

Canadian Bioethics Society

NEWSLETTER

See
inside...
CALL FOR ABSTRACTS

Volume 6, Number 1

February 2001



PRESIDENT'S LETTER

Christine Harrison 2000-2002

It is a pleasure and honour for me to be President of the Canadian Bioethics Society. I have been a member since the very beginning; looking back over the years of my involvement I have seen some changes, and many constants.

I remember the first annual meeting of the Society, which I attended as a student. I felt quite intimidated, although that was nothing compared to how I would feel the next year, when I presented my first conference paper at the meeting in Calgary. Since that time the involvement of students has increased, and we have all benefited from that.

The annual meeting continues to be an excellent opportunity for members to share their ideas, present their work, and network with colleagues. There have been twelve annual meetings, which means that most of the larger centres have organized the meeting at least once. Having chaired the meeting in Toronto, I know how much work is involved – hosting the meeting is a great service to the Society, and I know

that all who attend are grateful. The organizers of the conference in Quebec City this year provided us with an interesting and challenging experience, and I thank Edith DeLeury and her committee on your behalf. I hope to see you all in Winnipeg in October for the 2001 conference; Pat Murphy is chairing the meeting, the theme of which is "Imagine!...Bioethics at the Beginning of the 21st Century".

Throughout the years I have been involved in a variety of ways with the Executive of the Society. Members of the Executive have always shown deep commitment to the CBS, and are generous with their time and expertise. The current executive is no exception – the combined total of their years of service to the Society is overwhelming. We have already had one teleconference to discuss CBS business, and to plan for the coming year.

I have been trying to speak to as many CBS members as possible in order to hear from them what their thoughts are about the Society, its

role, strengths and weaknesses. Please email me or phone with your thoughts and ideas.

Several members have suggested that the CBS be more proactive, either by initiating projects or by taking public positions on issues.

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Canadian Bioethics Society NEWSLETTER

Charitable Registration #0876649-09

2000-2001 Executive Committee

| | |
|--------------------|------------------------|
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Marie-Eve Bouthillier (Student Representative)

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Paula Chidwick

This newsletter is published in both French and English and is distributed to CBS members in their preferred language. Members can obtain an additional copy in the alternate language upon request.

Newsletter submissions in the form of articles, letters, book reviews, notices and events are welcomed.

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President's Letter – continued from page 1 ...

This year a working group will continue to look at working conditions for bioethics, and the executive would be pleased to consider suggestions for other projects from members who are willing to organize them. The question of taking positions is one that many societies grapple with, and it has been raised a number of times in the CBS. It is a question that is worth revisiting from time to time, and an important one especially for a Society whose members work in areas related to ethics and human values.

One barrier to the pursuit of many projects is lack of funding. As a society, we used to have more money than we do now, largely because expenses have increased and it has always been a goal of the society that membership fees not be raised unless absolutely necessary. Unfortunately, this means that other things have had to go - for example, there used to be small regional grants available to support bioethics activities. Also, members of the executive used to have their expenses paid to attend the conference, where several business meetings occur. This is a dilemma that many societies must face - how to keep membership open to those whose financial resources are limited, yet at the same time provide services that make membership worthwhile.

One colleague to whom I spoke expressed concern that there appears to him to be some divisiveness among those who work in bioethics in Canada. He sometimes perceives a lack of collegiality and respect, and finds this disturbing in a group for whom respect is - or ought to be - a first principle. As I write this letter on New Year's Day, I hope that this perception is not widespread, and I hope that we will find a way to work together to make bioethics in Canada stronger, more inclusive, and respectful of the different ways individuals choose to do their work.

<christine.harrison@sickkids.ca>

CBS Newsletter

The Canadian Bioethics Society was founded in 1988. It seeks to 1) bring together persons and organisations concerned and involved in bioethics; 2) forge links between them, and provide a forum for the exchange of views and ideas; 3) assist in solving the problems of daily practice, and; 4) develop long term solutions to broader social questions. To help achieve these goals the Canadian Bioethics Society (CBS) publishes a newsletter. The newsletter was created to promote more effective communication between society members. It serves to inform members about news from the society, the Annual Conference and current ethical issues facing Canadians. Submissions should be sent to Paula Chidwick, Editor at pchidwic@uoguelph.ca

WORKING CONDITIONS FOR BIOETHICISTS

Significant progress has been made this past year on the issue of working conditions for bioethicists. At the last Annual General Meeting in Quebec City the membership passed a resolution to:

1. Formally receive, from the ad hoc Working Group on Employment Standards for Bioethics, the Draft Discussion Paper, "Working Conditions for Bioethics in Canada."
2. Publish this document as a work in progress on the CBS website, in both English and French, along with an invitation to comment.
3. Direct the CBS Executive to renew the Working Group and ask the Working Group to continue its work on this project and report back – preferably with a finished document for ratification at the 2001 Annual Meeting.

Please send comments on this draft paper to the editor at pchidwic@uoguelph.ca.

Draft Discussion Paper:

WORKING CONDITIONS FOR BIOETHICS IN CANADA

v. 8.0 (October 18, 2000)

Presented to the Canadian Bioethics Society by

An Ad Hoc Working Group on Employment Standards for Bioethics

Lead Author: Chris MacDonald, with Michael Coughlin, Christine Harrison, Abbyann Lynch, Pat Murphy, Mary Rowell, and George Webster

Preamble:

At the 1999 Annual Meeting of the Canadian Bioethics Society, a motion was put forward to establish a Working Group to look at the issues of employment and working conditions for ethicists practicing in a non-tenured environment. A complete treatment of working conditions for ethicists would require a discussion of the role related obligations and the consequent conditions necessary to permit the ethicist to meet those obligations. In a seminal work on this topic, Freedman (1994) described several characteristics of the clinical ethicist and examined working conditions related to communication, to uncertainty of task and authority, and to individual moral integrity. It is with the third topic that this ad hoc working group has chosen to begin.

This discussion paper concerns situations or circumstances where an ethics consultant in a Health Care Organisation (HCO) encounters serious wrong-doing, significant ethical disagreement, perhaps with an employer, real or potential moral compromise, questions of conscientious objection and/or a felt need to withdraw from a particular situation for moral reasons. The goal of this discussion paper is to illuminate the cause for special concern in such situations, and to promote the thoughtful resolution of such situations.

Discussion:

This document is primarily concerned with the employment of those persons hired by health care organisations explicitly for the purpose of providing the range of services normally provided by those who go by the title of "ethicist," "bioethicist" or "ethics consultant" (these terms will be used interchangeably in this document). To the extent, however, that other employees serve these same functions, these guidelines will apply to them, too. The Working Group recognizes that all employees of an organisation have at least some ethical responsibility for the ethical character of that organisation, and face some of the same issues that inspired this work.

"Ethicists," "bioethicists," and "ethics consultants" are people who, within a range of kinds of health care organisations, provide education and other kinds of support to facilitate appropriate ethical decision-making and behaviour within the organisation, and by the organisation as a whole. While job descriptions vary, typical activities include education, case consultation, and policy development and review. (See Baylis, 1994.)

All employees have ethical responsibilities, including responsibilities related to the overall moral character and behaviour of the organization that employs them. Those

hired specifically to function as ethicists have, by definition, special responsibilities in this regard. It should be recognized, of course, that, as Freedman has observed, "...there is no canonical description of the purposes of a health care ethics consultant...." However, almost without exception, ethicists have role-related duties and obligations that, minimally, by title or perhaps due to the expectations of others, suggests a higher standard with respect to knowledge, skills, abilities and ethical conduct.

Ethicists, like other employees, have a *prima facie* obligation to serve the interests and mission of the HCO. For reasons related to public accountability, the CEO and other senior managers of an HCO are charged with the responsibility to interpret and the mission and needs of the organisation, and to set appropriate policies. It is probably fair to say that there is a general obligation for employees to be respectful of the needs and goals of the organisation that employs them, as interpreted by management. *But there are limits to this obligation.* There is a broad body of literature suggesting that there are good reasons to limit the extent to which employees must defer to the judgment of senior management. There are good ethical arguments, and broad public support, for the idea that organisational employees ought to exercise their own judgment and follow their own conscience, even when doing so requires action that is at odds with the goals or actions of organisational managers. Ideally, managers of HCOs should cultivate and encourage an open and honest exchange of ideas and views, such that employees, including ethicists, will not feel that they face dilemmas regarding whether to defer to a decision taken by management, on one hand, or follow their own conscience, on the other.

It is instructive to note that many organisational employees perform jobs that call for them to voice concerns about conduct. They can be considered organizational trouble-shooters. These include, among others, quality control officers, health and safety inspectors, internal auditors, regular supervisors and union representatives. Such employees have a duty to voice moral concerns as part of their ordinary job descriptions, and organisations should make it an expectation that these employees in particular would speak up

as a matter of quality-management (See Bird, 1996, p. 243-244).

What goes for such employees must be even more true of those hired as ethicists. The role of the ethicist includes the unique obligation of speaking explicitly to moral concerns. She or he will often bear direct responsibility for speaking to concerns regarding the moral character and behaviour of the organisation. Such being the case, the ethicist will often be required to offer critiques of organisational behaviour and norms, and to speak uncomfortable truths.

The SHHV-SBC Task Force on Standards for Bioethics Consultation has this to say about the potential for conflict, here:

There is a potential conflict of interest if the ethics consultant is employed by or his/her job is dependent on the good will of a health care institution. Giving advice or otherwise acting against what the institution feels is in its own financial, public relations, or other interest may pose potential harm to the personal interests of the ethics consultant. This issue should be addressed proactively with the health care institution by any individual or group that plans to offer ethics consultation in that institution.

In an ideal world (or even in an ideal organisation), the role of the ethicist would be to offer guidance and critique in advance, before crisis occurs. The real world, however, and the organisations that inhabit it, are often far from ideal.

Summary of key points:

1. All employees of an organisation have at least some ethical responsibility for ethical conduct within the organisation, and for the ethical character of the organisation.
2. "Bioethicists" or "ethics consultants," while not categorically distinct in this regard, often have role-related duties and obligations that by title, or perhaps due to the expectations of others, suggests a higher standard with respect to knowledge, skills, abilities and ethical conduct.
3. This higher standard or expectation may result in conflict between the ethics consultant and the employing organisation.
4. The role of ethics consultants within health care organisations is an important one, and thus all parties concerned have reason to take steps toward avoiding such conflicts, and, when necessary, toward thoughtful resolution.

The special role of the ethicist – including in particular the role of commenting on the ethical conduct of the organisation as a whole – points to the need for particular conditions of employment. As noted above, the role of the ethicist will be determined in part by contract. However, we argue that the special role of ethicists – and the concomitant need for special protections – should be assumed, and that any deviations from these assumptions ought to be specified explicitly in the employment contract. The protections required in

CBS Website Update

By Chris MacDonald, Webmaster

This is just a brief statistical update on the usefulness of the CBS website.

In October of this year (the most recent month for which statistics are available), the CBS website was accessed some 1296 times (in comparison, the site was accessed only 525 times during October of 1998). The main page of the French version of the site was accessed 443 times during October, while the main page of the English version was accessed 780 times. (Neither of those statistics counts sub-pages that were accessed directly without going first to the main page.) The English version of Volume 5.1 of this Newsletter was downloaded 174 times, and the French version was downloaded 199 times. The "Jobs" page was accessed 441 times. During October, our site was accessed by visitors from more than 35 different countries. We received most of our traffic

from Canada, the U.S., France, New Zealand, and the U.K. (in that order).

Looking back a few months, the website was accessed 1047 times in September, 826 times in August, and 660 times in July (most websites are less active in summer).

This traffic seems to indicate that the CBS website is indeed serving a useful purpose, and is growing in popularity. Please remember that I'm always available to answer your questions about the website, and am always looking for suggestions as to how we can improve it.

Chris MacDonald,
Webmaster and
Member-at-Large, Atlantic
<chris.macdonald@dal.ca>

order to function adequately in the manner normally required of ethicists should be assumed to be part of the ethicist's terms of employment, rather than thought of as special conditions that must be argued for and negotiated.

A number of specific mechanisms might be utilized in order to prevent problems before they occur. To begin with, the ethicist's place in the organisational structure or hierarchy should be clearly specified. In particular, it should be clear (both to the ethicist and to others in the organisation) to whom the ethicist a) reports, and b) is accountable (i.e., to whom she or he must explain her actions). (For example, an ethicist might report to the Hospital Board, but be accountable to the CEO). Other examples of useful mechanisms might include agreed-upon standards for performance evaluation, and opportunities for peer review.

If employment conditions are poor, employer organisations will force down the quality of candidates applying

for these crucially important jobs. If HCOs are to make real their espoused commitment to the ethical provision of health care, and if the services of professional ethicists are seen to be central to this goal, then HCOs will see it as in their interest to ensure that ethicists work under conditions that are conducive to carrying out the consultative, educational, and critical work so central to the achievement of this commitment.

REFERENCES:

Francoise Baylis, ed., The Health Care Ethics Consultant, Totawa, New Jersey: Humana Press, 1994,

Frederick Bruce Bird, "The Muted Conscience: Moral Silence and the Practice of Ethics in Business," Quorum Books, Westport, Connecticut, 1996.

Benjamin Freedman, "From Avocation to Vocation: Working Conditions for Clinical Bioethicists," in Francoise Baylis, ed., The Health Care Ethics Consultant, Totawa, New Jersey: Humana Press, 1994, pp 109-132



CBS ANNUAL MEETING

will be held

October 11, 12, 13, 2001

Lombard Hotel – Winnipeg, Manitoba

Watch for details.



Bioethics at the Beginning
of the 21st Century

**13th ANNUAL CONFERENCE and MEETING of the
CANADIAN BIOETHICS SOCIETY**

The Fairmont Winnipeg
October 11-14, 2001
Winnipeg, Manitoba

Pre-Conference Day – October 11
“Ethics Consultation: Some Basics and Beyond”

Post-Conference Morning – October 14
“Ethics and the Media”

Contact...Pat Murphy
Chair, CBS 2001 Planning Committee
204-235-3619
murphypa@cc.umanitoba.ca

Conference
Website...www.hsc.mb.ca/cbs2001



La bioéthique à l'aube du
21^{ème} siècle

CANADIAN BIOETHICS SOCIETY
13th ANNUAL CONFERENCE AND MEETING

"Imagine!..... Bioethics at the Beginning of the 21st Century"

October 11-14, 2001 The Fairmont Winnipeg Winnipeg, Manitoba

CALL FOR ABSTRACTS

The CBS 2001 Abstract Committee invites members of the Canadian Bioethics Society and other interested parties to submit proposals for papers, workshops, colloquia and posters developing the Conference theme. The Committee will be particularly pleased to receive proposals: addressing enduring questions in Bioethics in a novel manner; critically anticipating issues in Bioethics; contemplating the place of "imagination" in ethical reflection; identifying new areas of research in Bioethics; treating "moral imagination" and ethics consultation; and describing innovative approaches to teaching in Bioethics.

Papers: Those wishing to be considered for a 20-minute oral presentation must submit a 250-word abstract on the official form. Authors should indicate whether they wish their paper to be considered for a poster presentation.

Workshops/Colloquia: Groups wishing to present their work in the format of a 90-minute workshop/colloquia must submit a three-page double-spaced outline of the proposed workshop/colloquia and a single 250-word abstract on the official form.

Posters: Those wishing to be considered for a poster presentation must submit a 250-word abstract on the official form. Materials for a poster presentation must fit into a 1.2 m x 1.2 m space.

Official Abstract Form: Abstracts must be submitted camera-ready on the official abstract form for reproduction in the Conference Program. The abstract form is available: (a) on the reverse of this page; (b) on the Conference website located at www.hsc.mb.ca/cbs2001/abstract; (c) from the Abstract Committee Chair listed below.

Student Competition: Students may submit abstracts to both the general competition and the student competition. Students **need not identify** themselves as students for the general competition. For information on the format of the student competition contact Marie Edwards, edwardsm@cc.umanitoba.ca

Abstracts must be received by April 15, 2001.

Submit Abstracts to: Dr. Jim Read, Chair, CBS 2001 Abstract Committee
The Salvation Army Ethics Centre
447 Webb Place
Winnipeg, Manitoba R3B 2P2
(Tel) 204-957-2412
(Fax) 204-957-2418
James.Read@sallynet.org

Constitutional Changes

At the last Annual General Meeting in Quebec City (2000) there was a discussion on Article 2.6 of the CBS Constitution. The Executive discussed the recommended changes and decided to leave Article 2.6 as is. Article 2.6 is now being presented to the membership for final comment. Please send any comments you may have to the editor at pchidwic@uoguelph.ca. The CBS Constitution will be on the website (www.bioethics.ca) for anybody interested in obtaining a copy. The proposed changes will be voted on at the next Annual General Meeting in Winnipeg, 2001.

Article 2.6 – Presently States:

2.6 The Executive Committee of the Society shall:

- (a) Alternate the Presidency between professionals in health sciences and professionals in ethics or law.
- (b) Have at least one Anglophone and one Francophone on the executive.
- (c) Have at least two professionals in ethics, one of whom may be a lawyer and one of whom must be an Aethicist@ (a professional employed to consult, research, or teach in bioethics, who has a doctorate in theology or philosophy).
- (d) Have at least one physician.
- (e) Have at least one nurse.
- (f) Have at least one graduate student/resident member in one of the disciplines related to bioethics.
- (g) Have; in addition to the five specified requirements of c, d, e, and f, additional members forming not more than a ten-member Executive Committee.

Article 2.6 – Proposed Changes:

Article 2.6: The Executive Committee shall represent the heterogeneous nature of the Society. Naming certain categories of representatives within this article is not meant to exclude from the Executive Committee those who are not named.

The Executive Committee of the Society shall:

- (a) Alternate the Presidency between professionals in health sciences and professionals in ethics and law
- (b) Have at least one Anglophone and one Francophone on the Executive
- (c) **Have at least one person from each of the following disciplines or categories who has or has had a significant involvement in teaching, research or clinical aspects of**
 - i. **Philosophy / theology**
 - ii. **Health law**
 - iii. **Medicine**
 - iv. **Nursing**
 - v. **Other health professions and the social sciences or humanities or health related research.**
- (d) Have at least one graduate student/resident member in one of the disciplines related to bioethics.
- (e) **Have; in addition to those specified in this article,** additional members forming not more than a 10 member Executive Committee

CONTACTING THE SOCIETY

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Student Representative Report

By Marie-Eve Bouthillier

Marie-Eve Bouthillier

Dear CBS students,

As the new Student Representative, it is a pleasure for me to establish this first contact with you. Firstly, I would like to say a warm hello and thank you to everyone who participated in the 12th Annual CBS Conference in Québec City, and especially to the students I had the occasion to meet. The week end was a very enriching experience both socially and with regards to the discussion and reflection on bioethics. CBS conferences provide a unique opportunity for creating ties between members and, of course, between students, of whom over fifty were present. I would like to emphasize the quality of the student presentations and congratulate the winners of the Student Abstract Competition (*see list below*).

During the Student Luncheon, Chris MacDonald, the former Student Representative, informed the group that his mandate had come to an end. As well, he mentioned that, for the first time in its history, the CBS has stipulated in its constitution that the Executive Committee must include a student member. I have been elected to fulfill this role. As a new member of the CBS and eager to take up the challenge conferred upon me, I invite you to send me your suggestions, comments and questions concerning the role of students.

In the course of discussions with several student members, I perceived a desire to improve communications between students across the country. It seems the idea of creating an e-mail network has been abandoned as a result of the lack of participation. However, it would be possible to provide a place where students could obtain information in order to contact one another. This could take the form of a Web page especially for students within the CBS site. I think it would be interesting to develop this idea further. Please do not hesitate to share your ideas with me on this topic. It is up to us to make the CBS internet network a useful resource appropriate to our needs.

Finally, I would like to invite you to send your comments regarding two particular issues. Firstly, I am currently reflecting on possible student activities for the next Annual Conference in Winnipeg. I am wondering if we should plan a discussion activity (plenary session) on a theme which concerns students specifically. Several ideas have already been suggested, such as possible career

opportunities in bioethics, and the challenges involved in university training. Secondly, I am wondering what contacts should be made with students in Winnipeg regarding social events. This second question pertains in particular to the Student Abstract Competition. The theme of the upcoming Conference is *Imagine!... Bioethics at the Beginning of the 21st Century*. I hope this will inspire many of you. I will confirm submission dates and other details at a later time.

LIST OF WINNERS (in alphabetical order)

Chantale Bouffard, Université Laval (Qc) L'impact des représentations dans la construction des normes éthiques de la génétique médicale (The impact of representation in the development of ethics norms in medical genetics)

Janneke Gradstein, Dalhousie University (N.S.) Canada in the Landscape of Two-tier Health Care

Richard Ouellet, Université Laval (Qc) Nouvelles polémiques en droit international quant au rôle de la science dans l'élaboration des normes sanitaires (Recent controversy in international law concerning the role of science in the development of sanitary norms)

Caroline Sori, University of Western Ontario The Drive to Consensus : " Groupthink " and the Research Ethics Board

Alison K. Thompson, University of Toronto (Ont.) Health Policy and the New Genetics : Ethical Issues in Consulting the Public

Kira Tomsons, Dalhousie University (N.S.) Health Care Resource Allocation : Integrating an Ethic of Care

Bryn Williams-Jones, University of British Columbia (B.C.) e-Commerce & e-Health : "Choice" in the Provision of and Access to Genetic Testing

I await your comments and suggestions.

Marie-Eve Bouthillier
Ph.D. candidate in Applied Social Sciences,
specialization in Bioethics
Université de Montréal

<bouthilm@magellan.umontreal.ca>

Limits of Confidentiality In Human Research

University of Toronto Symposium
Bernard M. Dickens

On April 28, 2000 Susan Pilon of the Ethics Unit of the Office of Research Services and Rosalind Waxman of the Research Office of the Faculty of Medicine collaborated to present a workshop on confidentiality in medical research involving human subjects. Chaired by Dr. Jeffrey Zaltzman of the medical school's Division of Nephrology and St. Michael's Hospital, the workshop was designed both to underscore the general requirement that investigators strictly protect confidentiality, but also to consider cases in which subjects' confidentiality must ethically be shared with third parties, or may even be subordinated to higher interests.

In his introductory overview, Bernard Dickens of the Faculty of Law, who chairs the Human Subjects Review Committee of the University's Office of Research Services, observed that investigators' ethical responsibility to maintain confidentiality applies to both the individual and collective or group participants in their studies, and that group consent to release from this responsibility can be difficult to obtain. It may be beneficial to members of a group to publicise that they were found to have a low incidence of an investigated disorder, for instance, but unethical thereby to imply a higher incidence in an identifiable contrasted group. Informing health service authorities of a group's significantly higher incidence may assist in diagnosing the disorder and training, placing and equipping service providers for treatment, but care is required to prevent group members' stigmatisation.

Dr. Nancy Kreiger of the medical faculty's Department of Public Health Sciences and Cancer Care Ontario considered confidentiality issues in epidemiological research. She addressed the ethics and process of approaching individuals when, under mandatory reporting laws concerning cancer cases, investigators have already learned of their identities and medical data, without their consent and often without their knowledge or recollection. The challenge is to justify an exception to the general rule that individuals should not be approached by strangers who know much of their medical histories, and to explain that consent is given at a political, legislated level rather than at the particular patient level.

Mental health research was the theme addressed by Dr. Pdraig Darby of the Department of Psychiatry, who chairs the Research Ethics Board of the Centre for Addiction and Mental Health. He considered how preservation of identities of subjects of research into the genetic basis of schizophrenia permitted both long-term follow-up care for such subjects and the offer of new therapies as they become available. This depends, however, on subjects' identities being shared with future care providers whose own identities, circumstances and potential therapies are unknown. Dr.

Darby also considered implications for research of the 1999 Supreme Court of Canada judgment in the case anonymized as *Smith v. Jones*, which set conditions under which a psychiatrist might lawfully warn police authorities that a diagnosed person was assessed to present a clear risk of causing imminent serious bodily harm to others.

Dr. Katherine Siminovitich of Mount Sinai Hospital, director of the University's Molecular Medicine Program, raised a number of further confidentiality issues in genetic research. She explained that genetic research necessarily implicates subjects' family members, and that the human genome project is driven by the need to understand, treat and prevent diseases that arise from both inheritance and environmental factors. Procurement of DNA samples and their storage and use in data banks raise critical questions of confidentiality in mass mechanised data management. The potential for DNA "fingerprinting" opens ways to identification of otherwise anonymous individual sample donors.

Issues of mandatory reporting of child abuse suspected in the course of research were addressed by Professor Denise Réaume of the Faculty of Law, who formerly chaired the OISE/Faculty of Education Ethics Review Committee. She reviewed how 1999 amendments to the provincial Child and Family Services Act had expanded legal duties to make reports to Children's Aid Societies, and addressed how potential research subjects can be informed of investigators' legal duties when such subjects, particularly parents, are asked to consent to participate in studies. She warned that investigators' suspicions may be triggered through research in which evaluation of possible child abuse is not anticipated, as well as investigations where evidence of abuse may more obviously be found, and reviewed legal sanctions for failure to report.

Dr. Shirley Lee of the medical school's Department of Family and Community Medicine and the University Health Network considered ethical conflicts that arise when health care providers are offered finders' fees to give names of their patients to other investigators whose studies the patients are eligible to enter. Such personal profit from surrender of their patients' names and confidential data is professionally considered unconscionable, and prohibited by hospital and university policies. An advantage of providing names, however, is that studies can be speeded from which patients in general and a health care provider's own patients in particular may benefit, and that suitable subjects may be identified economically, reducing study expenses and costs of resulting therapeutic products. Dr. Lee distinguished ethical payment for screening services from unethical payment for violation of confidentiality, and addressed risks that patient care may be distorted to make or keep patients eligible for studies.

Confidentiality issues in operation of the Ontario Cancer Registry were discussed by Dr. Eric Holowaty, who is Director of the Cancer Surveillance Unit in the Division of Preventive Oncology of Cancer Care Ontario, and in the Faculty of Medicine's Department of Public Health Sciences. He placed the prevailing volume of legislation and regulations on compulsory registration of cancer cases in the setting of national and international codes and guidelines, and stated the need of clearer statutes. He showed how cancer epidemiology has widened into public health surveillance, and the conflict between public dependency on accurate and complete information for health protection, and the public demand for protection of confidentiality against new data-gathering technologies that has resulted in restrictive laws. Cost-effective health care depends on access to data, which is facilitated by modern informatics, but electronic data gathering and easy internet transfers are mixed blessings.

Maureen Martell, formerly a clinical research co-ordinator at Toronto Hospital and now designing and monitoring drug studies at Pharma Medica Research Inc., a contract research organisation, addressed issues of confidentiality in pharmaceutical audit. She contrasted Phase I drug toxicity studies on single subjects, healthy volunteers who are often paid, with Phase III drug studies usually undertaken with informed, unpaid patients, and Phase IV

studies involving often anonymous data from users of marketed products. Study sponsors, usually commercial companies, expect their protocols and financial data to be confidential, but may want to audit the personal medical files of participants in studies of their investigational products. She emphasised that research data particularly of patients need to be shared among investigators and therapists, so that patients are not over-exposed to risks, and their different medications not compromise their care nor distort study outcomes.

Following the presentations, Robert Williams of the Joint Centre for Bioethics, a member of the research and bioethics committee at Scarborough Hospital, led a spirited general discussion, which included consideration of several case studies that involved issues addressed in the presentations. In conclusion, Dr. Peter A. Singer, Director of the Joint Centre for Bioethics, thanked workshop organisers, presenters and attendees, emphasising the significance of specialist and lay participation in review committees to due preservation of confidentiality, and the importance of maintaining ethical integrity in the hospital and university research enterprise.

Bernard Dickens is a law professor at the University of Toronto.

<bernard.dickens@utoronto.ca>



Assuming a Disability Perspective

Carolyn Ells

Philosophers rarely consider disability. Even in bioethics, where matters related to health receive special attention, the experience and implications of living with impairment rarely surface. Instead, an ill-defined view of the >ordinary= or >average= or >normal= person and the >ordinary= or >average= or >normal= life is typically used as the perspective from which to understand the human condition and to identify and define moral values and moral theories. John Rawls, for instance, assumes a healthy, unimpaired population when working out his theory of justice. Tom Beauchamp and James Childress make a similar assumption in their four-principles approach to biomedical ethics. They claim that by looking to the experience of Aordinary choosers≅ we should be able to develop and test a defensible theory of autonomy.¹ I suggest that this approach is wrongheaded.

Changing our perspective away from the >ordinary= person to the person with serious chronic impairment can help us to challenge and change liberal assumptions, to bring to light what is true about all of us but obscured by a liberal view. I will attempt to motivate a change of perspective, to use the experience of chronic impairment to inform and critique understandings about moral concepts and moral theories. For illustration, I consider

assuming a disability perspective to inform and critique theories of autonomy and respect for autonomy.

Those with serious chronic impairment have many more points of contact with health care services than those with acute injury or illness. Some are patients for their entire lives. Thus, the benefits and burdens of autonomy and loss of autonomy ought to be most significantly observed among people with serious chronic impairment. Attending to their experience is needed to have a full understanding of the implications of a theory of autonomy in health care.

A liberal view of the >ordinary= or >average= or >normal= person or the >ordinary= or >average= or >normal= life implies that people are independent, equally situated, beings. Holding such a view prevents us from delving deeply enough into the nature of the human condition to properly assess it. Significantly, an analysis of dependency in chronic impairment clearly illuminates the false belief that society is constituted by equally situated autonomous self-interested individuals. The experience of autonomy and loss of autonomy by those with chronic impairment helps to show that the inevitable interdependence of people is the pre-condition of moral equality in society and the pre-condition of autonomy as well.²

The experience of chronic impairment can yield important knowledge that is unavailable to those with acute illness or injury or those with no injury or illness. Those with chronic impairment may be well positioned to garner multi-faceted phenomenological and epistemic expertise, such as the understanding of their disease processes, the culture of medicine, and social mores. These understandings may bear on the nature and limits of self-determination, both generally and pertaining to health care.

Drawing on the expertise of people with chronic impairment could help us get clear about the tensions between human experience and the demands of culture (which affects what autonomy is thought to look like and what its >proper= goals should be). An adult who needs assistance to wash, eat, dress, use the toilet and so on, may notice societal disdain for dependencies of these sorts and myths about profound >independencies= of persons in general. Those who cannot rely on meeting societal expectations may notice the pervasive, assumed and accepted expectations about the body and its performance that society imposes. In these and other similar situations, those with chronic impairment may both notice and criticize aspects of the dominant culture that others in the culture may miss.³

Given their significant differences in experiences of independence, dependence, power, loss of power, health, and impairment, it is reasonable to expect that autonomous decisions may look different for people who have chronic impairment than for those without chronic impairment. Studies of quadriplegics, for example, find that as people lose bodily sensation, their bodies become largely irrelevant to them.⁴ Perhaps as the capacity to move one=s body becomes less important, the capacity for meaningful involvement in relationships may, alternatively, become an integral aspect of autonomy and one that is currently not attended to by a liberal view of autonomy. If so, the current scope of theories of autonomy may be too narrow. A theory of autonomy must, however, be inclusive of all instances of autonomy.

Liberal views of autonomy that require that autonomous persons be capable of freely acting on choices and that respect for autonomy only apply to those who are capable of so acting imply that some people with chronic impairment may not be autonomous persons and/or beings toward whom a duty to respect autonomy exists. Dependency and the limited ability to act on choices seems to preclude these possibilities. A study of the nature and scope of autonomy under conditions of chronic impairment may reveal that such views must be changed. Moreover, it may suggest that what is thought to be respect for autonomy ought to change as well.

Assuming the perspective of disability may help us to understand other moral values as well. For instance, the tendency for people with disability to rank their well-being higher than those without disability would rank well-being suggests very different understandings of the experience of disability and well-being, something that may challenge understandings of beneficence. An assessment of the experience of disability might also inform the values that should ground justice issues such as the allocation of resources. These reflections suggest that assuming a disability perspective can offer important insights for assessing moral theory.

REFERENCES

1. Beauchamp, T.L. and J.F. Childress, *Principles of Biomedical Ethics*. 4 ed. 1994, New York: Oxford University Press, p.123.
2. Kittay, E.F., *Love's Labor: Essays on Women, Equality, and Dependency*. 1999, New York: Routledge, p.50.
3. Wendell, S., *The Rejected Body: Feminist Philosophical Reflections on Disability*. 1996, New York: Routledge, p.69.
4. Murphy, R.F., *The Body Silent*. 1990, New York: W. W. Norton, p.193.

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The Paradox of "Do No Harm": Biomedical Iatrogenesis and Alternative Medicine

By Daniel Hollenberg

Statistics Canada recently revealed that approximately 1.7 million Canadians over the age of twelve reported using "alternative" or non-biomedical therapies in 1996-97.¹ A 1999 survey by the Fraser Institute reported that approximately 73% of the Canadian general public are now using some type of alternative medicine.²

"Alternative medicine" has been defined as all healing therapies that are deemed non-biomedical by the body of Western medicine, or as an "unrelated group of non-orthodox therapeutic practices, often with explanatory systems that do not follow conventional biomedical explanations".³

My main research objective was to understand how people experiencing serious chronic illness were using so-called “alternative therapies.” In addition to conventional Western medical treatment, I was interested in knowing what specific alternative therapies people with chronic illness may have been using, what they thought of these therapies, and most importantly, how they thought these therapies may have helped or hindered their illness.

As I progressed through the various “gate-keepers”, (i.e. physicians, therapists and family members) to people with chronic illness, I observed an interesting phenomenon. I observed that each individual with chronic illness at some point in their illness history had used a form of alternative or non-biomedical therapy to treat their illness. Moreover, as I began to talk with individuals using alternative therapies to treat their chronic symptoms, I noticed that in some cases these individuals were rejecting certain conventional medical treatments, such as drugs, because these drugs in their opinion had caused them more harm than good.

For example, Doug in his search for effective treatment for his chronic brain/head injury had experienced severe harm caused by various drugs which included the cessation of healthy bowel elimination, extreme fatigue, and a heart attack. Greg, a long-term HIV/AIDS survivor with chronic symptoms had made a conscious and educated decision to completely avoid HIV drug-treatment based on his belief that such drugs were toxic and side-effects harmful and that these factors contributed to early deaths of close friends. Ben, also diagnosed with HIV, was using alternative therapies to combat the deleterious side effects of HIV drug treatment which included severe nausea and anxiety. Most importantly, each individual claimed they had experienced powerful and non-toxic healing effects from various alternative therapies. These therapies ranged from extensive Naturopathic program to single therapies such as homeopathy and herbal therapy.

I felt it important to look further into the seemingly paradoxical observation, namely, that particular conventional medical treatments appeared to be causing more harm than good to certain patients. My inquiry began with the 4th century BC oath of Hippocrates which states that medicine should be based on those actions which “*help or at least to do no harm*”.⁴ Yet, it is apparent that even in the 18th century BC (well before the Greek era), penalties for harmful physician error were noted in the Code of Hammurabi.⁵ The Greeks later called this harm “iatrogenesis”, meaning physician-caused.⁶

Looking at the 19th -century AD rise of Western medicine as a profession, it appears that the amount of harm caused to patients by the medicines they were prescribed far

outweighed any healing benefit they received from these treatments.⁷ Nineteenth-century patients were lucky to survive medical treatments in the form of toxic purgatives such as calomel (mercurous chloride) and other heavy metals,⁸ or misguided surgical operations such as ovariectomy.⁹

Examining the last one hundred years of medicine there have been many examples of increased harm caused to patients by medical treatments or procedures. These examples have included, among many others, the 1961 disaster of the effects of the sleeping pill Thalidomide resulting in 5 000 infants born with deformed or missing limbs. As well, the 1974 United States Senate report states that 2.4 million unnecessary operations were performed each year causing 11 900 deaths per year.¹⁰ The 1991 Harvard Medical Practice Study concluded that harmful medical incidents affect more than 1.3 million hospitalized patients annually in the United States.¹¹ A recent study reported the death of up to 106 000 hospitalized patients in 1994 from adverse drug reactions (ADRs) in the United States.¹² While still debatable, a parallel study indicated that as many as 10 000 Canadians could be dying from ADRs each year.¹³ Between 5% and 13% of all hospital admissions are now attributed to iatrogenic medical treatments or diagnoses.¹⁴

It appears there is a paradox here in the medical tenet to “do no harm”, a “self-contradictory statement that at first seems true.”¹⁵ While countless physicians abide by this basic tenant of the Hippocratic Oath to “do no harm”, the entire history of medicine has been marked by episodes of harm caused to patients by medicine.¹⁶ It is not the Hippocratic Oath that has failed medicine. Rather, it is medicine that has failed part of the Hippocratic Oath. Today, the intent not to harm the patient, or non-maleficence, has been overridden by the intent to “do good”, or beneficence, thus justifying any harm caused to patients by the treatments they receive.¹⁴ Despite claims to the contrary, pre-market testing for new pharmaceuticals is increasingly being shortened, resulting in the early release of drugs into the consumer market before the long-term adverse effects are known in representative populations.¹⁷ While biomedicine has achieved many successes benefiting humankind,¹⁸ the failure of biomedicine to adhere to the tenet of “do no harm”, and its lack of recognition and prescription of less-harmful and equally beneficial alternative therapies,¹⁹ remains a paradoxical blemish on the face of medicine.

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NOTES

1. Statistics Canada. (1999). *Statistical Report on the Health of Canadians*. Ottawa: Health Canada.
2. Ramsay, C., Walker, M., Alexander, J. (1999). *Alternative Medicine in Canada: Use and Public Attitudes*. *Public Policy Sources Error! Reference source not found.*
3. National Institutes of Health. Web Page. (1996-1999).
4. Epidemics I. (1923-1988). In: *Hippocrates*. (Trans., WHS Jones. Loeb Classical Library). Cambridge, MA: Harvard University Press, vol. X:165.
5. 'Medicine' *Encyclopedia Britannica*. (1988). Chicago: Encyclopedia Britannica, vol.23:886.
6. Illich, I. (1976). *Limits to Medicine—Medical Nemesis: The Expropriation of Health*. London: Marion Boyars.
7. Hamowy, R. (1984). *Canadian Medicine: A Study in Restricted Entry*. Canada: The Fraser Institute.
8. Davies, D.M. (1991). *Textbook of Adverse Drug Reactions*. 4th edn. Oxford: Oxford University Press.
9. Mitchinson, W. (1991). *The Nature of Their Bodies: Women and Their Doctors in Victorian Canada*. Toronto: University of Toronto Press.
10. In: Porter, R. (1997). *The Greatest Benefit to Mankind: A Medical History of Humanity*. New York, London: W.W. Norton & Company:460,687.
11. Brennan, T.A., Leape, L.L., Laird, N.M. (1991). Incidence of adverse events and negligence in hospitalized patients. Results of the Harvard Medical Practice Study I. *New England Journal of Medicine* 324(6):370-6.
12. In: Lazarou, J., Pomeranz, B.H., Corey, P.N. (1998). Incidence of adverse drug reactions in hospitalized patients: A meta-analysis of prospective studies. *Journal of the American Medical Association* (279):1200-1205.
13. Lazarou, J., Pomeranz, B.H., Corey, P.N. (1998). Incidence of adverse drug reactions in hospitalized patients: A meta-analysis of prospective studies. *Journal of the American Medical Association* (279):1200-1205.
14. Sharpe, V.A., Faden, A.I. (1998). *Medical Harm: Historical, Conceptual, and Ethical Dimensions of Iatrogenic Illness*. Cambridge: Cambridge University Press:242.
15. Merriam-Webster. (1988). *Webster's Ninth New Collegiate Dictionary*. Springfield, Mass.: Thomas Allen & Son Limited.
16. The term "medicine" used here refers to the profession, discipline and practice of medicine, including related biomedical research, however, it is recognized that not all aspects of medicine are iatrogenic.
17. Friedman, M.A., Woodcock, J., Lumpkin, M.M., Shuren, J.E., Hass, A.E., Thompson, L.J. (1999). The safety of newly approved medicines: Do recent market removals mean there is a problem? *Journal of the American Medical Association* 281(18):1728-1734.
18. Commonly noted examples of medical successes include the extension of the human life-span (however, the exact cause still remains debatable), the early twentieth-century development of germ theory, anaesthetic and asepsis, vaccines such as for Polio and Smallpox, and recent advances in surgery, neurology, and emergency medicine.
19. Alternative therapies, generally, are known to have great success in the treatment of chronic illness. Compared to the history of biomedical iatrogenesis, alternative therapies are significantly less harmful to patients, however, even improperly prescribed alternative therapies can harm the patient. The soon-to-be- resolved lack of regulation of some alternative therapies (however, many (e.g. Naturopathy) are already regulated by their own policing bodies), such as herbs, does not necessarily mean they are ineffective or inherently iatrogenic in nature.

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