas, funcionalistas y estructuralistas diferirán en su conceptualización. Me remitiré a Malinowski y a Radcliffe Brown quienes definen *cultura* como conjunto de instituciones.

Para Malinowski una *institución* es un grupo humano vinculado a un medio ambiente, dotado de equipamiento material y del conoci-

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[1] Sócrates se llamaba a sí mismo "el tábano de Atenas" y no por nada fue condenado a beber cicuta.

miento para su uso, sumado a normas y leyes que gobiernan al grupo, más un conjunto de creencias y valores, *tendiente a cumplir una función*[2]. La función (y esto es muy importante) es satisfacer alguna necesidad psicobiológica del individuo. En otras palabras: dada una necesidad psicobiológica, allí estará la cultura para crear alguna institución que la satisfaga.

Por su parte, Radcliffe Brown, considera que la cultura y, por lo tanto las instituciones, no responden a las necesidades del sujeto sino que, por el contrario, satisfacen las necesidades de la sociedad. En este sentido, la institución subordina a cada individuo a las demandas sociales. La cultura, a través de las instituciones, impone pautas de conducta estandarizada con el fin de mantener el orden establecido. Por lo tanto, una institución es una forma de comportamiento estandarizado cuya función es resolver la tensión entre intereses, evitando una ruptura de las relaciones sociales que afectarían el funcionamiento de la estructura social; en tal sentido, la institución impone sanciones positivas (de aprobación) o negativas (de castigo) según se cumplan o no las normas*(5)*. Las religiones y el poder judicial son ejemplos paradigmáticos.

Observaciones sobre el estado actual de la bioética

La bioética llega a la Argentina de la mano de José Alberto Mainetti. Con él, el discurso bioético transitará por el campo de las humanidades médicas y estará fuertemente impregnado, en mi opinión afortunadamente, de contenidos históricos y sobre todo antropológicos. A través de la Fundación Mainetti y del Departamento de Humanidades Médicas de la Universidad de La Plata irá, poco a poco, adquiriendo entidad y transitando por las tres etapas evolutivas que distingue Fernando Lolas: las etapas emotiva, reconstructiva y de consolidación disciplinaria*(1)*[3]. En las características que describiré a continuación pretendo mostrar que en la bioética argentina coexisten estas tres etapas y que los peligros inherentes a cada una de ellas desvirtúan su cometido emancipatorio.

1. La confusión con el *legalismo* y la *juridificación* de los conflictos bioéticos

El discurso ético distingue entre *legalidad* y *legitimidad*. Aquello que es conforme a la ley positiva es legal. Aquello que es conforme a la ética es legítimo. Como es de suyo conocido, no todas las leyes son éticas, es decir, no todas las leyes responden a una fundamentación ética que las legitime. A su vez, no todo lo que puede ser ético es legal. Lo ideal sería que existiera una coincidencia plena entre lo ético y la ley, pero no siempre es así. Las leyes son insuficientes para garantizar que una sociedad sea justa pues no siempre protegen eficazmente los derechos de los ciudadanos y, además, no suelen contemplar los casos particulares.

La bioética, en tanto transdisciplina, ha de dialogar con el derecho positivo, pero evitando

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[2] Tomemos como ejemplo a la medicina o su equivalente en otras culturas (magia, curanderismo, hechicería, etc.). Ella es una institución que satisface la necesidad de mantener o restaurar el estado de salud del individuo, independientemente de lo que cada cultura entienda por salud. La materialización de dicha institución también variará de cultura en cultura, pero siempre podrán identificarse los elementos contenidos en la definición. En la medicina occidental, el grupo humano está conformado por los profesionales de la salud; el medio ambiente será el hospital, el centro de salud o el consultorio; el conocimiento está representado por el saber contenido en las distintas teorías médicas; existen normas y leyes que reglamentan el ejercicio profesional y, finalmente, creencias y valores compartidos.

[3] En la primera se moviliza fuertemente la opinión pública, todos son expertos porque todos tienen alguna sensibilidad frente a lo que pasa y todos opinan. En la segunda, los cultores de la nueva disciplina empiezan a ver sus conexiones históricas y sociales, existiendo aquí el peligro de asimilar lo nuevo a lo que ya se sabía. Finalmente, la tercera etapa de consolidación disciplinaria se caracteriza por la publicación de revistas especializadas, el otorgamiento de grados académicos, la fundación de sociedades, la creación de cofradías de expertos y la profesionalización. Esta etapa conlleva el riesgo de la mercantilización del saber bioético, de su conversión en un producto de mercado con la posibilidad de ser vendido, comprado o intercambiado.

la tentación de reducirse a él y de incurrir en el legalismo. La reflexión ética no sólo excede el marco de lo legal sino que, además, lo incluye como objeto de estudio en su intento de legitimación del derecho.

Sin embargo, en nuestro medio es habitual la confusión de la ética y, por lo tanto, de la bioética con el derecho y la deontología médica. Es frecuente observar, verbigracia, el tratamiento de problemas tales como el aborto, el transplante de órganos o la problemática referida al SIDA[4], exclusivamente desde la ley vigente. Junto al legalismo, se advierte una tendencia a juridificar la conflictividad bioética, en la convicción de que cada sentencia resuelve cada problema. Cabe señalar que "*juridificar* es un tipo de acción propio de sociedades con escasa libertad, mientras que en las sociedades más libres la necesidad de la regulación legal es menor porque los ciudadanos ya actúan correctamente*(6)".*

Es notoria la insistencia de los legisladores en la presentación de proyectos de ley sobre clonación, investigación con seres humanos, salud reproductiva o la tan mentada "muerte digna". Las propuestas se formulan con pasmosa superficialidad y sin que estos temas hayan sido siquiera motivo de un profundo y verdadero debate en la comunidad, como lo ha sido, por ejemplo, el tema de la eutanasia entre la población holandesa. Se respira un aire de ingenuo positivismo en estas pretensiones. Del mismo modo en que la filosofía decimonónica confiaba la resolución de los grandes problemas de la humanidad al desarrollo de la ciencia, nuestros legisladores (y no sólo ellos) apuestan a que la ley disuelva los dilemas bioéticos. Hecha la ley, resuelto el problema. Pero nada más lejos de la realidad.

Además, como señala Adela Cortina, el Estado exige el cumplimiento de las normas jurídicas promulgadas mediante la coacción, es decir, posee el poder de castigar a quien las transgreda. De esta manera, el derecho tiende a preservar la racionalidad estratégica en lugar de la racionalidad comunicativa[5] porque la ley suele cumplirse estratégicamente: por miedo a la sanción y no por propia convicción.

El legalismo y la juridificación de la bioética –en tanto imponen un modo de acción uniforme, en tanto no dejan espacio para la reflexión ni para el diálogo, en tanto impiden la realización de los diferentes proyectos de vida de los actores sociales– sólo contribuyen a dejar las cosas como están. La institución bioética, al igual que el apego farisaico a la ley, cumple así la función de mantener vigente el *ethos* hegemónico. El reduccionismo legal de los problemas éticos equivale a renunciar al análisis racional de los mismos y a no asumir la responsabilidad de las propias decisiones. El legalismo corresponde a la etapa infantil (Piaget) y convencional (Kohlberg) de la formación de la conciencia.

2. El *fundamentalismo* como otra estrategia para perpetuar el *statu quo*.

En la misma línea del legalismo, se advierte el peligro del fundamentalismo, sea este religioso o no. Para las ideologías antiliberales hay principios apodícticos y autoevidentes. Aquellos iluminados, que creen tener el privilegio de aprehenderlos, se endilgan el derecho y el deber de exigir su cumplimiento a todos,

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[4] En la Argentina existe la Ley Nacional de SIDA Nº 23.798/90 (Decreto reglamentario Nº 1.244/91). Si bien la misma pretende evitar la discriminación negativa así como respetar la autonomía, un análisis crítico de la misma pone de relieve algunas inconsistencias en relación con estos propósitos.

[5] K.O. Apel y J. Habermas distinguen entre racionalidad estratégica y comunicativa. Quien hace uso de la primera considera a los interlocutores como medios para sus propios fines; en este plano es factible la manipulación y la coacción. En cambio, una comunidad de diálogo que se maneje con la racionalidad comunicativa considerará a todos los interlocutores en simetría, con los mismos derechos de defender argumentativamente sus intereses y, finalmente, aceptará los proyectos compatibles con los intereses de todos, aunque difieran entre sí.

incluso mediante la fuerza. En nuestro ámbito latino y católico algunos discursos totalitarios suelen estar ligados a cosmovisiones religiosas. Para muchos, la tolerancia es todavía un vicio y la intolerancia una virtud. "La bioética se está convirtiendo en nuestro medio en un lugar de confrontación de las actitudes liberales y antiliberales, o tolerantes e intolerantes. El pluralismo es visto en nuestro mundo latino, aún hoy, como un grave y serio peligro*(7)*".

A diferencia de la secularidad presente en la bioética norteamericana, los discursos bioéticos latinoamericanos suelen estar sesgados por estas cosmovisiones religiosas, muchas veces de manera solapada o revestida de un maquillaje pseudopluralista. Al confundir ética con religión se corre el riego de adoptar posturas fundamentalistas. En estos casos, la sociedad deviene totalitaria, porque un grupo impone a los demás su ética de máximos y aquellos que no compartan ese ideal de felicidad impuesto se ven discriminados y/o coaccionados. Por desgracia, en la historia abundan los ejemplos que ilustran las graves consecuencias acarreadas por este tipo de actitudes.

Quien trabaje en ética seriamente ha de tener presente la diferencia entre *ética* y *moral*, así como ha de tener claro que no existe una única moral como tampoco una sola teoría ética. Deben ser reconocidas y respetadas las morales religiosas, pero también ha de rechazarse cualquier tipo de adoctrinamiento, pues ello atenta directamente contra la esencia de la bioética.

En este sentido es de destacar la posición de Tristram Engelhardt, quien confiesa ser "católico ortodoxo, tejano converso" y tener convicciones morales que difieren sustancialmente de su propuesta bioética. Su proyecto apuesta, sin embargo, a una sociedad libre y democrática y permite vincular a "extraños morales". Como estos extraños morales "no escuchan a Dios" de la misma manera, sólo resta la opción de un acuerdo pacífico entre ellos acerca de cómo encarar cada conflicto*(8)*.

Cuando una comunidad identifica la moral con la religión, los no creyentes se encuentran en una situación compleja. El apelar a argumentos para defender sus valores y principios es visto con reticencia pues, para los creyentes, la fundamentación de la obligación moral se halla sólo en la voluntad de Dios.

Estas posturas son incongruentes con una bioética entendida como disciplina dialógica. En este marco, su discurso se legitima precisamente por ser un diálogo secular y procedimental. No hay aquí, por lo tanto, lugar para "el *reduccionismo creencial* de aquellos que intentan imponer sus convicciones a otros y creen su deber propagar dogmas. Es por eso incongruente *ad initio* una bioética dogmática, fundamentada en un esfuerzo misionero o en el magisterio confesional *(3, pp. 29-39)*".

3. El *charlatanismo* como expresión de la etapa emotiva de la bioética

Como señalara, la etapa emotiva perdura en nuestra bioética y su mayor riesgo es el charlatanismo. En este tema no están ausentes los medios de comunicación. Lamentablemente, los medios no suelen aportar información, mucho menos conocimiento. Su propósito es comunicar la noticia; y noticia no es sólo lo nuevo o infrecuente sino lo que conmueve, aquello que provoca impacto social.

La presentación amarillista y, con inusitada frecuencia, de situaciones relacionadas con la eutanasia, el transplante de órganos, las técnicas de fertilización asistida y, más recientemente, con la clonación, provocan la curiosidad de la población e invitan a arduas polémicas en torno a los límites que ha de tener la ciencia.

Por cierto que ha de celebrarse la participación de la comunidad en estos asuntos, como en cualquier otro tema de interés público. Es más, uno de los méritos de la bioética es haber acortado las distancias entre "expertos" y profanos. Pero a lo que me refiero es al curioso fenómeno sociológico por el cual algunas personas se arrogan el derecho de dictaminar acerca de lo que está bien o está mal, de lo que debe o no debe hacerse, sin haber hecho siquiera el mínimo esfuerzo intelectual por fundamentar sus afirmaciones. Muchas veces se trata de buenas personas o de personas con buenas intenciones. Pero la bondad y la sensatez no se implican mutuamente.

Quizás convenga aquí recordar la clásica distinción aristotélica entre *doxa* y *episteme*. La primera es la opinión, el pre-juicio. La segunda es el conocimiento, el juicio. Todos podemos opinar y todos también podemos formular juicios. El problema de los charlatanes consiste en que presumen de doctos y se mantienen en el campo de la *doxa* considerándola *ortodoxia*.

También aquí sería atinado distinguir entre el saber moral y el conocimiento ético. Moral y ética coinciden en el lenguaje normativo en que se expresan pero difieren en otros múltiples aspectos. La moral presupone principios y los aplica a casos concretos, responde a la pregunta *qué debo* hacer frente a esta o aquella situación. Es un saber espontáneo, pre-reflexivo, pre-sistemático y a-crítico. Se desenvuelve en el plano de lo que es de hecho, de *facto*. En cambio, a la ética le interesa saber de dónde extraen su validez las normas o costumbres, de dónde surge su obligatoriedad. En otras palabras, indaga por el *por qué debo*; pretende pasar de lo que es de *facto* a lo que es de *jure*, del plano del *ser* al plano del *debe ser*. La reflexión ética intenta *fundamentar* las normas, las costumbres, los valores; es la aplicación de la razón a ese conjunto de creencias, hábitos y códigos de normas que cada cultura posee como una de sus características constitutivas*(9)*.

Nuestros charlatanes se mueven en el plano de la *doxa* y de la moral. Pero el tratamiento serio de cualquier tema (incluso más allá de la bioética) supone la deliberación crítica. Esto significa reconocer que la razón tiene, por un lado, presupuestos y, por otro, la capacidad de reflexionar sobre ellos críticamente. Significa, asimismo, reconocer los límites de la racionalidad: el hecho de que la razón humana no puede dirimir definitivamente las distintas cuestiones. No sólo Dios, también la Razón ha muerto. Por eso, quien delibera críticamente sabe que no hallará un respuesta definitiva, pero también sabe que tiene que considerar distintas opciones y que no todas ellas están sustentadas por argumentos del mismo peso*(7)*.

Resulta llamativo observar que en el charlatanismo (en ese manejo acrítico, asistemático y pre-reflexivo de los temas éticos) pueden distinguirse, al menos, dos grupos de individuos. Por un lado, encontramos a aquellos que, llegados a cierta edad deciden incursionar en este campo del mismo modo que lo harían en cualquier actividad lúdica o recreativa. Suelen ser profesionales de la salud que han gozado de éxito y prestigio en su profesión, por ejemplo eximios cirujanos o destacados jefes de servicio. Pasados los años de labor y encaramados aún en el reconocimiento obtenido en su vida académica, creen estar en condiciones de dictaminar, como lo hicieron quizás legítimamente en sus respectivas especialidades, sobre asuntos morales[6]. Por otro lado, hallamos a una serie de individuos que, en este caso,

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[6] Alguien ha dicho que la medicina ha salvado a la ética. Análogamente he escuchado decir a otros que la bioética ha salvado a la historia de la medicina. Hasta los ochenta, era frecuente en nuestro medio que los médicos, llegados a su edad jubilatoria, incursionaran en la historia de la medicina con la misma superficialidad y falta de rigor que hoy se observa en bioética. Los historiadores respiran ahora aliviados.

no suelen proceder exclusivamente del campo de la medicina; se trata de personas simples, posiblemente bien intencionadas, pero cuyo afán de protagonismo llega a obnubilar de tal modo su autocrítica que son capaces de hablar de todo en cualquier lugar y ocasión.

La bioética viene a funcionar aquí como aquella institución que satisface las necesidades psicológicas de la meno/andropausia de los unos y de la megalomanía de los otros. El tema parece menor pero en realidad no lo es, porque también conlleva el peligro del autoritarismo. Autoritarismo que no siempre es fácil de identificar, pues suele estar encubierto por el velo de la seducción que estas buenas personas despliegan: "la ignorancia piadosa, cuando es militante y pontifica, hace un daño irreparable a la bioética*(3, p. 69)*". Yo agregaría: y a la sociedad.

4. La *expertocracia* exclusiva y excluyentes de los "bioéticos"

Como ocurre con cualquier disciplina, la bioética –al entrar en la etapa de consolidación– cuenta con sus propios especialistas. Por cierto es éste un peligro incipiente en nuestro medio ya que lo que más abunda son los representantes del tópico anterior. Sin embargo, poco a poco se advierte esta tendencia hacia la expertocracia. Ello ocurre en la medida en que proliferan los posgrados en este campo, pues quienes egresan suelen confundir, a veces, el tipo de experticia que han adquirido.

Muchos egresados se ofrecen como asesores o consejeros bioéticos y el mercado suele ser, en ocasiones, propicio, pues es tal el desconocimiento sobre el tema que no pocas instituciones sanitarias aspiran a contratar a estos presuntos expertos con el propósito de hallar solución a todos sus problemas. Del consultor ético se espera pragmatismo, esa respuesta acertada que evite la incomodidad psicológica de la incertidumbre y, por qué no, los costos de la administración sanitaria y de los tribunales de justicia.

Se olvidan que, en bioética como en ética, más que problemas existen dilemas y más que resolución hay, con suerte, disolución de los mismos. Quienes demandan soluciones de expertos, en el fondo buscan una autoridad moral que les permita garantizar e imponer una determinada política sanitaria. No comprenden que ni Dios, ni la Razón ni la Bioética evitarán la perplejidad que se siente frente a cualquier conflicto moral, como así tampoco nos liberarán de estar condenados a la libertad.

Cuando esto ocurre, esto es, cuando el experto decide y dictamina, nuevamente la bioética se desvirtúa y funciona como institución que satisface, o bien la necesidad de protagonismo del experto o bien la necesidad de persistencia del sistema. La bioética acaba formando parte de lo establecido. Porque, como también sostiene Tristram Engelhardt "estas consultas y este asesoramiento pueden desembocar en la imposición de una visión moral, de una ideología u ortodoxia moral particular como si la razón misma lo exigiese. Tales asesores trabajan en parte como lo hacen sacerdotes, rabinos o pastores en un contexto religioso, pero sin admitir una actitud sectaria *(8, p. 17)*". Y, en este sentido, el peligro que representa el experto es aún mayor al del charlatán o al del fundamentalista, pues bajo el prestigio cosmético de una formación académica (*knowledge is power*) pretende conocer e imponer una determinada moral secular material.

Como afirma Victoria Camps, el personaje denominado con el barbarismo "bioeticista" nunca se equivoca ni podría hacerlo porque, como de ética se trata, se supone que aquí no hay lugar para la mala *praxis*, como en las especialidades médicas. La verdad o la falsedad no pertenecen a la ética. Hago propias las siguientes expresiones:

> *"Por mi parte, veo un peligro en la concepción de la ética que pretende equipararla a cualquier otra disciplina. El conocimiento moral no es exactamente un conocimiento más, sumable a los distintos saberes, cada vez más específicos y especializados. Ni el filósofo, el eticista o como quiera llamársele, tiene que convertirse en un experto entre otros, un experto que atiende a un aspecto del conocimiento que él domina porque ha hecho de él su profesión. El peligro es profesionalizar la bioética y crear al 'bioeticista'(10)*".

Pero, entonces, ¿deberíamos continuar con la formación académica de posgrado?, ¿puede o no haber expertos o especialistas en bioética? Y si la respuesta es afirmativa, ¿a qué tipo de experticia y competencias se hace referencia?

Por mi parte considero que es deseable que continúe la formación en bioética, tanto en el posgrado como en el pregrado, en especial en las carreras vinculadas a la salud. Ahora bien, cuando hablamos de formación de posgrado en bioética debería quedar claro que el propósito no es formar especialistas o expertos que resuelvan los problemas morales. Creo haber argumentado lo suficiente a este respecto e insisto que en una sociedad libre, pluralista y democrática no hay lugar para la profesión de moralista. Por lo tanto, las competencias que ha de tener quien tome estos cursos se limitarán a un papel algo más modesto que el de dar respuestas categóricas. Su tarea será la de poner su formación humanística al servicio del análisis de los conflictos éticos, iluminándolos como tales, descubriendo los valores en juego y permitiendo la participación simétrica de todos los afectados en la toma de decisiones. La pericia (*expertise*) del mal llamado bioeticista será más un "saber cómo" que un "saber qué". En síntesis, su experticia ha de ser procedimental, es decir, la identificación del procedimiento justo para intentar resolver el problema.

Esperar otro tipo de competencias del egresado es sencillamente insensato porque el discurso bioético (se ha dicho hasta el cansancio) es un discurso *sui generis*; como señala Fernando Lolas: un saber de los intersticios que dejan entre sí diversas disciplinas, un discurso transdisciplinario. Nadie que no sea omnisciente puede arrogarse la propiedad de semejante empresa.

5. El *snobismo* bioético (*last but not least*)

He aquí una característica de reciente adquisición: la bioética se ha puesto de moda. No sólo todos quieren ser "bioéticos" sino que también todo, es decir, cualquier cosa deviene un fenómeno bioético. En este sentido, la vaguedad que caracteriza el término ha contribuido a evitar un atinado recorte de la realidad. Resulta llamativo, por ejemplo, que la corrupción presente en algunos sectores del gobierno o de la administración pública o privada sea considerada un problema bioético, incluso entre quienes dicen saber de la materia. Otro tanto ocurre con el bioterrorismo, las armas biológicas, las guerras en general, la participación de los profesionales de la salud en actos de tortura, los abusos sexuales o los debates feministas, por citar algunos ejemplos. No cabe duda de que en todas estas cuestiones exista un problema ético. Pero no todo problema ético es un problema bioético. No tener esto claro es nuevamente confundir los campos y reducir la ética, cuyo ámbito de reflexión es mucho más amplio, a una disciplina que tiene bastante de ética pero que no la incluye totalmente.

Conclusiones

Jürgen Habermas distingue tres racionalidades: técnica, hermenéutica y emancipatoria. Cada una se vincula con algún tipo de interés. La primera, con intereses técnicos y tiene como finalidad el dominio y control de la naturaleza. La segunda se relaciona con intereses comunicativos, su propósito es la comunicación y el entendimiento (aunque, a veces, la incomunicación y los malos entendidos) entre individuos y comunidades. La tercera tiene que ver con intereses que persiguen la emancipación, la liberación. Esta racionalidad es propia de la reflexión y de las disciplinas críticas.

En una comunidad ideal de diálogo, los hablantes no están condicionados más que por intereses emancipatorios, de modo tal que la autorreflexión permite establecer modos de comunicación haciendo razonables las interpretaciones*(11)*. En este contexto, el mejor argumento es aquél que nadie impone, pero que se impone a todos. La bioética debería promover la realización de esta comunidad ideal de comunicación. De todas las definiciones de bioética, y en el marco teórico de la ética discursiva, rescato la siguiente como el medio más adecuado para alcanzar ese objetivo:

> *"Como bioética en este carácter (procedimental y metodológico) entendemos las formas de empleo del diálogo para articular y en lo posible resolver los dilemas causados por las ciencias y las tecnologías(3, p.20)".*

De esta definición resalto los siguientes aspectos:

1) Se trata de una disciplina dialógica, por lo tanto, secular y procedimental.

2) En bioética no hay problemas *strictus sensus* sino más bien dilemas o, mejor, poliemas. Esto significa que no existe una única solución y también que cualquier solución implica un nuevo problema. De allí la importancia de respetar la diferencia de opiniones fundamentadas.

3) De lo anterior se deduce que no siempre (o casi nunca) es posible dar respuestas categóricas. Muchas veces debemos contentarnos con la elucidación del conflicto. Por ello, no puede haber expertos.

Si optamos por los intereses emancipatorios, por la realización de la comunidad ideal de diálogo y aceptamos la anterior definición de bioética, es claro que esta disciplina ha de pertenecer al nivel postconvencional de la conciencia moral, es decir, ha de ir más allá de las normas jurídicas, religiosas o sociales. En este sentido no puede ni debe funcionar como institución. De permanecer en el nivel convencional, como creo corre el riesgo de estar en base a las características que he expuesto, negará el pluralismo y pseudolegitimará lo que es de hecho.

Defender el pluralismo no significa caer en el relativismo absoluto, sino aprobar las opciones defendibles argumentativamente y que no se opongan a los intereses del otro. Una opción es correcta cuando puede ser aceptada por todos los afectados y surge del diálogo en condiciones de libertad y de simetría, es decir, cuando es el resultado de la racionalidad comunicativa y no de la manipulación, la coacción o la negociación estratégica. Por cierto que cada quien llevará a la mesa de discusión sus propias convicciones e intentará que sean compartidas por los otros; todo esto es legítimo en tanto el camino sea la invitación a través de la persuasión, en el marco del respeto por las diferencias.

Es aquí donde tiene lugar la tolerancia o, más bien, preferiría hablar de solidaridad. Como se sabe, el principio de tolerancia surge en el siglo XVII, como una manera práctica de poner fin a siglo y medio de guerras entre católicos y protestantes. En su origen no implicaba, entonces, un reconocimiento positivo del derecho que el otro tiene a sus propias creencias o valores. Se trataba más bien de un compromiso táctico y negativo de no beligerancia. Cuando se acepta que las creencias del otro deben respetarse porque ellas son en sí mismas respetables, la tolerancia abre paso a la libertad de conciencia, tarea que ha tenido como pioneros a Espinoza y Locke*(12)*. La bioética debería avanzar por este camino y conducirnos a la solidaridad: tolerancia, libertad de conciencia, solidaridad.

Tolerar es aceptar pasivamente y con resignación los intereses del otro, porque no queda otro remedio. Respetar la libertad de conciencia es reconocer el derecho a la diferencia pero, en mi opinión, también negativamente. Por el contrario, la solidaridad conlleva la actitud activa y positiva de colaborar con los proyectos del prójimo, por mucho que ellos difieran de nuestras propias convicciones.

Esta comunidad ideal de comunicación sólo puede realizarse cuando se respetan, glosando a Adela Cortina, aquellos mínimos morales esenciales para la convivencia democrática: el reconocimiento del otro como persona así como de sus necesidades, proyecto e intereses vitales; la disposición a razonar y a alcanzar acuerdos mediante argumentos; el compromiso en la mejora material y cultural tendiente a alcanzar el máximo de simetría y, como se ha dicho, el reemplazo de la tolerancia por el compromiso activo, es decir, por la solidaridad y la fraternidad. En síntesis, de lo que se trata es de aprender de una buena vez que *respetar no es sinónimo de compartir* y que el respeto por el otro es condición *sine qua non* de la vida democrática.

Referencias

1. Lolas Stepke F. El discurso bioético y la acción social. En: *Actas de la Primera Jornada de Bioética de la Facultad de Medicina de la Universidad de Buenos Aires*. Buenos Aires: Facultad de Medicina; 2002: 77-8.
2. Lolas Stepke F. *Oficio de anotar*. Santiago de Chile: Editorial Universitaria; 2000: 175.
3. Lolas Stepke F. *Temas de bioética*. Santiago de Chile: Editorial Universitaria; 2002: 15-25.
4. Lolas Stepke F. *Bioética y Antropología Médica*. Santiago de Chile: Mediterráneo; 2000: 59-60.
5. Lischetti M. *Antropología*. Buenos Aires: EUDEBA; 1985: 24.
6. Cortina A. *Ética de la empresa*. Madrid: Trotta; 2000: 50.
7. Gracia Guillén D. *Fundamentación y enseñanza de la bioética*. Bogotá: El Búho; 2000: 63.
8. Engelhardt HT. *Los fundamentos de la bioética*. Barcelona: Paidós; 1995: 27.
9. Maliandi R. *Ética: conceptos y problemas*. Buenos Aires: Biblos; 1991: 50.
10. Camps V. *Una calidad de vida*. Barcelona: Ares y Mares; 2001: 214.
11. Ferrater Mora J. *Diccionario de Filosofía.* Barcelona: Ariel; 1994: 1542.
12. Gracia Guillén D. *Bioética Clínica*. Bogotá: El Búho; 2001: 125-126.

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BIOÉTICA Y DISCAPACIDAD PSIQUIÁTRICA: ASPECTOS CLÍNICOS Y JURÍDICOS

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Resumen: La presente monografía busca establecer un nexo interdisciplinario entre la bioética y los aspectos clínicos y jurídicos que se conectan en la atención, protección y rehabilitación de las personas afectadas por enfermedades psiquiátricas. El análisis se centra en aquellas personas adultas, privadas de razón como consecuencia de un proceso psicopatológico, titulares de todos sus derechos civiles, pero que, por motivos de la enfermedad, se encuentran con dificultades para ejercerlos.

Palabras clave: Bioética, enfermo psiquiátrico, incapacidad, demente

BIOETHICS AN PSYCHIATRIC DISSABILITY: CLINICAL AN JURIDICAL APECTS

Abstract: This monography seeks to establish an interdisciplinary link between bioethics and the clinical and juridical aspects that connect with attention, protection and rehabilitation of persons with psychiatric illness. The analysis is centered those adults, on deprived of reasoning because of a psycopathologic process, entitled to civil rights, but with dificulties to exercise them due to their illness.

Key words: Bioethics, psychiatric patient, incapacity, insane

BIOETICA E INCAPACIDADE PSIQUIÁTRICA: ASPECTOS CLÍNICOS E JURÍDICOS

Resumo: A presente monografia busca estabelecer nexo interdisciplinar entre bioética e aspectos clínicos e jurídicos na atenção, proteção e reabilitação de pessoas portadoras de enfermidades psiquiátricas. A análise é centrada em pacientes adultos privados de razão em decorrência de processo psicopatológico, titulares de todos direitos civis, mas que, em função da enfermidade, encontram-se em dificuldades para exercê-los.

Palabras chave: Bioética, paciente psiquiátrico, incapacidade, demente

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La bioética como disciplina emerge desde el estudio sistemático de los comportamientos humanos en el área de las ciencias de la vida y del cuidado de la salud. El presente trabajo se introduce en el análisis que puede desarrollar la bioética en el área específica de la psiquiatría y sus implicancias jurídicas. En este contexto es factible examinar problemáticas tales como confidencialidad de los tratamientos, uso de psicofármacos, investigación en psiquiatría, modos de internación involuntaria, participación de los pacientes en la toma de decisiones que los involucran, y muchas otras.

Las personas que desarrollan su quehacer profesional en psiquiatría, están conscientes de que, constantemente, deben transgredir la libertad de los pacientes para protegerlos de ellos mismos y de otras personas, como familiares o vecinos de los enfermos. Los estados de pérdida de juicio de la realidad y la falta de autocontrol de los impulsos despiertan en las personas que rodean al enfermo un gran temor. Por su parte, el equipo de salud encargado de la atención en las primeras etapas de la crisis mantiene una actitud de alerta y de prevención de riesgos.

El trabajo que presentamos busca un nexo interdisciplinario entre la bioética y los aspectos clínicos y jurídicos que se conectan en la atención, protección y rehabilitación de las personas afectadas por enfermedades psiquiátricas. Dada la amplitud del tema, nuestro análisis se centrará en aquellas personas adultas, privadas de razón como consecuencia de un proceso psicopatológico, titulares de todos sus derechos civiles, pero que, por motivo de la enfermedad, se encuentran con dificultades para ejercerlos.

Nos parece fundamental, en una primera instancia, expresar los argumentos que sustentan la aplicación de la bioética en la psiquiatría y el derecho. Respecto de la primera, los pacientes psiquiátricos –como todos los seres humanos– desarrollan capacidades en orden a satisfacer las necesidades básicas que le reportan un bienestar en su vida cotidiana[1] : es lo que se denomina “lineamiento práctico”. El tomar una decisión, por ejemplo, participa de este ámbito práctico porque implica que la persona asume roles y establece esquemas de actividades concordantes con dichos roles; ello se aprecia como rutinas cotidianas. Existe, además, lo que se denomina “lineamiento conceptual”, esto es, aquellos fundamentos que se encuentran o podrían encontrarse impresos detrás de las decisiones humanas; pertenecen también a este aspecto, ya que el hombre es parte de una situación macrosocial que lo obliga a asumir creencias, valores e ideologías que sustentan la elección de las decisiones. Éstos constituyen el esquema de usos sociales (morales) que cada persona debe cumplir para ser aceptada como miembro de la comunidad. El no cumplimiento de estos usos es sancionado por la sociedad, y las vías más habituales establecidas son las reclusiones psiquiátricas o penales, según corresponda.

Es necesario establecer los elementos morales que están presentes en una persona con capacidad de participar en una decisión, y apreciar en forma previa si una persona está en condiciones de participar socialmente con acierto. Los elementos morales que aparecen al tratar el tema son: el sentido moral, el buen juicio, la conciencia de cada situación, el aceptar límites, el mantener buenas costumbres. Para apreciar la expresión de los elementos morales se requiere determinar algunos comportamientos tipo que emite la persona que conserva su moralidad en forma habitual.

Para el desarrollo de este análisis es necesario el examen de los contenidos morales. Se

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[1] Max Neef M. *Desarrollo a Escala Humana.* Montevideo: Editorial Nordan - Comunidad; 1993: 49.

trata, así, de un interés que se ajusta coherentemente a los propósitos de la bioética, ya que por constituir ésta el nexo entre dos planos de la vida humana se considera, precisamente, “la disciplina que combina el conocimiento biológico con el conocimiento de los sistemas de valores humanos”[2]. En esto se funda la idea de recuperar la identidad de personas morales en el ámbito de las enfermedades mentales.

En este sentido, la bioética, como disciplina sintetizadora de la ética filosófica, conserva el carácter especulativo y reflexivo de ésta, unido a los conocimientos teórico-prácticos que se requieren y se adquieren en el trabajo de las ciencias de la salud. La vida del ser humano necesita del cuidado de los elementos que la constituyen en su esencia, es decir, necesita salvaguardar sus valores para así conservar su propia humanidad, sin excepción de condiciones. La bioética asume esta tarea procurando guiar las acciones en la atención sanitaria sin que éstas dañen la integridad y dignidad de las personas involucradas. Se cuestiona dicha aplicación en dimensiones más específicas, como sectores de reclusión psiquiátrica. ¿Participan los pacientes psiquiátricos en las decisiones que los involucran? De no ser así, ¿es factible hablar de actos bioéticos generados única y exclusivamente desde posiciones directivas? En recintos psiquiátricos da la impresión de que no es así.

Después de varios años de práctica clínica en el área de la psiquiatría, escuchando, observando y compartiendo cotidianamente actividades con personas afectadas por la singular situación de ser enfermo mental, nos llama la atención que individuos con evidentes perturbaciones en los contenidos y curso formal del pensamiento, presenten comportamientos adecuados en situaciones que surgen espontáneamente en el devenir diario. Ello les permite resolver en forma armónica hechos de bastante contingencia, como resolución de problemas o manejo de acontecimientos de emergencia.

En estas personas se percibe la vigencia de algo común a todos los seres humanos: existe el uso de las mismas palabras, se elaboran juicios, se comunican intenciones, se establecen conversaciones como una necesidad de formar vínculos. Lo anterior nos lleva a inferir que existe un sentimiento o sensación de humanidad que se conserva, una capacidad que aún persiste y que les permite distinguir lo bueno de lo malo, lo bello de lo feo, lo correcto de lo incorrecto.

Ética y Práctica Psiquiátrica

La capacidad humana que recogeremos para desarrollar la vinculación entre ética y actividad psíquica es la conocida bajo el concepto de “sentido común”[3], según la doctrina de Kant. Éste organiza la propiedad de juzgar que posee cada persona considerando la afectividad involucrada en las situaciones reales, junto con la base de conceptos teóricos que actúan a modo de principios fundamentales, como son las normas y reglas o juicios de valor.

La noción de “sentido común”, en general, puede ser definida como el efecto del juego de las capacidades mentales, en el supuesto de que opera bajo la disposición de las facultades que permiten cumplir una tarea específica. Se distinguen tres grandes facultades: el pensar, cuya dirección es el conocer, o **sentido común lógico**; la voluntad, cuya dirección es el desear hacer o **sentido común moral**; y el sentir, que guía la manifestación del placer o **sentido común estético**.

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[2] Potter V.R. Humility with Responsibility: A Bioethcs for Oncologists. *Presidential Address. Cáncer Research* 1975; 35: 2297- 9.

[3] Kant I. *Crítica de la Facultad de Juzgar.* Buenos Aires: Editorial Losada S.A.; 1961.

La persona con discapacidad psíquica, al igual que todo ser social, se encuentra inmersa en las normas culturales establecidas por la comunidad a la cual pertenece, conocidas como "buenas costumbres". Sin embargo, se ve a diario enfrentada a inclinaciones sensibles, también comunes a los otros individuos de la comunidad, como son el egoísmo, la vanidad, el miedo y la inseguridad, entre otras. Se suman a este ambiente relacional las alteraciones psicopatológicas propias de su condición particular, como son los trastornos en el enjuiciamiento de la realidad, la impulsividad, el egocentrismo, el desapego afectivo, etc.; alteraciones éstas que dificultan notablemente la interacción con otras personas.

Un examen de cada forma específica de "sentido común" nos muestra una vinculación con los tipos clínicos de desajustes conductuales que origina la enfermedad mental.

A. La alteración del sentido común lógico o el uso ilegítimo del sentido común lógico (de acuerdo con la doctrina de las facultades kantianas) se aprecia en aquellas personas que manifiestan a través de la expresión verbal, gestual y/o corporal, una percepción alterada del mundo que las rodea.

El juicio de la realidad se elabora a partir de la percepción del mundo externo, pero el ser humano también convive con su mundo interno de fantasías, imaginaciones y ensueños. Un individuo sano (con uso legal de sus facultades), delimita con precisión y claridad las fronteras que separan las realidades interna y externa. Logra aceptar una integración dialéctica entre lo real y lo irreal.

Cuando la irrealidad invade parcial o totalmente la realidad, la lógica del entendimiento habitual se subordina a la interpretación atípica que puede generar una persona. La falta de integración lógica entre ambas realidades se muestra en la escisión que se vive en la esquizofrenia.

Nuestro conocimiento del mundo y de nosotros mismos se expresa a través de las ideas. Ellas se constituyen desde una vivencia de la realidad para traducirse al final en un juicio de realidad. A partir de éste se construyen las ideas normales (lógicas).

Si la vivencia de la realidad es "correcta", el juicio de realidad será adecuado. Si la vivencia de realidad se perturba, el juicio de realidad será errado y las ideas que se construyan a partir de ese juicio serán desviadas de lo usual.

Las personas afectadas por esquizofrenia constituyen una gran población de enfermos mentales que, después de sufrir las fases agudas de la patología, van alcanzando lentamente la estabilización, pero sobre la base de un deterioro psicosocial, denominado defecto esquizofrénico. Este defecto no constituye un factor tan invalidante, como lo advierten familiares y personas dedicadas a su protección. En este grupo de personas centraremos más adelante nuestro análisis.

Para completar la interpretación de los otros cuadros psicopatológicos, a la luz de la descripción del sentido común, debemos completar el examen que hemos iniciado con las expresiones ilegítimas (morbosas) de las otras funciones del sentido común.

B. La alteración del sentido común moral (o su uso ilegítimo) provoca los desajustes conductuales más evidentes para la comunidad que convive con la persona afectada. Se traduce en la pérdida de los límites sociales, desadecuación del contexto cultural, falta de respeto u oposición activa a los usos sociales, y exagerado egocentrismo, entre otros rasgos. Estas características configuran el perfil de la persona definida clínicamente con un trastorno de personalidad. Ello se expresa técnicamente como un patrón permanente e inflexible de la experiencia interna y del comportamiento que se aparta acusadamente de las expectativas de la cultura y del ambiente sociocultural. Es estable a lo largo del tiempo y comporta malestar para el sujeto y su entorno.

La concordancia entre el entendimiento y la razón, como una actitud reflexiva para conocer las cosas sujetas a normas y aceptarlas, no está presente al desencajar esta función del sentido común. Según los criterios internacionales para el diagnóstico del trastorno antisocial, la persona con este problema presentaría:

- Fracaso para adaptarse a las normas sociales en lo que respecta al comportamiento legal, como lo indica el perpetrar repetidamente actos que son motivo de detención.

- Deshonestidad, expresada en la acción de mentir repetidamente, utilizar apodos, estafar a otros para obtener un beneficio personal o placer.

- Impulsividad o incapacidad para planificar el futuro.

- Irritabilidad y agresividad, indicadas por repetidos altercados verbales y físicos.

- Despreocupación imprudente por su seguridad o la de los demás.

- Irresponsabilidad persistente, indicada por la incapacidad de mantener un trabajo con constancia o de hacerse cargo de obligaciones económicas.

- Falta de remordimientos, como lo indica la indiferencia a la justificación de haber dañado o maltratado a otro.

Las alteraciones a este nivel de la conciencia moral resultan, por su propia definición, permanentes en el tiempo, y la atribución de responsabilidad a estos actos frente al entorno social, corresponde a la psiquiatría forense y sus implicancias penales.

C. La alteración del sentido común estético no provoca grandes conflictos en la convivencia social de los individuos. Tradicionalmente se acepta la particularidad en asuntos de gustos de cada persona. Se puede percibir su alteración cuando se presenta un desborde de la imaginación que no logra formularse en conceptos o expresiones entendibles para los demás, como es el caso del excentricismo y la bizarrería. Se trata de un sentido común que habitualmente permanece conservado, representando por ello una vía de comunicación, a veces más expedita que el diálogo formal para las personas con alteraciones en la expresión verbal lógica (por ejemplo: arteterapia, músicoterapia, aromaterapia).

La enfermedad mental representa un obstáculo importante que dificulta el desarrollo de lo que debe ser la vida humana, porque afecta, precisamente, la relación entre el individuo y el mundo. Sin embargo, las dificultades se van aminorando en la medida en que se alejan los períodos de crisis y se recibe atención especializada (psicofármacos, psicoterapia, rehabilitación).

Una patología psiquiátrica de larga evolución, que es origen de discapacidad psíquica permanente y que afecta a parte del grupo de personas recluidas en recintos psiquiátricos, es la esquizofrenia (alteración del sentido común lógico, preferentemente).

Las personas esquizofrénicas, en general, presentan dificultad en la comunicación con los demás, no utilizan del modo usual los comportamientos verbales y no verbales. Su mímica es pobre y sus gestos pueden parecer lentificados, mecánicos y estereotipados. En algunos casos la expresión corporal es discordante con la emoción o relato verbal. Las categorías definidas internacionalmente clasifican los síntomas en positivos y negativos. Los primeros, que se presentan en brotes agudos de la enfermedad, corresponden a alteraciones en el contenido y en la forma de estructurar las ideas, alteraciones del lenguaje y comunicación y desorganización comportamental. Estos síntomas disminuyen en porcentaje importante con el tratamiento de psicofármacos[4]. Los síntomas negativos, producidos principalmente en etapas crónicas, son de intensidad variable y se relacionan directamente con el defecto esquizofrénico que provoca un considerable deterioro psicosocial: corresponden al aplanamiento afectivo, abulia, desgano. Existen antecedentes de que el aplanamiento afectivo produce una disminución en la expresión de emociones y lenguaje corporal, lo que genera un déficit en el desarrollo de habilidades comunicativas y, como consecuencia de lo mismo, en las habilidades sociales. Sin duda, esto interfiere en las relaciones interpersonales que puedan establecer las personas esquizofrénicas afectando, en forma primaria, las relaciones con su familia o personas cercanas. Además, es importante señalar el efecto que esto provoca en los demás, quienes perciben al esquizofrénico como desinteresado, retraído, callado.

Las manifestaciones anteriormente descritas varían en intensidad a medida que se compensan psicopatológicamente; así, las personas van recuperando su participación social y, al mismo tiempo, el ejercicio de sus derechos civiles. En este proceso debe participar el equipo interdisciplinario de salud que se desempeña en el área.

Ética y Práctica Jurídica en Relación con la Discapacidad Psiquiátrica

En esta parte del análisis abordaremos los elementos constitutivos del marco jurídico relativo a los distintos estados de incapacidad de las personas. Continuaremos con un acercamiento a los aspectos jurídicos que se relacionan con el sujeto portador de una enfermedad mental, en este caso esquizofrenia compensada y, finalmente, propondremos la integración de estos elementos en la atención y reeducación social del enfermo psiquiátrico.

Las diversas situaciones que afectan a los pacientes psiquiátricos plantean desafíos para el derecho que la ciencia jurídica suele enfrentar, a veces, sin mucha precisión. Desde luego, no se trata de un enfoque puramente jurídico, pues la ciencia del derecho se apoya también en la ciencia médica: es ésta la que determina –a veces también sin mucha precisión– los ámbitos de sanidad y enfermedad. Con todo, los efectos de tal determinación son conclusivos e importantes pues para el Derecho no existen estadios intermedios: el paciente psiquiátrico está o no privado de su capacidad para actuar en la vida jurídica.

Desde el punto de vista jurídico, la capacidad es la aptitud legal que tienen todos los individuos para adquirir derechos civiles y para ejercitarlos por sí mismos. Clásicamente se distingue entre capacidad de goce –la aptitud legal para adquirir derechos– y capacidad de ejercicio –la aptitud legal de una persona para ejercitar por sí misma los derechos que le competen, sin el ministerio o la autorización de otra–. La

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[4] Los tratamientos psiquiátricos han sido beneficiados notablemente con el avance tecnológico a nivel de la farmacología. Las conductas agresivas e insociables han logrado modificarse con el uso de elementos químicos; ello ha significado el reintegro a la vida social, evitándose las reclusiones hospitalarias por largo tiempo. Sin embargo, el uso de los psicofármacos constituye un frecuente dilema bioético para los profesionales de la atención psiquiátrica pues todos presentan efectos secundarios, lo que requiere de un cuidadoso control de sus límites terapéuticos para no caer en casos de yatrogénesis.
Cf. López Azpitarte E. *Ética y Vida: desafíos actuales.* Cap. 16 “Los psi cofármacos”. Madrid: Ediciones Paulinas; 1991: 295-308.

capacidad de goce la tiene todo individuo por el solo hecho de ser persona, siendo uno de los atributos esenciales de la personalidad. La capacidad de ejercicio, en cambio, si bien constituye la regla general, puede no estar presente en ciertas personas, las cuales, en atención a su edad, salud mental u otra causa expresamente contemplada por la ley, son consideradas incapaces de ejercer sus derechos. En otras palabras, si bien son titulares de derechos –es decir, poseen capacidad de goce– no pueden ejercerlos por sí mismas.

Las incapacidades de ejercicio pueden ser, básicamente, de dos tipos: absolutas y relativas. Son incapaces absolutos los dementes, los impúberes y los sordomudos que no pueden darse a entender por escrito. Son incapaces relativos los menores adultos y los pródigos o disipadores bajo interdicción de administrar sus bienes.

Las personas mentalmente sanas, en consecuencia, pueden encontrarse en una situación de incapacidad debido a su minoría de edad. En efecto, son incapaces absolutos los impúberes, es decir, el varón que no ha cumplido 14 años y la mujer que no ha cumplido 12 (artículo 26 del Código Civil). Estas personas, como –por lo demás– todos los incapaces absolutos, sólo pueden actuar en la vida jurídica representados. Por otra parte –y según hemos señalado más arriba– son incapaces relativos los menores adultos, esto es, las mujeres que han cumplido 12 años y los varones que han cumplido 14, pero que aún no han llegado a la mayoría de edad (18 años). Estas personas no carecen totalmente de juicio, como sí ocurre –según la ley– con los impúberes, pero no pueden administrar eficientemente sus negocios. En consecuencia, pueden actuar en la vida jurídica representados o autorizados por su representante legal.

En el ámbito de la bioética, esta incapacidad de los menores de edad tiende a ser morigerada. Así, existen diversos cuerpos normativos –especialmente instrumentos internacionales– que toman en consideración el asentimiento del niño, por ejemplo, para participar en una investigación científica, respecto de la cual los padres o los representantes legales del menor han otorgado su consentimiento. En este sentido, se otorga plena validez a la negativa del menor a participar en estas investigaciones, primando la voluntad del menor por sobre el consentimiento de los padres o representantes, cuando corresponda.

En el caso de individuos adultos, el ordenamiento jurídico chileno contempla tres casos de incapaces: los dementes, los sordomudos que no pueden darse a entender por escrito y los pródigos o disipadores bajo interdicción de administrar sus bienes. Los primeros, son incapaces absolutos porque carecen de voluntad jurídicamente eficaz; los segundos, por no poder exteriorizarla; los disipadores, por último –que son aquellos que dilapidan sus bienes en forma desproporcionada a sus haberes, manifestando una total falta de prudencia– son incapaces relativos, no son enfermos mentales y si tienen algún desequilibrio intelectual no es suficiente como para considerarlos absolutamente incapaces. La incapacidad de estos últimos, a diferencia de los dementes y sordomudos, se refiere sólo a los actos patrimoniales y no al derecho de familia; en consecuencia, podrán casarse, impugnar la paternidad que le ha sido reconocida, etc.

Los pródigos y los dementes que han sido puestos en entredicho de administrar sus bienes y los sordomudos que no pueden darse a entender por escrito requieren de un representante legal, que en este caso se denomina curador general (artículo 342 del Código Civil). Con todo, es del caso señalar que, en la práctica, estas reglas tienden a morigerarse, por cuanto existe una amplia gama de actos y contratos cotidianos, de cuantías menores, cuya celebración no requiere el cumplimiento de solemnidades especiales –se trata de contratos consensuales, en su gran mayoría– que estos incapaces suelen celebrar sin que intervenga para nada su representante legal (por ejemplo, contrato de transporte y compraventa de especies muebles de menor valor, entre otros).

Ahora bien, la ley establece que toda persona es legalmente capaz, excepto aquellas que la ley declare incapaces (artículo 1447 del Código Civil); en consecuencia, la capacidad se presume y, por consiguiente, debe probar la incapacidad el que la alegue.

En la materia que nos ocupa, es del caso señalar que, para que una persona se encuentre en interdicción por demencia, es necesario que el juez decrete judicialmente que el curador está autorizado para ejercer su cargo.

La denominación que utiliza el legislador civil chileno para referirse a esta clase de incapaces absolutos no debe entenderse en el sentido que la psiquiatría moderna da a la expresión demente, sino que alusiva a todo aquel que esté privado de razón o que tenga sus facultades mentales substancialmente alteradas, es decir, como sinónimo de enfermedad mental (así, por ejemplo, el artículo 456 del Código Civil dice que el adulto que se halla en un estado habitual de demencia, deberá ser privado de la administración de sus bienes, aunque tenga intervalos lúcidos).

En materia penal, la capacidad equivale a la imputabilidad y la incapacidad se traduce en inimputabilidad. A este respecto, el ordenamiento jurídico chileno establece que está exento de responsabilidad penal *"el loco o demente, a no ser que haya obrado en un intervalo lúcido (...)"* (artículo 10 del Código Penal). Al igual que en el caso de la legislación civil, las expresiones "loco o demente" no están empleadas en un sentido técnico.

Respecto de los enfermos hospitalizados en establecimientos de atención psiquiátrica, el Código Sanitario (artículo 133) establece que los directores de estos establecimientos serán curadores provisorios de los bienes de dichos enfermos, cuando carecieren de curador o no estén sometidos a patria potestad, mientras permanezcan internados o no se les designe curador, de acuerdo con las normas del derecho común.

En nuestra cultura judeocristiana, en una primera etapa, los enfermos mentales graves fueron considerados como "castigo de Dios", "figuras demoníacas" o "encarnaciones del demonio", con el consiguiente tratamiento de crueldad y reclusión de por vida. Con posterioridad, el enfermo mental se "domestica" mejorando el trato a su respecto. Es ésta la época del desarrollo de las ciencias del comportamiento, que buscan las causas del estado patológico y consideran la posibilidad de reeducación. La etapa en que nos encontramos actualmente se caracteriza por la reivindicación de los derechos de las personas, independientemente de las diversas y específicas situaciones en que éstas puedan encontrarse. Así, surgen los catálogos de derechos de los consumidores, de los pacientes, de los enfermos mentales, de los impedidos, entre otros. En este mismo sentido, diversos instrumentos internacionales han establecido estadios intermedios entre capacidad e incapacidad civil, empleando la denominación "impedido", reconociendo derechos y estableciendo cautelas y obligaciones de la sociedad en relación con ellos.

La Declaración de los Derechos de los Impedidos, proclamada por la Asamblea General de las Naciones Unidas, en su resolución 3447, de 1975, señala que el término "impedido" designa a toda persona incapacitada de subvenir por sí misma, en su totalidad o en parte, a las necesidades de una vida individual o social normal a consecuencia de una deficiencia congénita o no, de sus facultades físicas o mentales.

Agrega esta Declaración que el impedido tiene esencialmente derecho a que se respete su dignidad humana y que tiene los mismos derechos fundamentales que sus conciudadanos de la misma edad, lo que supone, en primer lugar, el derecho a disfrutar de una vida decorosa lo más normal y plena posible. Asimismo, hace aplicable a los impedidos el párrafo 7 de la Declaración de los Derechos del Retrasado Mental –proclamada por la Asamblea General de las Naciones Unidas en su resolución 2856, de 20 de diciembre de 1971– el cual prescribe que, si debido a la gravedad de su impedimento, no es capaz de ejercer efectivamente todos sus derechos, o si se hace necesario limitar o incluso suprimir tales derechos, el procedimiento que se emplee a los fines de esa limitación o supresión deberá entrañar salvaguardas jurídicas que protejan al impedido de abuso. Dicho procedimiento deberá basarse en una evaluación de su capacidad social realizada por expertos calificados. Asimismo, tal limitación o supresión quedará sujeta a revisiones periódicas y reconocerá el derecho de apelación a autoridades superiores.

El ordenamiento jurídico chileno, en la Ley N° 19.284 de 1994 –que establece normas para la plena integración social de personas con discapacidad– señala en su artículo 3° que *"(...) se considera persona con discapacidad a toda aquella que, como consecuencia de una o más deficiencias físicas, síquicas o sensoriales, congénitas o adquiridas, previsiblemente de carácter permanente y con independencia de la causa que las hubiere originado, vea obstaculizada, en a lo menos un tercio, su capacidad educativa, laboral o de integración social".* Por su parte, el Reglamento para la Evaluación y Calificación de la Discapacidad (D.S. N° 2.505, del Ministerio de Salud, de 1995), define en el artículo 2° lo que se entiende por discapacidad educativa, laboral y de integración social. Con respecto a esta última, señala que *"es aquella en la que una persona por sus deficiencias psíquica o mental, física y/o sensorial presenta un menoscabo de su capacidad de inserción en las actividades propias de la sociedad humana, de la familia y/o de los grupos organizados de la sociedad, viendo disminuidas así sus posibilidades para realizarse material y espiritualmente en relación a una persona no discapacitada en situación análoga de edad, sexo, formación, capacitación, condición social y familiar y de igual localidad geográfica".*

El derecho, en general, no hace mayores diferenciaciones en relación con los pacientes psiquiátricos, por cuanto no discrimina según los procesos patológicos de las enfermedades mentales, ni respecto de la conservación de las diversas formas de sentido a que se ha aludido más arriba. Estimamos, en consecuencia, que aquí se abre un gran espacio para la bioética, en la consideración de la autonomía moral, con base en el respeto a la dignidad humana. Bajo esta mirada, hechos jurídicamente aceptables, pueden no serlo desde el punto de vista ético, como, por ejemplo, disponer de los bienes del pupilo-paciente sin recibir su asentimiento, disponer el cambio de su lugar de residencia u otros análogos.

El enfoque del mejor interés del incapaz debiera orientar a las personas a su cargo. Jurídicamente está consagrado en el Código Civil chileno respecto del menor e, implícitamente, respecto de las personas sujetas a guarda, quienes, al decir de la ley, deben dar a los incapaces la protección debida en interés de ellos (artículos 338 y siguientes del Código Civil). Dicha visión permite considerar también la opinión del sujeto, en la medida que se concilie con su mejor interés.

Desde la bioética, una ética de la fragilidad nos parece pertinente, ya que implica el deber moral de proteger a los más débiles. Precisamente, ésta ha sido la historia de los derechos humanos, una reacción frente al abuso de que han sido víctimas los más débiles. La protección de tales derechos representa un claro avance ético de la humanidad.

La fragilidad del impedido puede ser violentada por actos de comisión o de omisión. En el primer caso podría estar, por ejemplo, el sometimiento del incapaz mental a investigaciones que no supongan un beneficio real y directo para su salud o bien que no consideren su rechazo. Ello a menos que, cumpliéndose las restantes condiciones de resguardo que se establecen para personas sanas, el experimento tenga por objeto –mediante una mejora significativa del conocimiento científico del estado de la persona, de su enfermedad o de su trastorno– contribuir a lograr en un determinado plazo, resultados que permitan obtener un beneficio para la persona afectada o para otras personas de la misma categoría de edad o que padezcan la misma enfermedad, el mismo trastorno o las mismas características. Lo anterior, siempre y cuando el experimento sólo presente para la persona un riesgo o inconveniente mínimo[5].

Finalmente, otra forma de violencia, esta vez por omisión, se produce frente al abandono del impedido por la sociedad, comunidad, equipo sanitario o familia, quienes tienen como imperativo ético y jurídico, la obligación de brindarles protección.

Las medidas de protección, como se señaló, están establecidas en el mejor interés del impedido y no pueden significar, en modo alguno, formas de conculcar los derechos que a éste competen. Habrá situaciones en que, respecto de determinados estadios de enfermedades psiquiátricas, será indispensable aplicar medidas de contención u otras que impliquen limitación de la libertad, como, por ejemplo, internación obligatoria en establecimientos psiquiátricos. Si así fuere, éstas debieran circunscribirse al tiempo indispensable para adoptar las medidas médicas que el impedido requiera, protegiendo también, y en subsidio, a la comunidad.

En este sentido, y conforme a lo ya expresado, podemos concluir que:

- El derecho sólo toca a las situaciones en que están en riesgo los derechos de las personas, momento en el cual la norma jurídica o ley establece salvaguardas. En lo no reglado, está el amplio espacio de libertad, tanto respecto del paciente como de la familia u organización social que la reemplaza.
- La psiquiatría, en especial cuando sus acciones están destinadas a la manutención o recuperación de la capacidad autogestora de las personas, enfrenta la necesidad imperiosa de definir conceptos y normas que regulen éticamente las relaciones entre los miembros del equipo de salud y las personas afectadas por discapacidad psíquica.
- En la base de toda norma que pueda establecerse está el respeto de la dignidad humana, lo que implica que cualquiera sea la naturaleza o gravedad de los trastornos o deficiencias que el impedido (en este caso mental) sufra, tiene los mismos derechos fundamentales que el resto de las personas de su edad. Ello implica también el derecho a disfrutar de una vida decorosa, lo más normal y plena posible.

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[5] Convenio para la Protección de los Derechos Humanos y de la Dignidad del Ser Humano con respecto a las aplicaciones de la Biología y de la Medicina: Convenio sobre los Derechos Humanos y la Biomedicina. Consejo de Europa, 4 de abril de 1997. *Revista de Derecho y Genoma Humano* 1997; 7.

Bibliografía

Allport G. *La Personalidad. Su configuración y desarrollo.* Barcelona: Editorial Herder; 1973.

American Psychological Association. *Code of Professional Ethics*. Washington DC: Am.Psy.Ass.; 1987.

American Psychiatric Association. Model Law on Civil Commitment of the Mentally ill. En: *APA Issues in Forensic Psychiatry.* Washington DC: Am.Psy.Press; 1984.

Benzi I. *El Sentido Común y la Comunicabilidad Universal en Kant.* Santiago de Chile: Publicaciones Especiales de la Universidad de Chile. Serie Ensayos 2ª ed.: 1981.

Benzi I. *Razón y Libertad. Capacidades humanas de cumplir lo humano*. Santiago de Chile: Publicaciones Especiales de la Universidad de Chile. Serie Ensayos; 1987.

Capponi R. *Psicopatología y Semiología Psiquiátrica.* Santiago de Chile: Editorial Universitaria; 1987.

Consejo de Europa. Convenio para la Protección de los Derechos Humanos y la Dignidad del Ser Humano con respecto a las aplicaciones de la Biología y la Medicina. *Revista de Derecho y Genoma Humano* 1997; 7.

Franca-Tarragó O. *Ética para Psicólogos: Introducción a la Psicoética.* Bilbao: Editorial Descleé de Brouwer; 1996.

Gafo J. *10 Palabras Clave en Bioética*. Navarra: Verbo Divino; 1993.

Gracia D. *Fundamentos de Bioética.* Madrid: Eudema S.A.: 1989.

Gracia D. *Introducción a la Bioética: Siete Ensayos.* Bogotá: Editorial El Búho; 1991.

Gracia D. *Bioética Clínica. Ética y Vida.* Bogotá: Editorial El Búho; 1998.

Gracia D. *Ética en los Confines de la Vida.* Bogotá: Editorial El Búho: 1998.

Hooft PF. *Bioética y Derechos Humanos.* Buenos Aires: Ediciones Desalma; 1999.

Kant E. Crítica de la Facultad de Juzgar, Buenos Aires: Editorial Losada S.A.; 1961.

López Azpitarte E. *Ética y Vida: desafíos actuales.* Madrid: Ediciones Paulinas; 1991.

Max-Neef M. *Desarrollo a Escala Humana.* Barcelona: Icaria Editorial; 1994.

Pacheco M. *Derechos Humanos. Documentos Básicos.* Santiago de Chile: Editorial Jurídica de Chile; 1992.

Rosenbaum M. *Ética y Valores en Psicoterapia.* México: Fondo de Cultura Económica; 1985.

Rueda L. *Conciencia Moral en las personas con discapacidad de causa psíquica.* Santiago de Chile: Programa Regional de Bioética OPS/OMS; 1999.

Acta Bioethica 2003; año IX, N^{O} 2

MALAGÓN-LONDOÑO, GUSTAVO & GALÁN MORERA, RICARDO (Editores)
La salud pública: situación actual, propuestas y recomendaciones. Editorial Médica Panamericana, Bogotá, 2002. 492 pp.

Es indudable que en las últimas décadas las condiciones generales de salud en las Américas han mejorado considerablemente. Sin embargo, múltiples son los desafíos cualitativos y cuantitativos que deben ser afrontados en los albores del siglo XXI. En efecto, a pesar del gran progreso que ha experimentado la ciencia y la tecnología, nuevas epidemias han surgido y otras enfermedades, asociadas con la pobreza, la violencia y la transición epidemiológica aún se perpetúan[1].

La publicación que comentamos aborda, precisamente, estos nuevos desafíos, destacando como puntos centrales aquellas fortalezas que, sin lugar a dudas, caracterizan la salud pública del futuro: la prevención y la promoción.

El libro es una recopilación de 23 artículos de connotados profesionales latinoamericanos, los cuales abordan diferentes temáticas relacionadas con la salud pública desde sus particulares disciplinas. Así, en los sucesivos capítulos podemos apreciar los enfoques dados a diversas materias principalmente desde el ámbito de la medicina, pero también desde la ingeniería, la economía, el derecho y las ciencias sociales.

Los 23 capítulos en que se divide el libro se refieren a los siguientes tópicos: *Responsabilidad y cobertura de la salud pública* (Malagón-Londoño, Gustavo); *Evolución, situación actual y prospectiva de la salud pública* (Galán Morera, Ricardo; Arredondo Pérez, Luis Gilberto; Rodas Botero, Juvenal, y Uribe Uribe, Luis Javier); *Principios orientadores de la salud pública desde el derecho a la salud* (Velásquez Fandiño, Selva); *Salud ambiental* (Cadena Lezama, María Amparo); *Contaminación del suelo y salud* (Burbano Diago, Julio); *Vivienda y salud* (Burbano Diago, Julio); *Geopolítica, salud pública y medicina social. A propósito del caso Colombia* (Sotomayor Tribín, Hugo Armando); *Magia, religión e higiene en la historia latinoamericana. El caso Colombia* (Sotomayor Tribín, Hugo Armando); *Zoonosis y enfermedades transmisibles comunes al hombre y a los animales* (Vega Aragón, Ricardo León); *Las sustancias peligrosas* (Jaramillo Botero, José Hernán); *Alimentos del nuevo milenio: una solución al problema de salud pública. Alimentos tradicionales y nuevos alimentos* (Soto Rojas, Marta Elena); *Factores de riesgo y protección del consumo en salud pública* (Soto Rojas, Marta Elena); *Medicamentos y la salud pública del futuro* (Prada Martínez, Gonzalo David); *La transición epidemiológica* (Uribe Uribe, Luis Javier); *Equidad en salud y corrientes de reforma en servicios de atención a la enfermedad y en salud pública* (Málaga C., Hernán y Lolas Stepke, Fernando); *Participación comunitaria en el plan local de salud* (Málaga C., Hernán); *Formulación del plan local: prevención, control y eliminación de problemas de salud* (Málaga C., Hernán; Moreira, Marcia y Lombardi, Clovis); *Sistema de información en salud* (Reynales Londoño, Jairo); *Desastres y su impacto en salud pública* (Lozano Oliveros, Roberto); *Avances científicos y tecnológicos. Inmunología y vacunas* (Parra-López, Carlos Alberto); *Educación continua de los trabajadores de la salud* (Malagón-Londoño, Gustavo); *Bioética y salud pública* (Lolas Stepke, Fernando), e *Intervenciones en salud pública* (Galán Morera, Ricardo y Uribe Uribe, Luis Javier).

En síntesis, un libro que merece ser consultado por todos aquellos que se desempeñan en el ámbito de la salud pública, pues nos esboza propuestas y recomendaciones concretas para el mejoramiento progresivo del bienestar de nuestra sociedad.

Adelio Misseroni

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[1] Pan American Health Organization, www.paho.org/Spanish/DPI/100/100feature20.htm

DÜWELL, M. & STEIGLEDER, K. (Editores)
Bioethik. Eine Einführung.
Suhrkamp Taschenbuch, Suhrkamp, Frankfurt/Main, 2003. 454 pp.

La prestigiosa colección de libros de bolsillo Suhrkamp, que reproduce lo más selecto de la producción en el área de las ciencias sociales, las humanidades y las ciencias del lenguaje, agrega ahora un título que expresamente alude a la bioética. Es interesante comprobar que los temas y las formas de su abordaje no difieren considerablemente de lo que es dable encontrar en la literatura estadounidense. Ello no debiera ser extraño, toda vez que desde el neologismo bioética hasta los principales tópicos cubiertos por este campo de estudio provienen de desafíos descubiertos y planteados en ese contexto cultural. Lo que este libro agrega es, no obstante, una perspectiva novedosa sobre algunos puntos y la pureza de una tradición europea modulada por una historia particularmente compleja. La experiencia del nacionalsocialismo y los avatares de la medicina y la ciencia bajo las peculiares condiciones de Alemania no están expresamente desarrollados, aunque su impronta se deja ver en algunos de los autores que contribuyen a este volumen.

El libro se divide en dos grandes secciones. La primera, titulada Teorías y Concepciones, incluye una desigual cobertura de los temas habituales. Especial dedicación se presta, por ejemplo, a Hans Jonas y Tristram Engelhardt, junto a la teoría de Alan Gewirth, las aportaciones de Norman Daniels y el trabajo de Beauchamp y Childress. La bioética feminista y las perspectivas de la narrativa y de la virtud reciben adecuado tratamiento. En general, esta sección puede leerse con provecho en el contexto de cursos introductorios, toda vez que sus artículos son breves y didácticos.

La segunda parte del libro, intitulada Problemas y Discusiones, contiene artículos misceláneos. Su variedad permite esperar tratamientos diferentes, perspectivas discrepantes, niveles de tratamiento temático dispares. Con todo, es una sección ilustrativa y útil como referencia en cursos básicos y avanzados. Interesante es, además, que parte de la literatura citada por los auotres de esta sección es europea y especialmente alemana, lo cual convierte al volumen en una referencia complementaria a los textos más habituales. Entre los temas tratados se encuentran, por ejemplo, el estatuto moral del embrión humano, los problemas del diagnóstico prenatal y preimplantación, clonación, medicina de transplantes, ética alimentaria y animal, técnicas genéticas y experimentación humana. Considerando la variedad, este apartado contiene útiles tratamientos breves de los temas que ofrece.

Es probable que la barrera idiomática impida que este libro tenga difusión en países hispanohablantes o angloparlantes. No obstante, es importante dar noticia de su aparición para que se advierta la amplitud del debate en temas bioéticos, la existencia de producción en lengua alemana de alta calidad y la presencia de editoriales cuidadosas en la selección y oferta de temas bioéticos en la interfaz de muchas disciplinas.

Fernando Lolas Stepke

ORGANIZACIÓN PANAMERICANA DE LA SALUD OPS/OMS Y AGENCIA SUECA PARA EL DESARROLLO INTERNACIONAL

Exclusión en Salud en países de América Latina y el Caribe.
Unidad de Políticas y Sistemas de Salud, 2003

Establece el marco conceptual y una metodología para medir la exclusión en salud y muestra los resultados de la medición en seis países de la región.

La exclusión en salud es un tema de creciente importancia en el ámbito de las políticas públicas, no sólo como un problema que se debe enfrentar y resolver, sino como herramienta de análisis para evaluar las intervenciones destinadas a mejorar el estado de salud de las personas.

A pesar de la importancia de esta forma de exclusión como fenómeno social y como problema de políticas públicas, en la actualidad no se la encuentra en la lista de temas prioritarios de la agenda político social de los países de la Región, y las reformas sectoriales sólo la han tocado de manera indirecta y fragmentaria.

Un factor que obstaculiza el enfrentamiento adecuado de la exclusión en salud en los países de la Región es que, en la actualidad, no se conoce con exactitud su magnitud, sus factores causales y a quiénes afecta. Tampoco está claro cuáles son las intervenciones que han demostrado ser más eficientes para combatirla. Esto se debe principalmente a dos razones: el carácter multicausal de la exclusión en salud, que hace que su medición sea compleja, y la escasez de instrumentos metodológicos para caracterizar y medir el problema.

El libro presenta el resultado de los estudios realizados entre 2001 y 2003 en seis países de América Latina y El Caribe, con el objetivo de caracterizar y medir la exclusión en salud. Plantea un marco conceptual para abordar este problema y propone una metodología de medición basada en un análisis que tiene componentes cuantitativos y cualitativos. El componente cuantitativo consta de dos elementos: la medición, a través de una batería de indicadores, del impacto de diversos factores sobre la exclusión en salud y un análisis econométrico que muestra la interacción entre dichos factores.

Los resultados del estudio muestran que los factores más importantes de exclusión en salud difieren para cada país. En algunos de ellos los factores externos al sistema de salud (barreras de entrada) contribuyen más a explicar este fenómeno, mientras que, en otros, son factores vinculados a la oferta de servicios de salud (factores internos) los que tienen un mayor valor explicativo.

“El conjunto de las metodologías utilizadas para la medición de la exclusión en salud en este estudio, mostró ser altamente explicativo del fenómeno de la exclusión en salud en sus distintas dimensiones y de manera integrada. La medición de la exclusión, realizada de esta manera, puede constituir un instrumento importante para la definición de políticas sociales en los países...”

Cecilia Acuña

MARTÍNEZ OLIVA, LUIS

Justicia y Medicina Pública. Del principio ético a los desafíos en su aplicación.
Departamento de Salud Pública y Epidemiología, Facultad de Ciencias Médicas, Universidad de Santiago de Chile, 1999.

El autor de este trabajo de investigación es Director del Departamento de Salud Pública y Epidemiología de la Facultad de Ciencias Médicas, de la Universidad de Santiago de Chile. Analiza los principios éticos que rigen la Medicina Pública, desde la visión de los aportes de la bioética, por un lado, y de la situación concreta de Chile, por otro. “En América Latina y especialmente en Chile –según palabras de propio autor– , la medicina pública es la principal forma de oferta de atención sanitaria (...) y la principal respuesta a las necesidades de salud o atención médica de la mayoría de los habitantes de esta Región, en particular para aquellos de más escasos recursos”.

Por esto, es necesario profundizar en las distintas teorías de la justicia, de los derechos y obligaciones en salud y, sobre todo, de la posible competencia entre el principio de equidad en el acceso a los servicios de salud y el de eficiencia en las instituciones sanitarias. Expone el autor cuál sería “la opción del mínimo decente”, así como los dilemas éticos que se producen en las soluciones a la equidad, control de costos y seguros solidarios. Parte de una concepción renovada y cristiana del concepto de justicia, que tiene a la solidaridad como complemento necesario.

ORTÚN RUBIO, VICENTE.

“Organización de los servicios sanitarios en el estado de bienestar.”
En: Parejo L., et al, coord. *La organización de los servicios públicos sanitarios.*
Marcial Pons, Madrid, 2001, 47-70.

El autor es director del Departamento de Economía y Empresa (CRES) del Centro de Investigación en Economía y Salud, de la *Universitat Pompeu Fabra* de Barcelona. El objetivo del trabajo es analizar el cambio en las instituciones y en las organizaciones de mayor relevancia para el planteamiento de modificaciones en la componente sanitaria de Estado del Bienestar español. Las instituciones son tres: Estado, Mercado y Normas Clínicas; y las organizaciones son cuatro: burocracia descentralizada, organizaciones sin finalidad lucrativa, cooperativas de profesionales sanitarios y organizaciones sanitarias integradas.

Analiza el autor, exhaustivamente, los cambios en las instituciones de salud, sobre todo en su gestión económica, la competencia gestionada entre ellas y los condicionantes políticos de los cambios y reformas que se han producido. Tiene interés como modelo comparativo que podría también aplicarse al análisis de la situación de los diferentes países de Latinoamérica, con condicionamientos económicos y políticos muy diversos. También es de destacar el papel que, en las propias reformas, se le reconoce a las normas clínicas como institución relevante en el ámbito de la salud: el modelo de decisiones clínicas y de relación profesional de la salud-paciente tiene enorme influencia en la elaboración de las políticas por parte de Estado y en el desarrollo de la oferta y la demanda en el mercado sanitario.

INFORME SESPAS 2002.

Invertir para la salud. Prioridades de salud pública.
Sociedad Española de Salud Pública y Administración Sanitaria, Madrid, 2003.

Amplio y exhaustivo informe que anualmente publica la Sociedad Española de Salud Pública y Administración Sanitaria. En esta ocasión, se trata de dos volúmenes. El primero está centrado en la vigilancia de la salud, los problemas de salud prioritarios y emergentes, y el análisis del sistema de salud en España. En el segundo se examinan las prioridades en la organización de la atención en salud en España, la atención primaria, los hospitales, los servicios de salud pública, y las políticas públicas y sus preferencias sociales y prioridades en salud.

Se analizan, en primer lugar, los datos del sistema de salud y los proporcionados por la sociología: los indicadores sanitarios por comunidades autónomas, las desigualdades en salud que tienen su raíz en la pobreza o en el género; problemas como el uso de drogas ilegales y el tabaco, la alimentación y nutrición, el medio ambiente y la salud.

Al estudiar el sistema de salud en España, se recoge la frustrada "independización" de la asistencia sanitaria pública del sistema de Seguridad Social; el nuevo modelo de financiación autonómica; y el sector farmacéutico, entre otros.

En el segundo volumen, se analizan las prioridades en la organización de la atención en salud, con el impacto que han tenido las políticas de la Unión Europea en los distintos sistemas sanitarios. Se exponen distintos estudios sobre la situación en la atención primaria; los hospitales y la garantía de atención de calidad y su gestión; los servicios de salud pública; y las políticas públicas, preferencias sociales y prioridades en salud. Dentro de estos capítulo, destacamos el escrito por Mirentxu Corcoy sobre "Etica y prioridades en salud y servicios sanitarios", donde estudia el respeto a los derechos fundamentales en la medicina predictiva y la ética de la distribución de los recursos.

INSTITUTE OF MEDICINE, 2002.
Future of Public's Health in the 21st Century.
National Academies Press, Washington DC, 2003.

En 1988 el *Institute of Medicine* realizó un primer informe sobre el futuro desarrollo de la Salud Pública en Estados Unidos. Ahora se repite con el análisis de los cambios ocurridos en el sistema de salud en estos últimos años y el estudio de las tendencias presentes en las iniciativas de políticas de salud, sobre todo en el informe *Health People 2010, healthy people in healthy communities*.

La hipótesis de trabajo es que la salud de las poblaciones y los individuos es producto de factores no solamente clínicos, sino también sociales, económicos y políticos. Analiza la actuación de los distintos profesionales que intervienen en los procesos del sistema público de salud y ofrece unas recomendaciones para los individuos, para las comunidades y para las instituciones de salud.

Programa de acción comunitario en el ámbito de la salud pública en Europa (2003-2008).
Parlamento Europeo, Estrasburgo, 2003.

El programa, que complementa las políticas nacionales, tiene por objeto proteger la salud humana y mejorar la salud pública.

El 23 de septiembre de 2002 el Parlamento Europeo y el Consejo aprobaron un nuevo programa de acción comunitario en el ámbito de la salud pública que se aplicará durante seis años (desde el 1° de enero de 2003 hasta el 31 de diciembre de 2008).

El nuevo programa se basa en tres objetivos generales: proporcionar información sanitaria, reaccionar rápidamente ante los riesgos sanitarios y fomentar la salud actuando sobre los factores determinantes de ésta. Se establecen vínculos entre actividades como las redes, las respuestas coordinadas, los intercambios de experiencias y la formación o la divulgación de información y conocimientos que se reforzarán mutuamente. El objetivo es elaborar un enfoque integrado dirigido a la protección y la mejora de la salud. Como parte de este enfoque integrado, se ha concedido especial atención a la creación de vínculos con otros programas y acciones comunitarios. La evaluación del impacto sobre la salud de las propuestas presentadas en virtud de otros programas y actividades comunitarios –como la investigación, el mercado interior, la agricultura o el medio ambiente–, se consideran un instrumento para asegurar la coherencia de la estrategia comunitaria.

Para lograr la principal finalidad y los objetivos generales del programa, es esencial que haya una eficaz cooperación entre los Estados miembros, así como un diálogo con los principales actores (como las organizaciones no gubernamentales). Se insta a las instituciones, asociaciones, organizaciones y organismos del ámbito de la salud a que presenten proyectos para la aplicación de las prioridades específicas definidas anualmente por la Comisión, que, a este fin, recibe la ayuda de un comité compuesto por representantes nacionales de los Estados miembros.

TABLA DE CONTENIDOS
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Recensiones

Have, H. & Janssens R. eds. *Palliative care in Europa.*
(revisor Roberto Llanos Zuloaga)

Lolas, F. *Escritos sobre vejez, envejecimiento y muerte.*
(revisor Roberto Llanos Zuloaga)

Advisory Committee on Health Research - World Health Organization. *Genomics and World Health*.
(revisor Fernando Lolas)

Mattei, J.F. *The Human Genome*.
(revisor Fernando Lolas)

Buchanan, A. Brock, D.W. Daniels, N. & Wikler D. *Genética y Justicia.*
(revisor Francisco León Correa)

Agazzi, E. *El bien, el mal y la ciencia. Las dimensiones éticas de la empresa científico-tecnológica.*
(revisor Francisco León Correa)