

18th Annual
Canadian Bioethics Society Conference
May 30 – June 1, 2007

3rd International
Conference on Clinical Ethics Consultation
June 1 – June 3, 2007



University of Toronto
Joint Centre for Bioethics

Ethics Matters

Joint Ethics Conference – Toronto, Ontario



L'éthique, c'est important

une conférence conjointe en éthique – Toronto, Ontario

18^{ième} conférence annuelle
Société canadienne de bioéthique
du 30 mai au 1^{er} juin 2007

3^{ième} conférence internationale
sur l'éthique clinique et la consultation
du 1^{er} juin au 3 juin 2007

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Letters of Welcome / Lettres d'accueil

Message of Welcome from Director, Joint Centre for Bioethics

As Director of the University of Toronto Joint Centre for Bioethics (JCB), it is a sincere pleasure to welcome all participants and speakers to the 2007 Joint Ethics Conference, a conference of the 18th Canadian Bioethics Society and 3rd International Conference on Clinical Ethics and Consultation. It is my feeling that this conference represents the beginning of a new era in Bioethics worldwide—one where those in the field of bioethics remember and respect the inherent complexity of the field; the breathtaking scope of issues encountered and the diverse methodologies and discourses employed to understand them. There is also a recognition of the essential interdependence of the interdisciplinary and inter-professional roots of bioethics. I also sense a commitment to a new generation of bioethics scholars and practitioners. This conference is evidence of the profoundly enriching context of international collaboration. It is the effort of each of us in this collaboration that will truly show that ethics matters.

I would like to take this opportunity to thank the steering committee and the other program organizers for all their hard work and commitment to the preparation of this conference. As anyone knows who has prepared for such an event it is a result of the efforts of many people at many different places along the way who contribute long hours, dedication and ingenuity. Words are insufficient to express my gratitude. I would also like to thank the Canadian Bioethics Society and its executive, along with George Agich and Stella Reiter Theil (the founders of the International Clinical Ethics Conference) for their ongoing commitment to these unique conferences that raise bioethics issues worldwide. Our ability to collaborate this year was a great privilege and opportunity. I would also like to thank the impressive cadre of plenary speakers who have agreed to speak at this conference as well as the 190 concurrent speakers that will speak across the five days of this conference.

Enjoy Toronto!

Best wishes,

Ross Upshur

Message du directeur du Joint Centre for Bioethics

En tant que directeur du *Joint Centre for Bioethics* de l'Université de Toronto, il me fait plaisir de souhaiter la bienvenue à tou(te)s les participant(e)s et les présentateur(trice)s à la conférence conjointe en éthique, regroupant la 18^{ème} conférence annuelle de la Société canadienne de bioéthique et la 3^{ème} conférence internationale sur l'éthique clinique et la consultation. J'ai le pressentiment que cette conférence constituera le début d'une nouvelle ère pour la bioéthique à travers le monde – une conférence où les spécialistes du domaine embrassent toute sa complexité : du large spectre d'enjeux qui la composent aux divers discours et méthodologies utilisés pour la comprendre. C'est également à travers la reconnaissance de son caractère interdisciplinaire et inter-professionnel, toujours en interdépendance depuis l'origine de la bioéthique. Je constate aussi l'engagement d'une nouvelle génération de chercheurs et de praticiens. Cette conférence confirme la profondeur et la richesse de contenu que produit la collaboration internationale. C'est grâce à l'effort de tous et chacun, au sein de cette collaboration, que nous démontrerons que l'éthique, c'est important.

Je profite de l'occasion pour remercier le comité directeur et les autres organisateurs pour leur excellent travail et pour leur engagement dans la préparation de cette conférence. Tous ceux et celles qui ont déjà organisé un tel événement savent que le résultat n'est possible qu'avec l'effort de plusieurs personnes, dans différents endroits, pendant de nombreuses heures, avec plus qu'un soupçon de dévouement et d'ingéniosité. Les mots me manquent pour exprimer ma gratitude à leur égard. Je voudrais aussi remercier la Société canadienne de bioéthique et son comité exécutif, George Agich et Stella Reiter-Theill (co-fondateurs des conférences internationales en éthique clinique) pour leur engagement sans fin à ces conférences, qui soulèvent des enjeux éthiques mondiaux. Notre capacité à collaborer cette année a été un grand privilège et une occasion unique. Je désire aussi remercier l'impressionnant corpus de conférenciers qui ont accepté de présenter à cette conférence, de même que les 190 présentateurs des séances simultanées qui partageront leurs travaux au cours des cinq jours de la conférence.

Amusez-vous bien à Toronto!

Meilleurs vœux,

Ross Upshur

Letters of Welcome / Lettres d'accueil

Letter of Welcome from CBS President

As President of the Canadian Bioethics Society, it is an honour for me to welcome you to our 18th annual conference.

This year, we have the privilege of holding our conference together with the 3rd *International Conference on Clinical Ethics and Consultation*. Speaking for the executive committee, I would like to give a warm thank you to our Toronto colleagues who have generously agreed to take on this imposing challenge.

This year is very important for our society. We will present, during our annual general meeting, the results of discussions and meetings on the direction of the society for the next decade. This exercise is crucial. As the theme of the conference reminds us, "Ethics Matters", it is essential for our society to support in a creative manner our commitment to this field. Therefore, I invite all of you to the general meeting and ask that you participate to the decision-making that will shape our future as a moral community.

Have a good conference!

Bernard Keating, Ph.D.

Welcome Students!

It is both an honour and a pleasure to welcome you to Toronto! It is my hope that you enjoy your time at the conference and in the city. There is a lot going on for students at this conference that you should be aware of. Wednesday night, we are having our customary *Student Meet & Greet* -- join us in the hotel restaurant! Thursday morning, we have our *Student Annual General Meeting* -- come out and have your voice heard on important student issues. Thursday night, some more social time at the *Student Dinner*. Friday morning is our first ever *Student Mentor Breakfast* -- it's not too late to be involved. Let the registration desk know you would like to participate -- you will not be disappointed at this intimate learning and networking opportunity.

I am thrilled to have the highest number of student delegates ever at a CBS/SCB Conference -- the student body keeps growing and expanding ... we are the future generation of bioethics! Don't forget to check out your fellow students in their presentations scheduled throughout the conference! This conference is truly unique as we have joined forces with the 3rd International

Lettre de bienvenue du président de la SCB

C'est un honneur pour moi de vous souhaiter, à titre de président de la Société canadienne de bioéthique, la bienvenue à notre 18^{ième} conférence annuelle.

Nous avons, cette année, le privilège de tenir notre colloque conjointement à la 3^{ième} *Conférence internationale sur l'éthique clinique et la consultation*. Je me fais le porte-parole de l'Exécutif pour remercier chaleureusement nos collègues de Toronto qui ont généreusement accepté de relever cet imposant défi.

Pour notre société, cette année est charnière. Nous présenterons en Assemblée générale annuelle les conclusions qui se dégagent de la consultation à propos des orientations pour la prochaine décennie.

L'exercice est capital. En effet, si comme le thème de la conférence le souligne, «L'éthique, c'est important», il est essentiel que votre société supporte de façon créative votre engagement dans ce domaine. Je vous invite donc à venir, en très grand nombre, à l'assemblée pour participer aux décisions qui construiront notre avenir comme communauté morale.

Bonne conférence!

Bernard Keating Ph.D.

Bienvenue aux étudiant(e)s!

C'est à la fois un honneur et un plaisir de vous souhaiter la bienvenue à Toronto. J'espère que vous aimerez la conférence et la ville de Toronto. Il y a plusieurs activités qui sont prévues pour les étudiant(e)s au cours de la conférence. Voici ce que vous devez savoir : mercredi soir, nous avons notre traditionnel rendez-vous d'accueil *Meet & Greet*. Venez nous rencontrer au restaurant de l'hôtel. Jeudi matin, nous avons l'assemblée générale annuelle des étudiant(e)s. Venez partager vos opinions sur de nombreux sujets d'intérêt pour les étudiants de la SCB. Jeudi soir, une autre activité sociale : le souper des étudiant(e)s. Vendredi matin, il y a le petit-déjeuner étudiant avec mentors – il n'est pas trop tard pour vous inscrire. Au comptoir de l'inscription, dites que vous êtes intéressé(e) à participer. Vous ne serez pas déçu(e)s d'avoir cette occasion unique de créer des contacts.

Je suis heureuse de vous annoncer que nous avons le plus grand nombre d'étudiant(e)s délégué(e)s jamais vu à une conférence de la SCB. Le nombre d'étudiant(e)s ne cesse de croître. Nous sommes la future génération

Letters of Welcome / Lettres d'accueil

Conference on Clinical Ethics and Consultation! Take advantage of the stimulating discussion, the diversity of keynote speakers and the networking opportunities.

Lastly, and most importantly a note of thanks to the many students across our great country who pulled together to make this conference a guaranteed success! A special extended thanks to student committee chairs Robin Hayeems, Pam Kolopack and Lise Levesque! Once again – Welcome to Toronto and Welcome to the Conference. Get your feet wet – enjoy the city's distinctive flare, meet new people, network with your fellow delegates, and soak up all this conference has to offer!

... Oh and stay tuned -- by the end of this conference, we will have a *brand new* student executive member-at-large! My term has come to an end. Thank you to everyone who has made my journey as student executive representative as invigorating and incredible as it has been. I look forward to watching our society grow.

Shannon Madden

Canadian Bioethics Society,
Student Representative

Student University Representatives

Holly Longstaff, Morgan Fankboner, Amy Middleton, Nina Preto, Shail Rawal, Erin McFadden, Nir Lipsman, Diego Silva, Leah State, Emily Austin, Shawna Gutfreund, Gillian Nycum, Anais Rameau, Meredith Schwartz, Ainsley Donohue, Patrick Bedford, Lorelei Newton, Shannon Madden, Josee Dufour, Nathalie Egalite, Lisa Schultz, Susan Ronald

de la bioéthique! N'oubliez pas d'encourager vos confrères et consoeurs étudiant(e)s en assistant à leurs présentations tout au long de la conférence. Cette conférence est vraiment unique puisque nous avons joint nos forces avec la 3^{ième} conférence internationale sur l'éthique clinique et la consultation. Profitez de toutes ces discussions stimulantes, de la richesse des conférenciers invités et des occasions de réseautage.

Enfin, je désire remercier tous les étudiant(e)s de partout à travers le Canada qui ont uni leurs efforts pour garantir le succès de cette conférence. Un merci tout spécial aux présidents du comité des étudiant(e)s: Robin Hayeems, Pam Kolopack et Lise Lévesque! Encore une fois, Bienvenue à Toronto! Et Bienvenue à la conférence! Mouillez-vous! Participez aux activités, rencontrez de nouvelles personnes, découvrez la ville, créez des contacts avec vos collègues étudiant(e)s, profitez de tout ce que cette conférence peut offrir!

Restez attentifs, d'ici la fin de cette conférence, nous aurons un nouveau ou une nouvelle représentant(e) des étudiant(e)s puisque je termine mon mandat. Merci à tous ceux et celles qui ont fait que mon expérience à titre de représentante des étudiant(e)s ait été des plus incroyables et des plus stimulantes. J'espère de tout cœur voir la SCB continuer de croître.

Shannon Madden

Société canadienne de bioéthique,
Représentante des étudiant(e)s

Représentants étudiants des Universités

Holly Longstaff, Morgan Fankboner, Amy Middleton, Nina Preto, Shail Rawal, Erin McFadden, Nir Lipsman, Diego Silva, Leah State, Emily Austin, Shawna Gutfreund, Gillian Nycum, Anais Rameau, Meredith Schwartz, Ainsley Donohue, Patrick Bedford, Lorelei Newton, Shannon Madden, Josee Dufour, Nathalie Egalite, Lisa Schultz, Susan Ronald

Letters of Welcome / Lettres d'accueil

Welcome Message from International Conference of Clinical Ethics Consultation Founders

As founders of the International Conference of Clinical Ethics Consultation series, we are delighted to welcome you to Toronto for the 3rd International Conference. At the same time, we want to thank and congratulate our colleagues in the Joint Centre for Bioethics of the University of Toronto for hosting the third conference. Their effort and skill in organizing this meeting in conjunction with the Canadian Bioethics Society (CBS) is evident in the high quality of the program. The linkage with CBS reminds us that Canada has long been a fertile field for clinical ethics and that the Joint Centre is one of its pioneering programs.

You may have noticed that this Conference is designated, "Clinical Ethics and Consultation." This title reflects the evolving approaches to establish ethics support services in the clinical contexts in addition to consultation. In addition, it is increasingly important to encourage research on clinical ethics.

Since the first Conference held in 2003 in Cleveland, Ohio and the second held in 2005 in Basel, Switzerland, *you* - the participants - have shown that clinical ethics is less a unitary movement than a complex field of inquiry and practice. While clinical ethics is most lively and active in North America and Europe, it is expanding beyond these areas as well. We have seen, furthermore, that there is a plethora of original and important work being undertaken around the world to improve patient care and professional relations. This third conference expands the program content of the first meetings in terms of geography, health care systems, and topics.

Even in times where health care and university budgets are restricted, you are finding ways to continue to develop and extend clinical ethics services into new settings with much enthusiasm and creativity. We look forward to the program and to our continuing conversations with you about clinical ethics and consultation in the days and, hopefully, years ahead.

Sincerely yours,

George J. Agich, Ph.D.
Professor of Philosophy
Director, BGeXperience Program
Bowling Green State University

Stella Reiter-Theil, Ph.D., Dipl.-Psych
ANNE FRANK Professor and Director
Institute for Applied Ethics and Medical Ethics
University of Basel, Switzerland

Message de bienvenue des fondateurs de la conférence internationale sur l'éthique clinique et la consultation

En tant que fondateurs de la série de conférences internationales sur l'éthique clinique et la consultation, nous sommes enchantés de vous souhaiter la bienvenue à Toronto. Par la même occasion, nous voulons transmettre nos remerciements et nos félicitations à nos collègues du *Joint Centre for Bioethics* de l'Université de Toronto, qui accueillent cette troisième conférence. Leurs efforts et leurs grandes capacités d'organisation, en collaboration avec la Société canadienne de bioéthique (SCB), transparaissent dans la qualité du programme. La liaison avec la SCB nous rappelle que le Canada est un terreau fertile pour l'éthique clinique, et que le *Joint Centre for Bioethics* est l'un des programmes pionniers dans ce domaine.

Vous avez sans doute remarqué que cette conférence s'intitule «Éthique clinique et Consultation». Ce titre reflète l'évolution des approches dans l'élaboration de services de soutien et de consultation en éthique dans les contextes cliniques. Ajoutons qu'il est de plus en plus important d'encourager la recherche en éthique clinique.

La première conférence a eu lieu en 2003 à Cleveland, en Ohio. La deuxième s'est tenue en 2005, à Bâle, en Suisse. Mais c'est vous, les participant(e)s, qui avez su montrer que l'éthique clinique n'est pas un mouvement unitaire, mais un champ complexe de recherches et de pratiques. Même si l'éthique clinique est plus présente en Amérique du Nord et en Europe, elle semble prendre de plus en plus de place ailleurs dans le monde. Nous avons constaté qu'il existe une multitude de travaux originaux qui sont entrepris à travers le monde pour améliorer les soins aux patients et les relations professionnelles. Cette troisième conférence a un contenu élargi, en termes de diversité géographique, de systèmes de soins de santé et de sujets d'intérêt.

Même en ces moments de restrictions budgétaires, tant pour les universités que pour les organisations de santé, vous avez trouvé des façons de continuer le développement et l'expansion des services d'éthique clinique dans différents contextes, avec beaucoup de créativité et d'enthousiasme. Nous avons très hâte de découvrir le programme, et de poursuivre avec vous ce dialogue sur l'éthique clinique et la consultation, et cela, pour les jours et les années à venir.

Cordialement,

George J. Agich, Ph.D.
Professeur de philosophie
Directeur, Programme BGeXperience
Université Bowling Green State

Stella Reiter-Theil, Ph.D., Dipl.-Psych
Professeure financée par le Fonds ANNE FRANK et Directrice
Institut d'éthique appliquée et d'éthique médicale
Université de Bâle, Suisse

Letters of Welcome / Lettres d'accueil

Message from the Steering Committee

On behalf of the Steering Committee for the Joint Ethics Conference (18th Canadian Bioethics Society and the 3rd International Conference on Clinical Ethics Consultation), we would like to welcome you to Toronto. The theme for this conference—Ethics Matters—suggests that this field of ethics in which we are all involved has an important contribution to make to global society. We are here together at this conference to discover what that contribution might be with scholars, professionals, and students from all corners of the planet. This theme also suggests that we are all in this endeavor together—while at the same time embracing the widespread diversity across professions, educational backgrounds, stages of development, disciplines, methodologies and cultures that is inherent in the field of bioethics—all with an eye to contributing something significant to ethical life on this planet. We sincerely hope that you will enjoy your time at this conference through intellectual stimulation, good food and many social and networking opportunities.

We would like to say a few 'thank yous' to all of the people that have made this conference possible. First to the Canadian Bioethics Society and George Agich and Stella Reiter-Theill (founders of the international clinical ethics conference) for establishing these conferences. Secondly to the University of Toronto Joint Centre for Bioethics (JCB) for hosting this conference, its many JCB conference chairs and committee members and volunteers who worked very hard to make this conference a reality. A special thanks goes out to the members of the international conference advisory board who provided us with guidance along the way, as well as to the scientific review committee who reviewed the large number of abstracts we received and helped put our program together. We would also like to thank the Toronto Marriott Downtown Hotel and staff for providing us with the friendly setting for this meeting, as well as the various vendors, printers, interpreters, and translators who each did their part to contribute to the success of this conference. Of course we owe a debt of gratitude to the plenary speakers, concurrent session speakers, poster participants and postcard exhibitors who will frame this conference in its content, as well as to all of the participants. We are so excited that participants and speakers are joining us from literally all around the world—with representatives from every continent except Antarctica, as far away as New Zealand, Cameroon, India, Taiwan, Europe, South America, and North America.

We hope while you are in Toronto you will take part in the many diverse social and cultural opportunities that

Message du comité directeur

Au nom du Comité directeur de la conférence conjointe en éthique (18^{ième} conférence annuelle de la Société canadienne de bioéthique et 3^{ième} conférence internationale sur l'éthique clinique et la consultation), nous vous souhaitons la bienvenue à Toronto. Le thème de cette conférence «L'éthique, c'est important» suggère que ce champ de réflexion, dont nous faisons partie, permet de contribuer à faire une meilleure société. Nous sommes ici rassemblés à cette conférence pour découvrir ce que peut être cette contribution à travers la pensée de chercheurs, de professionnels et d'étudiants en provenance des quatre coins du monde. Ce thème suggère également que nous sommes tous réunis dans cette entreprise - tout en reconnaissant la diversité des professions, des formations, des stades de développement, des disciplines, des méthodologies et des cultures qui sont inhérents au champ de la bioéthique- avec l'intention de contribuer de façon significative à la vie éthique sur cette planète. Nous espérons que vous saurez profiter de la stimulation intellectuelle, de la bonne bouffe et des nombreuses activités sociales qu'offre cette conférence.

Nous aimerions dire quelques «Merci» à tous ceux et celles qui ont rendu cette conférence possible. Premièrement, la Société canadienne de bioéthique, George Agich et Stella Reiter-Theill (co-fondateurs des conférences internationales en éthique clinique) pour la mise sur pied de cette conférence. Deuxièmement, le *Joint Centre for Bioethics* (JCB) de l'Université de Toronto, qui accueille cette conférence, c'est-à-dire ses nombreux présidents, membres de comités et bénévoles qui ont travaillé fort pour que cette conférence se réalise. Un merci tout spécial va aux membres du comité consultatif international qui nous ont guidé pour l'organisation, et au comité scientifique, qui a évalué un très grand nombre de résumés, et qui a aidé à mettre le programme de la conférence en place. Nous aimerions aussi remercier le *Toronto Marriott Downtown Hotel* et ses employés qui nous ont très gentiment fourni le lieu et les moyens nécessaires à la mise en place de la conférence, ainsi que les différents fournisseurs, imprimeurs, interprètes et traducteurs qui ont aussi contribué au succès de cette conférence. Bien entendu, nous témoignons toute notre gratitude aux conférenciers invités, aux différents présentateurs des sessions simultanées, des affiches et des cartes postales, qui façonneront le contenu de cette conférence, de même que tous les participants. Nous accueillons avec enthousiasme la venue des participants et des conférenciers, qui nous arrivent de partout à travers le monde - avec des représentants de chaque continent sauf l'Antarctique, de la Nouvelle-Zélande, du Cameroun, de l'Inde, de Taiwan, d'Europe, d'Amérique du Sud et du Nord.

Conference Committees / Comités de la conférence

this city has to offer, including the conference dinner on Friday night at the CN Tower—a Toronto landmark. We have provided you with some other dining suggestions, as well as identified some cultural experiences that may interest you—a wonderful play, a concert, or a Blue Jay's baseball game perhaps?

Enjoy your time in Toronto,

The Joint Conference Steering Committee

Christine Harrison, Brenda Knowles and Sue MacRae

Nous espérons que vous participerez aux nombreuses activités sociales et culturelles qu'offre la ville de Toronto, y compris le souper à la Tour du CN, point d'intérêt de la ville de Toronto. Nous vous avons également suggéré d'autres endroits intéressants pour sortir, manger ou pour faire une sortie culturelle- une pièce de théâtre, un concert, ou pourquoi pas une joute de baseball ?

Profitez bien de votre séjour à Toronto,

Le comité directeur de la conférence conjointe

Christine Harrison, Brenda Knowles et Sue MacRae

PLANNING COMMITTEE

The Planning Committee gratefully acknowledges contributions by the following:

Steering Committee

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Sue MacRae, RN

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Kyle Anstey, MBioeth PhD

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Shannon Madden

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Le comité organisateur remercie chaleureusement les personnes suivantes:

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Sue MacRae, Inf. aut.

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Toronto, Ontario

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Kyle Anstey, MBioeth, Ph.D.

Boursier en éthique clinique
University of Toronto Joint Centre for Bioethics
Toronto, Ontario

Shannon Madden

Représentante des étudiants, Société canadienne de bioéthique, Programme de collaboration étudiante,
University of Toronto Joint Centre for Bioethics

Conference Committees / Comités de la conférence

Hazel Markwell, DTh PhD

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University of Toronto Joint Centre for Bioethics
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Abstract Review Process:

Approximately 450 abstracts were submitted for review. Each abstract was blindly reviewed by two members of the Scientific Review Committee (members listed below). As much as possible, abstracts were reviewed by individuals with relevant expertise. Decisions were based on the ratings and comments of reviewers. Because of the high number of abstracts received, only one abstract per first author was accepted. We greatly appreciate the efforts made by both those who submitted and by those who reviewed the high quality abstracts we received.

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Nous avons reçu environ 450 résumés. Chaque résumé, préalablement dénominalisé, a été évalué par deux évaluateurs du comité scientifique (voir la liste des membres ci-dessous). Autant que possible, les résumés ont été évalués par des personnes possédant une expertise en lien avec le sujet. Toutes les décisions ont été prises en fonction des évaluations et des commentaires des évaluateurs. Si vous avez soumis plus d'un résumé, nous avons dû en choisir qu'un seul, vu le nombre important de soumissions que nous avons reçues. Nous sommes très reconnaissants envers le précieux travail des évaluateurs et envers tous ceux et celles qui nous ont envoyé des résumés de très grande qualité.

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PROGRAM HIGHLIGHTS



POINTS SAILLANTS DU PROGRAMME

CBS Pre-Conferences / Préconférences de la SCB

GLOBAL HEALTH & ETHICS

Date: May 30, 2007

Time: 8:30 a.m. to 4:15 p.m.

Location: Munk Centre for International Studies, Vivian and David Campbell Conference Facility

Co-hosts: Canadian Institutes of Health Research & Network for Health in an Unequal World: Global Ethics & Policy Choices

This pre-conference is designed to help people who want to include ethical issues about global health in their teaching; conduct research and write about ethical issues in global health; and take appropriate action in response to health inequities.

CHILDREN'S AND ADOLESCENTS' PARTICIPATION IN DECISION MAKING: ETHICAL AND DEVELOPMENTAL CONSIDERATIONS

Date: May 30, 2007

Time: 8:15 a.m. to 5:00 p.m.

Location: The Hospital for Sick Children

Hosts: Bioethics Department, The Hospital for Sick Children, Toronto, Ontario, Canada

At the conclusion of this conference participants should be able to identify ethical and developmental concepts that support the inclusion of children and adolescents in decision-making about their healthcare, as well as challenges and cautions that should be taken into consideration.

SANTÉ DANS LE MONDE ET ÉTHIQUE

Date: 30 mai 2007

Heure : 8h30 à 16h15

Lieu: Munk Centre for International Studies, Vivian and David Campbell Conference Facility

Présentée par: Instituts de recherche en santé du Canada & Réseau pour la santé dans un monde inégal : Éthique mondiale et choix politiques

Cette préconférence a été mise sur pied pour aider les personnes désirant inclure dans leurs enseignements les aspects éthiques en santé mondiale, mener des recherches et écrire sur les aspects éthiques en santé mondiale, et développer des actions adéquates pour réduire les inégalités.

LA PARTICIPATION DES ENFANTS ET DES ADOLESCENTS À LA PRISE DE DÉCISION: CONSIDÉRATIONS ÉTHIQUES ET DÉVELOPPEMENTALES

Date: 30 mai 2007

Heure: 8h15 à 17h

Lieu: The Hospital for Sick Children

Hôte: Département de bioéthique, The Hospital for Sick Children, Toronto, Ontario, Canada

À la fin de cette conférence, les participants seront en mesure d'identifier les concepts éthiques et développementaux en faveur de l'inclusion des enfants et des adolescents dans la prise de décision à l'égard des soins, de même que les défis qu'elle pose et la prudence qu'elle requiert.

Plenary Speakers / Présentateurs des séances plénières

ASSOCIATED MEDICAL SERVICES / CANADIAN BIOETHICS SOCIETY LECTURE*

Date: Wednesday, May 30, 2007 – 7:00 to 8:30 p.m.

Speaker: Michael Ignatieff

* *The speaker will present in both English and French.*

The AMS/CBS Lecture is an endowed annual lecture held in conjunction with the Canadian Bioethics Society and sponsored by Associated Medical Services, Inc. Associated Medical Services, Inc. (AMS) was established in 1937 by Dr. Jason Hannah as a pioneer prepaid not-for-profit health care organization in Ontario. With the advent of medicare AMS became a charitable organization supporting innovations in academic medicine and health services, specifically the history of medicine and health care, as well as innovations in health professional education and bioethics. This year's AMS/CBS Lecture will be given by Michael Ignatieff.



Michael Ignatieff is the Deputy Leader of the Liberal Party of Canada and Member of Parliament for Etobicoke Lakeshore. Born in Toronto and educated at Trinity College, University of Toronto, he gained a doctorate in history at Harvard in 1976. He is the author of 15 fiction and non-fiction books which have been translated into twelve languages. He holds honorary degrees from 7 universities. He has won the Governor Generals

Award for Non-Fiction, the Heinemann Prize, the Lionel Gelber Prize, The Gemini Award, the Hannah Arendt Prize and a number of other awards for his writing. He was short-listed for the Booker Prize for his novel, *Scar Tissue*.

He has taught at the University of British Columbia, Cambridge University, the London School of Economics and between 2000 and 2005 was Professor of Human Rights and Director of the Carr Center for Human Rights Policy at the Kennedy School of Government, Harvard University. He has also worked in journalism and broadcasting, having begun his career as a staff writer at *The Globe and Mail*. He has hosted programs on the CBC, TVO, BBC and Britain's Channel 4, and was a frequent contributor to *The Observer*, *The New Yorker* and *The New York Times Magazine*. In 2000, he delivered the Massey Lectures for CBC Radio, entitled

CONFÉRENCE ASSOCIATED MEDICAL SERVICES / SOCIÉTÉ CANADIENNE DE BIOÉTHIQUE*

Date: mercredi, 30 mai 2007, de 19h à 20h30

Présentateur: Michael Ignatieff

* *Le présentateur parlera en français et en anglais.*

La conférence AMS/SCB est une conférence annuelle, rendue possible grâce à la SCB et au financement d'AMS Inc. L'organisme AMS Inc. a été fondé en 1937, par Dr. Jason Hannah. Cet organisme sans but lucratif, qui offrait un régime conventionnel de soins médicaux, a été l'un des premiers du genre en Ontario. Avec la création du régime d'assurance maladie, AMS Inc. est devenu un organisme de charité permettant de financer des innovations dans le domaine de la recherche médicale et des soins de santé, plus particulièrement sur des sujets touchant l'histoire de la médecine et des soins de santé, la formation professionnelle et la bioéthique. Cette année, la conférence AMS/SCB sera donnée par Michael Ignatieff.

Michael Ignatieff est le leader adjoint du Parti libéral du Canada et député de la circonscription d'Etobicoke Lakeshore. Né à Toronto, il a étudié au Trinity College de l'Université de Toronto. Il a obtenu son doctorat en histoire en 1976 à l'Université Harvard. Il est l'auteur de 15 livres, (ouvrages scientifiques et romans), qui ont été traduits en 12 langues. Il a reçu des titres honorifiques de plus de sept universités. Il a remporté le prix littéraire du Gouverneur général (ouvrage documentaire), le prix Heinemann, le prix Lionel Gelber, le prix Gemini, le prix Hannah Arendt et de nombreux autres prix pour ses livres. Michael a été finaliste du prix Booker pour son roman *Scar Tissue* (1993).

Il a enseigné à l'Université de la Colombie-Britannique, à Cambridge, à la London School of Economics, et de 2000 à 2005, il a été professeur en droits humains et directeur du Carr Center for Human Rights Policy à la Kennedy School of Government de l'Université Harvard. Michael a aussi travaillé comme journaliste, dans la presse écrite, à la télévision et à la radio. Il a commencé sa carrière au *Globe and Mail*. Il a ensuite été commentateur pour des émissions de la CBC, TVO, BBC et le Britain's Channel 4. De plus, il a souvent écrit dans *The Observer*, *The New Yorker* et *The New York Times Magazine*. En 2000, il a donné les Massey Lectures, intitulées «The Rights Revolution», pour la radio anglaise de radio Canada (CBC).

Plenary Speakers / Présentateurs des séances plénières

The Rights Revolution.

In 2001, he was the Canadian representative on the International Commission on Intervention and State Sovereignty, an effort to codify the international community's responsibility and right to protect people on humanitarian grounds when they are unable to defend themselves from persecution. He is married to Zsuzsanna Zsohar and has two children—Theo and Sophie—from a previous marriage.

En 2001, il a siégé comme représentant canadien pour la Commission internationale sur l'intervention et la souveraineté des États, qui a pour objectif d'élaborer des normes relatives aux droits et responsabilités de la communauté internationale en matière de protection humanitaire des peuples subissant de la persécution. Il est marié à Zsuzsanna Zsohar et il a deux enfants, Théo et Sophie, nés d'un précédent mariage.

Plenary Speakers / Présentateurs des séances plénières

PLENARY SESSION

Date: Thursday, May 31, 2007 - 8:55 to 10:00 a.m.

Title: Real-World Bioethics, Heroic Risks, and the Risks of Heroism

Speaker: Chris MacDonald

This talk will examine the risks inherent in 'engaged' (as opposed to ivory-tower) bioethics, and enquire into the best sorts of responses to such risks. In particular, it will examine the argument for heroic individual action, and situate such calls within a larger context of debates over professionalism and institutional responsibility.



Chris MacDonald is an Associate Professor and Graduate Programme Coordinator in the Philosophy Department at Saint Mary's University. He has published widely on topics ranging across business ethics, professional ethics, bioethics, and moral theory, and was lead author for the Canadian

Bioethics Society's *Draft Model Code of Ethics for Bioethics*. His research has been supported by grants from the Canadian Institutes of Health Research, the Social Sciences and Humanities Research Council of Canada, and the Nova Scotia Health Research Foundation. He was recently a Visiting Scholar at Alberta's Provincial Health Ethics Network during Bioethics Week. MacDonald's research is currently focused on ethical issues faced by biotechnology companies, and on philosophical problems related to corporate moral motivation.

SÉANCE PLÉNIÈRE

Date: jeudi, 31 mai 2007 - de 8h55 à 10h

Titre: La réalité bioéthique, risques héroïques et le risque de l'héroïsme

Présentateur: Chris MacDonald

Le présentateur examinera les risques inhérents à une bioéthique engagée (par opposition à une bioéthique faite dans une tour d'ivoire). Il tentera de faire voir les risques associés à cette entreprise et les solutions pour y répondre. Il regardera de plus près la position de l'action héroïque individuelle et tentera de la situer dans le contexte plus large des débats autour de la professionnalisation et des responsabilités organisationnelles.

Chris MacDonald est professeur agrégé et coordonnateur du programme de cycles supérieurs au Département de philosophie de l'Université Saint Mary's. Il a beaucoup publié sur différents sujets dont l'éthique des affaires, l'éthique professionnelle, la bioéthique et la théorie morale. Il a été l'auteur principal du projet de modèle de code d'éthique pour les bioéthiciens de la SCB. Ses recherches ont été financées par les Instituts de recherche en santé (IRSC), le Conseil de recherches en sciences humaines du Canada (CRSH) et par le Fonds de recherche en santé de la Nouvelle-Écosse. Il a récemment été chercheur invité au *Provincial Health Ethics Network* (PHEN) en Alberta lors de la semaine de la bioéthique. Les recherches de Chris Macdonald se concentrent actuellement sur les enjeux éthiques rencontrés par des compagnies de biotechnologies et sur les problèmes philosophique en lien avec la motivation morale en milieu corporatif.

Plenary Speakers / Présentateurs des séances plénières

PLENARY SESSION*

Date: Thursday, May 31, 2007 - 4:30 to 5:30 p.m.

Title: Ethics in policy-making: Where there is a will there is a way

Speaker: Ghislaine de Langavant

* *The speaker will be presenting in French.*

Can ethics matter to policy making? Drawing on her experience of, and reflections on, the role played by bioethics in assisting policy making, Ghislaine de Langavant will seek to demonstrate how complexity, public engagement and social mediation are intimately linked concepts that need to be considered together if one wishes to promote the relevance of bioethics for policy making.



Ghislaine Cleret de Langavant has a background both in science and bioethics with a Ph.D. in Biomedical Sciences (on methodology in bioethics), an M.Sc. in Nutrition and a B.Sc. in Biochemistry. In 2001 she published *Bioéthique: Méthode et Complexité* with "Les Presses de L'Université du Québec". Her fields of interest cover method in bioethics, complexity, knowledge

transfer, citizen participation in policy making and the ethical implications of genomics. An active member of the international association for health technology assessment (INAHTA) working group on ethics in health technology assessment for the past three years, of the Clinical Research Institute of Montreal (IRCM) ethics committee for the past eight years (1999 - Feb 2007). Mrs. de Langavant also chaired the ethics committee of Procréa inc. from January 1999 to September 2001. Mrs de Langavant is frequently invited to give talks and to offer expert advice for various organizations. She was a consultant researcher in bioethics for seven years (Dec. 1999 - March 2007) at the Quebec Agency for Health Services and Technology Assessment (AETMIS). Since March 2007, Ghislaine Cleret de Langavant is deputy health commissioner for the province of Quebec, responsible for bioethics and public participation.

SÉANCE PLÉNIÈRE*

Date: jeudi, 31 mai 2007 - de 16h30 à 17h30

Titre: L'éthique dans l'élaboration des politiques publiques : quand on veut, on peut

Présentatrice: Ghislaine de Langavant

* *La présentatrice parlera en français.*

Est-ce que l'éthique est importante dans l'élaboration des politiques? En partant de son expérience et de ses réflexions sur le rôle des bioéthiciens dans l'élaboration des politiques, Ghislaine de Langavant tentera de démontrer que la complexité, la participation du public et la médiation sociale sont des concepts intimement reliés, qui doivent être mis ensemble lorsqu'il s'agit de montrer la pertinence de la bioéthique pour l'élaboration des politiques publiques.

Ghislaine Cleret de Langavant possède une double formation en science et en bioéthique. Elle détient un doctorat en sciences biomédicales option bioéthique (sur la méthode en bioéthique), une maîtrise en nutrition et un B.Sc. en biochimie. En 2001, elle a publié *Bioéthique: Méthode et Complexité* aux Presses de l'Université du Québec. Ses intérêts de recherche portent sur la méthode en bioéthique, la complexité, le transfert des connaissances, la participation du public dans l'élaboration des politiques publiques et les enjeux éthiques de la génomique. Depuis trois ans, elle fait partie du groupe de travail sur l'éthique et l'évaluation des technologies de la santé de l'association internationale de l'évaluation des technologies de la santé (INAHTA). De 1999 à février 2007, elle fut membre du comité d'éthique de la recherche de l'Institut de recherche clinique de Montréal (IRCM) et de janvier 1999 à septembre 2001, elle a présidé le comité d'éthique de la recherche de Procréa Inc. Mme de Langavant est fréquemment invitée à faire des présentations et à offrir son expertise dans plusieurs organisations. Elle a été chercheuse consultante en bioéthique pendant sept ans (décembre 1999 à mars 2007) à l'Agence d'évaluation des technologies et des modes d'intervention en santé (AETMIS). Depuis mars 2007, elle est commissaire adjointe à l'éthique pour le Commissaire à la santé et au bien-être de la province de Québec sur des dossiers touchant la bioéthique et la participation du public.

Plenary Speakers / Présentateurs des séances plénières

PLENARY SESSION

Date: Friday, June 1, 2007 – 8:55 to 10:00 a.m.

Title: Integrated Ethics at the US Veterans Health Administration

Speaker: Ellen Fox

Ellen will describe a large-scale, intensive organizational change initiative that integrates clinical and organizational ethics into a comprehensive model to improve ethics quality throughout the largest health care system in the US.



Ellen Fox, MD, is an internal medicine physician who serves as Director of the National Center for Ethics in Health Care of the Veterans Health Administration—the largest health care system in the United States. Previously she served as Director of End-of-Life Care for the Institute for Ethics of the American Medical Association, and Director of the Education for Physicians on End-of-Life Care (EPEC) Project (1997-98). She

also served as Director of the Program in Clinical Ethics at the University of Illinois at Chicago Medical School (1994-97) and as a core faculty member at the MacLean Center for Clinical Medical Ethics at the University of Chicago (1992-94). Originally from Arlington, Virginia, Dr. Fox graduated summa cum laude from Yale College and earned her MD from Harvard Medical School. She received her residency training at Yale, where she also served as Chief Resident. She completed her ethics fellowship at the University of Chicago. She is widely published and has participated on various national and international panels and projects. Her areas of special expertise include ethics consultation, ethics education, ethics evaluation, organizational ethics, and ethical issues in end-of-life care.

SÉANCE PLÉNIÈRE

Date: vendredi, 1er juin 2007– de 8h55 à 10h

Titre: Intégrer l'éthique au US Veterans Health Administration

Présentatrice: Ellen Fox

Ellen décrira une initiative à grande échelle visant à intégrer l'éthique clinique et organisationnelle à l'intérieur d'un modèle global visant à améliorer la qualité de l'éthique dans le plus grand système de santé des États-Unis.

Ellen Fox, MD, est une interniste qui travaille, à titre de directrice, au *National Center for Ethics in Health Care of the Veterans Health Administration*, le plus gros système de santé aux États-Unis. Auparavant, elle a été directrice des soins en fin de vie de l'*Institute for Ethics of the American Medical Association*, et en 1997-98, directrice du projet de formation des médecins sur les soins en fin de vie (*Education for Physicians on End-of-Life Care EPEC*). Elle a aussi été directrice du programme d'éthique clinique de l'Université de l'Illinois à l'école de médecine de Chicago (1994-97), et l'un des principaux membres du corps professoral du *MacLean Center for Clinical Medical Ethics* à l'Université de Chicago (1992-94). Originaire d'Arlington en Virginie, Dr Fox a gradué du *Yale College* avec la mention «Très bien». Elle a obtenu son doctorat en médecine de la *Harvard Medical School*. Elle a complété une formation en éthique (Fellowship) à l'Université de Chicago. Plusieurs de ses travaux ont été publiés et elle a participé à plusieurs panels et projets d'envergure nationale et internationale. Son champ de spécialisation comprend la consultation éthique, la formation en éthique, l'évaluation, l'éthique organisationnelle et les enjeux éthiques des soins en fin de vie.

Plenary Speakers / Présentateurs des séances plénières

ALLOWAY LECTURE

Date: Friday, June 1, 2007 – 4:00 to 5:00 p.m.

Title: Is there a moral obligation to address spiritual needs of patients and their caregivers?

Speaker: Daniel Sulmasy

The purpose of the Alloway Lecture Series, established by the Maranatha Foundation in 1993, is to bring to the University of Toronto each year one or more experts of international stature in the broad field of bioethics to deliver lectures on topics related to ethical aspects of organ transplantation, when possible, but the Lectures are not limited to this field of medical ethics. This year's presenter is Daniel Sulmasy.

Dan will discuss the ethics of introducing spirituality into health care practice. He will argue that rather than being something that should be permitted, attending to the spiritual needs of patients and their loved ones should be considered a moral obligation. The literature suggests that the reason for doing so is a link between spirituality and health outcomes. For moral and scientific reasons, Dan will argue that this is exactly the wrong reason, will provide a convincing alternative argument in favor of doing so, and discuss the moral issues that arise when physicians, nurses, and other health care professionals take up this task.



Dr. Sulmasy, a Franciscan Friar, holds the Sisters of Charity Chair in Ethics at St. Vincent's Hospital, Manhattan, and serves as Professor of Medicine and Director of the Bioethics Institute of New York Medical College, Valhalla, NY. He received his A.B. and M.D. degrees from Cornell University and completed his residency, chief residency, and post-doctoral fellowship in General Internal Medicine at the Johns Hopkins Hospital. He received his Ph.D. in philosophy from Georgetown University in 1995. From 1991 to 1998 he served on the faculty at Georgetown, where he was Director of the Center for Clinical Bioethics and Senior Research Scholar of the Kennedy Institute of Ethics. He was appointed to the New York State Task Force on Life and the Law by Gov. George Pataki in 2005. His research interests include the ethics of end-of-life decision-making, ethics education, and spirituality in medicine. He is the author of four books—*The Healer's Calling*, *Methods in Medical Ethics*, *The Rebirth of the Clinic*, and *A Balm for Gilead*. He serves as editor-in-chief of the journal, *Theoretical Medicine and Bioethics*. His numerous articles have appeared in medical, philosophical, and theological

CONFÉRENCE ALLOWAY

Date: vendredi, 1^{er} juin 2007, de 16h à 17h

Titre: Y a-t-il une obligation morale de prendre en compte les besoins spirituels des patients et de leurs proches?

Présentateur: Daniel Sulmasy

La série de conférences Alloway, mise sur pied par la Fondation Maranatha en 1993, a comme objectif de faire venir à chaque année, à l'Université de Toronto, un ou des experts du domaine de la bioéthique, pour une présentation sur les aspects éthiques de la transplantation d'organe. Toutefois, ces conférences ne se limitent pas seulement à ce thème de l'éthique médicale. Cette année, le présentateur invité est Daniel Sulmasy.

Dan discutera des aspects éthiques de l'introduction de la spiritualité dans les soins. Il tentera de faire valoir que de prendre en compte les besoins spirituels des personnes et de leurs proches n'est pas seulement quelque chose que l'on peut faire, mais quelque chose que l'on doit faire, une obligation morale. Les écrits suggèrent qu'il est justifié de le faire puisque cela a un impact bénéfique sur la santé. Toutefois, Dan démontrera que c'est une mauvaise raison. Il proposera un autre argument valable pour le faire. Il discutera des enjeux éthiques qui surviennent lorsque des médecins, des infirmières et d'autres professionnels de la santé décident de prendre en compte les besoins spirituels de leurs patients.

Dr. Sulmasy, un moine franciscain, est titulaire de la chaire Sisters of Charity en éthique à l'Hôpital St. Vincent's de Manhattan. Il est professeur de médecine et directeur du Bioethics Institute of New York Medical College, Valhalla, NY. Il a obtenu son baccalauréat et son doctorat en médecine de l'Université Cornell. Il a fait sa résidence et sa formation post-doctorale (Fellowship) en médecine générale interne à l'hôpital Johns Hopkins. Il a complété un Ph.D. en philosophie à l'Université de Georgetown en 1995. De 1991 à 1998, il a été directeur du Center for Clinical Bioethics et chercheur principal du Kennedy Institute of Ethics à l'Université de Georgetown. En 2005, il a été nommé par le Gouverneur George Pataki pour siéger à la New York State Task Force on Life and the Law. Ses intérêts de recherche comprennent l'éthique et les décisions en fin de vie, la formation en éthique et la spiritualité, et la médecine. Il est l'auteur de quatre livres : *The Healer's Calling*, *Methods in Medical Ethics*, *The Rebirth of the Clinic*, and *A Balm for Gilead*. Il est le rédacteur en chef de la revue *Theoretical Medicine and Bioethics*. Ses nombreux articles ont paru dans des revues médicales, philosophiques et théologiques. Enfin, il a beaucoup enseigné aux États-Unis et à l'étranger.

Plenary Speakers / Présentateurs des séances plénières

PLENARY SESSION—INTERNATIONAL PANEL

Date: Saturday, June 2, 2007 – 8:55 to 10:00 a.m.

Title: Reflections/experiences from the developing world: clinical ethics beyond the ethics of clinical research

Panel: Jens Mielke, Robyna Khan, Anant Bhan

This panel, made up of clinical ethicists from the developing world, will explore the realities of clinical ethics in their separate contexts. They will highlight some challenges such as poverty, inequity, low levels of funding in public health, corruption and cultural norms which create specific ethical difficulties in their countries (Pakistan, India and Zimbabwe). Some suggestions for solutions will be offered.



Professor Jens Mielke has taught clinical neurology and bioethics to undergraduate and graduate medical students at the College of Health Sciences of the University of Zimbabwe in Harare since 1995. His interest in bioethics led to his association with the Joint Centre for Bioethics at the University of Toronto, where he completed a

Master's degree in bioethics in 2002 during a sabbatical. A neurologist and internist by training, he has a background in epilepsy and HIV medicine research, with more recent publications in priority setting and research ethics in an African setting. He is a founding member of the Zimbabwe Association of Doctors for Human Rights and a visiting lecturer to the University of Cape Town Bioethics Center Research Ethics programme.



Dr. Robyna Khan is a graduate of the Masters in Health Sciences program of the Joint Centre for Bioethics, University of Toronto. She is a consultant anesthesiologist working currently as assistant professor at Aga Khan University, Karachi, Pakistan. She is involved in all spheres of bioethics related activities within the university and is one of the main resource

persons for bioethics in Aga Khan University. She is a member of clinical ethics group (Hospital Ethics

SÉANCE PLÉNIÈRE—PANEL INTERNATIONAL

Date: Samedi, 2 juin 2007 de 8h55 à 10h

Titre: Réflexions et expériences des pays en développement: l'éthique clinique au-delà de l'éthique de la recherche clinique

Panel: Jens Mielke, Robyna Khan, Anant Bhan

Ce panel, constitué d'éthiciens cliniques provenant de pays en développement, explorera les réalités de l'éthique clinique dans ce contexte. Les membres du panel feront ressortir les défis, tels que la pauvreté, l'iniquité, le manque de financement en santé publique, la corruption et les normes culturelles, qui génèrent des difficultés éthiques spécifiques à leurs pays : Pakistan, Inde et Zimbabwe. Certaines solutions seront proposées.

Depuis 1995, le **professeur Jens Mielke** enseigne la neurologie clinique et la bioéthique aux étudiants de médecine du *College of Health Sciences* de l'Université du Zimbabwe à Harare. Son intérêt pour la bioéthique l'a amené à compléter une maîtrise en bioéthique, en 2001, lors de son année sabbatique, au *Joint Centre for Bioethics* de l'Université de Toronto. En plus d'être formé comme neurologue et comme interniste, Dr Mielke a aussi une formation de chercheur dans le domaine de l'épilepsie et du VIH. Toutefois, ses plus récentes publications portent sur l'allocation des ressources et l'éthique de la recherche en contexte africain. Il est le fondateur de l'Association des médecins pour les droits humains du Zimbabwe et maître de conférences invité au programme d'éthique de la recherche du Centre de bioéthique de l'Université de Cape Town.

Dr. Robyna Khan est diplômée du programme de maîtrise en sciences de la santé du *Joint Centre for Bioethics* de l'Université de Toronto. Elle est anesthésiste, mais travaille actuellement comme professeure adjointe à l'Université Aga Khan, à Karachi, au Pakistan. Étant l'une des principales personnes ressources en bioéthique à l'Université Aga Khan, elle est impliquée dans toutes les activités de l'Université gravitant autour de la bioéthique. Elle est membre du groupe en éthique clinique (comité d'éthique en milieu hospitalier), du comité d'éthique de la recherche et du groupe sur la formation en bioéthique de l'Université. Son travail au sein de ces divers groupes l'a amenée à organiser plusieurs activités académiques et éducationnelles au Pakistan.

Plenary Speakers / Présentateurs des séances plénières

Committee), research review process (Ethics Review Committee) and bioethics education (Bioethics Group) in the university. Working with these groups, she has organized multiple educational and academic activities in Pakistan. Her main areas of interest are pediatric anesthesia, bioethics education, and clinical ethics.



Anant Bhan is a physician based in Pune, India. He has done his masters in bioethics from the University of Toronto Joint Centre for Bioethics. He has worked with civil society organizations and in a government health research institute in India. He is presently working as an independent researcher and as a consultant bioethicist to the Ethical, Social and Cultural Program for the

Grand Challenges in Global Health Initiative. He is interested in clinical ethics of relevance to the developing world including global/public health and bioethics, equity, health systems, and gender-related issues.

Ses champs d'intérêt sont l'anesthésie pédiatrique, la formation en bioéthique et l'éthique clinique.

Anant Bhan est médecin et il travaille à Pune, en Inde. Il a fait une maîtrise en bioéthique, au *Joint Centre for Bioethics* de l'Université de Toronto. Il a travaillé dans plusieurs organisations de la société civile et dans un institut gouvernemental de recherche en santé en Inde. Il travaille actuellement en tant que chercheur indépendant et consultant en bioéthique pour le programme éthique, culture et société de la *Grand Challenges in Global Health Initiative*. Il s'intéresse à l'éthique clinique dans les pays en développement, notamment à la santé mondiale et la bioéthique, à l'équité, aux systèmes de santé et aux enjeux liés au genre.

Plenary Speakers / Présentateurs des séances plénières

PLENARY SESSION

Date: Saturday, June 2, 2007 - 4:00 to 5:00 p.m.

Title: Global Bioethics – The Ethics Program of UNESCO

Speaker: Henk ten Have

UNESCO is an intergovernmental organization with 191 Member States. It is concerned with a broad range of issues regarding education, science and culture. Since the 1970s the Organization has occasionally examined bioethical questions in connection to the emerging life sciences. The focus on bioethics was institutionalized in 1993 with the establishment of the International Bioethics Committee and a work program and budget for international activities. The program has been expanded in 1998 with the foundation of the World Commission on the Ethics of Scientific Knowledge and Technology, which is addressing other areas of applied ethics such as environmental ethics, science ethics and technology ethics. Since 2002 UNESCO is also coordinating the activities of international bodies through the Inter-Agency Committee on Bioethics.

One major objective in this international framework is the development of international normative standards. This is particularly important since many Member States only have a very limited infrastructure in bioethics, lacking expertise, educational programs, bioethics committees and legal frameworks. UNESCO has adopted three declarations in the field of bioethics: the Universal Declaration on the Human Genome and Human Rights (1997), the International Declaration on Human Genetic Data (2003), and the Universal Declaration on Bioethics and Human Rights (2005). Such declarations, however, will remain paperwork without clear efforts to implement them into practices. The main activities of the ethics program of UNESCO are currently focused on translating the principles of universal ethics into various practices in different countries. The presentation will discuss two practical programs: the Assisting Bioethics Committees (ABC) project which is helping countries (Malawi, Madagascar, Ghana and Jamaica) to set up well functioning national bioethics committees, and the Ethics Education Program (EEP) that is identifying existing ethics teaching programs in all countries, proposing an international core curriculum in bioethics, as well as offering a training course in teaching of ethics.

Henk ten Have is Director of the Division of Ethics of Sciences and Technology at UNESCO, Paris, France. He has studied medicine and philosophy at Leiden University, the Netherlands. He received his medical degree in

SÉANCE PLÉNIÈRE

Date: samedi, 2 juin 2007– de 16h à 17h

Titre: Bioéthique globale: le programme éthique de l'UNESCO

Présentateur: Henk ten Have

L'UNESCO est une organisation intergouvernementale formée de 191 états membres. Elle s'intéresse à un éventail d'enjeux touchant l'éducation, la science et la culture. Depuis 1970, elle s'est peu à peu mise à examiner des questions bioéthiques en lien avec le développement des sciences de la vie. L'accent mis sur la bioéthique fut institutionnalisé en 1993 par la création du comité international de bioéthique (CIB), d'un programme et d'un budget pour des activités internationales. Le programme a pris de l'expansion en 1998 par la mise sur pied de la Commission mondiale d'éthique des connaissances scientifiques et des technologies (COMEST), qui se penche sur d'autres champs de l'éthique appliquée, dont l'éthique de l'environnement et l'éthique de la science et des technologies. Depuis 2002, l'UNESCO, via le Comité inter-agence de bioéthique, coordonne les activités régionales et internationales de différentes organisations et différents groupes travaillant de près ou de loin en bioéthique.

Dans ce contexte international, un des principaux objectifs est le développement de normes et de standards. Ceci est particulièrement important puisque plusieurs États ne possèdent pas d'infrastructure en bioéthique, ni d'expertise, ni de programmes de formation, ni de comités ou de cadres normatifs. L'UNESCO a adopté trois Déclarations dans le domaine de la bioéthique : la Déclaration universelle sur le génome humain et les droits de l'homme (1997), la Déclaration internationale sur les données génétiques humaines (2003) et la Déclaration universelle sur la bioéthique et les droits de l'homme (2005). Cependant, ces Déclarations pourraient ne rester que des écrits si aucun effort n'est fait pour les mettre en pratique. Les activités principales de l'UNESCO visent à traduire les principes universels en des pratiques concrètes dans différents pays. La présentation portera sur deux aspects pratiques du programme: 1) Assistance aux comités de bioéthique. Un projet qui aide actuellement des pays (Malawi, Madagascar, Ghana et Jamaïque) à mettre sur pied des comités nationaux de bioéthique. 2) Programme de formation en éthique, qui recense les programmes existant déjà dans différents pays, et qui propose un programme d'enseignement en bioéthique et de la formation sur l'enseignement de la bioéthique.

Plenary Speakers / Présentateurs des séances plénières



1976 from Leiden University and his philosophy degree in 1983. He worked as researcher in the Pathology Laboratory, University of Leiden (1976-1977), as practising physician in the Municipal Health Services, City of Rotterdam (1978-1979), and as Professor of Philosophy in the Faculty of Medicine and Faculty of Health Sciences, University of Limburg, Maastricht (1982-1991). Since 1991 he has been Professor of

Medical Ethics and Director of the Department of Ethics, Philosophy and History of Medicine in the University Medical Centre Nijmegen, the Netherlands. Since September 2003 he joined UNESCO as Director.

He is involved in many public debates concerning euthanasia, drug addiction, genetics, choices in health care and resource allocation. His research has focused on ethical issues in palliative care. He has been coordinator of the European Commission funded Project, 'Palliative Care Ethics'. Also, he serves on numerous editorial boards. He is editor-in-chief of the recently established journal, *Medicine, Health Care and Philosophy*. He has been co-founder and secretary of the European Society for Philosophy of Medicine and Health Care. He published *Medische Ethiek* (1998; revised edition 2003), a textbook for medical curricula (also translated in Lithuanian language). His other recent books include *Palliative care in Europe. Concepts and Policies* (Amsterdam, the Netherlands; IOS Press; 2001), *Bioethics in a European perspective* (Dordrecht, the Netherlands; Kluwer Academic Publishers; 2001), and *The Ethics of Palliative Care: European Perspectives* (Buckingham, UK; Open University Press; 2002). In 2004 he has published (with co-editor Ruth Purtillo) the book *Ethics and Alzheimer Disease* (Johns Hopkins University Press, Baltimore). His most recent publication is a book on euthanasia (*Death and medical power. An ethical analysis of Dutch euthanasia practice*. Open University Press, 2005).

In UNESCO he is involved in a wide range of international activities in bioethics, such as the drafting of a Universal Declaration of Bioethics and Human Rights as well as the promotion of ethics teaching (with a current priority for Latin America and East and Central Europe). He is also responsible for international activities in environmental ethics, science ethics (exploring the drafting of a Code of Conduct for Scientists) and space ethics (developing a declaration of ethical principles for the peaceful use of outer space).

Henk ten Have est directeur du Programme de l'UNESCO sur l'Éthique des sciences et des technologies, à Paris en France. Il a étudié la médecine et la philosophie à l'Université Leiden aux Pays-Bas. Il y a obtenu son diplôme de médecine en 1976 et celui de philosophie en 1983. Il a travaillé comme chercheur au laboratoire de pathologie de cette même université (1976-1977), et comme médecin pour les Services de santé municipaux de la ville de Rotterdam (1978-1979). Il a ensuite été professeur de philosophie à la Faculté de médecine et à la Faculté des sciences de la santé de l'Université de Limburg, à Maastricht (1982-1991). Depuis 1991, il est professeur d'éthique médicale et directeur du Département d'éthique, de philosophie et d'histoire de la médecine au centre médical de l'Université de Nijmegen, aux Pays-Bas. Depuis septembre 2003, il est directeur à l'UNESCO.

Il est engagé dans plusieurs débats publics concernant l'euthanasie, la dépendance aux drogues, la génétique, la prise de décision dans les soins de santé et l'allocation des ressources. Ses recherches portent sur les enjeux éthiques en soins palliatifs. Il a été coordonnateur du projet «Éthique et soins palliatifs», financé par la Commission européenne. Il a participé à de nombreux comités éditoriaux. Il est rédacteur en chef de la nouvelle revue *Medicine, Health Care and Philosophy*. Il est le co-fondateur et secrétaire de la *European Society for Philosophy of Medicine and Health Care*. Il a publié *Medische Ethiek* (1998, édition révisée 2003), un manuel scolaire de médecine (traduit en lituanien). Parmi les livres qu'il a publiés, on retrouve: *Palliative care in Europe. Concepts and Policies* (Amsterdam, Pays-Bas; IOS Press 2001), *Bioethics in a European perspective* (Dordrecht, the Netherlands; Kluwer Academic Publishers; 2001), et *The Ethics of Palliative Care. European Perspectives* (Buckingham, UK; Open University Press; 2002). En 2004, il a publié (en coédition avec Ruth Purtillo) le livre *Ethics and Alzheimer Disease* (Johns Hopkins University Press, Baltimore). Son plus récent livre, *Death and medical power. An ethical analysis of Dutch euthanasia practice*. (Open University Press, 2005), porte sur l'euthanasie.

À l'UNESCO, il participe à de nombreuses activités internationales sur le thème de la bioéthique. Il a participé à la rédaction de la Déclaration universelle sur la bioéthique et les droits de l'homme et à la promotion de l'enseignement en éthique (en mettant la priorité sur l'Amérique Latine et l'Europe de l'Est et Centrale). Il est aussi responsable de certaines activités internationales sur l'éthique de l'environnement, l'éthique de la science (cherchant à rédiger un code de conduite pour les scientifiques) et l'éthique spatiale (cherchant à élaborer une déclaration de principes éthiques pour une utilisation pacifique de l'espace).

Plenary Speakers / Présentateurs des séances plénières

PANEL PRESENTATION

Date: Sunday, June 3, 2007 - 11:00 to 12:00 a.m.

Title: Challenges for Clinical Ethics as It Develops Internationally

Panel: George J. Agich, Stella Reiter-Thiel, & Ross Upshur

This panel will focus on some of the challenges that clinical ethics faces as it develops internationally including the distinct needs of developing versus developed world contexts. Among these challenges to be discussed is, first, a tendency for ethics committees to be established as "alibi committees" rather than robust change-effecting bodies. Second, the degree to which defining what kind of preparation is necessary for individuals to perform ethics consultation is an issue. Is there an emerging consensus or disagreement about the responsibilities of clinical ethics consultants? Third, to what degree, if any, should ethics consultation be clinical, that is, engaged in the daily care of patients and conversation with relatives rather than functioning at a distance such as an ethics committee review of cases? Fourth to what extent is a clinical ethics model useful and required in under-resourced settings.



George J. Agich is Professor of Philosophy, Senior Research Fellow in the Social Philosophy & Policy Center, and Director of the BGeXperience Program (the university's values program) at Bowling Green State University. He is a pioneer in ethics consultation. Beginning in the mid-70s, he conducted ethics consultations as well

as directed and founded ethics committees and ethics consultation services in a number of community, psychiatric hospitals and academic medical centers. He serves on the American Society for Bioethics and Humanities Ethics Consultation Task Force and is active in clinical ethics in international circles. He also co-directs the International Association of Bioethics (IAB) Network on Bioethics Education and is a member of the IAB Board of Directors.

PRÉSENTATION DE PANEL

Date: dimanche, 3 juin 2007 de 11h à 12h

Titre: Les défis de l'éthique clinique dans son développement international

Panel: George J. Agich, Stella Reiter-Thiel, & Ross Upshur

Ce panel mettra l'accent sur les défis que rencontre l'éthique clinique dans son développement international, et soulignera également les besoins particuliers des pays en développement. Parmi les défis qui seront discutés, il y a, premièrement, la tendance des comités d'éthique à devenir des «comités prétextes» au lieu d'être de solides instances favorisant le changement. Deuxièmement, la question du niveau de formation nécessaire à la pratique de la consultation éthique sera abordée. Y a-t-il consensus ou désaccord quant aux responsabilités des consultants en éthique clinique ? Troisièmement, le panel se penchera sur la question de savoir dans quelle mesure l'éthique doit être «clinique», c'est-à-dire impliquée dans les soins quotidiens aux patients et dans les conversations avec les proches, au lieu de fonctionner à distance, à la manière des comités d'éthique faisant l'analyse des cas. Quatrièmement, les participants tenteront de voir dans quelle mesure un modèle d'éthique clinique est utile et requis dans un contexte où les ressources manquent.

George J. Agich est professeur de philosophie, chargé d'étude principal au *Social Philosophy & Policy Center*, et Directeur du programme BGeXperience à l'Université *Bowling Green State*. Il est un pionnier de la consultation éthique. Il a débuté au milieu des années 1970. Il a depuis mené des consultations éthiques, ainsi que mis sur pied des services de consultation éthique dans plusieurs endroits, dont des hôpitaux psychiatriques et des centres médicaux universitaires. Il participe aux travaux du groupe d'étude sur la consultation éthique de la American Society for Bioethics and Humanities (ASBH) et il est très actif en éthique clinique sur le plan international. Il codirige le réseau sur la bioéthique et l'éducation de l'Association internationale de bioéthique (International Association of Bioethics, IAB), et il est membre de son conseil d'administration.

Plenary Speakers / Présentateurs des séances plénières



Prof. Dr. rer. soc. Stella Reiter-Theil, Dipl.-Psych.

has been a pioneer in building curricula and institutions of medical and health ethics in Austria, Germany and Switzerland; she has been active in various European / international projects. Stella Reiter-Theil is ANNE FRANK Professor and Director of the "Institute for Applied Ethics and Medical Ethics" (IAEME) at the Medical Faculty,

University of Basel. She is a member of the Board of Directors of the "Department of Public Health" and directs the "Transfaculty Program of Applied Ethics" at the University of Basel. She has established an interdisciplinary research program on clinical ethics and is also engaged in projects of ethics in psychology and the life sciences (PhD program medical and health ethics). Stella Reiter-Theil's teaching covers the obligatory courses of Medical Ethics throughout all six years of study in the Basel curriculum. She is a member of the Steering Committee directing the international post-graduate curriculum "European Master in Bioethics", a joint program of the Universities of Nijmegen, Leuven, Padua and Basel. Together with George Agich, she initiated the series of International Conferences: *Clinical Ethics Consultation, 2003, 2005, 2007*. She has developed and advises ethics support services in various health institutions; also, she has served in numerous national (Federal Health Dept./Germany; Senate, Swiss Academy of Medical Sciences) and international ethics committees (e.g. CIOMS, WHO). She is directing the new Distant Learning Program "Ethics Consultation in Health Care". Website: www.unibas.ch/aeme

Prof. Dr. rer. soc. Stella Reiter-Theil, Dipl.-Psych., a été une pionnière dans le développement de programmes d'enseignement et d'institutions en éthique médicale en Autriche, en Allemagne et en Suisse; elle a été active au sein de plusieurs projets européens et internationaux. Stella Reiter-Theil est titulaire de la chaire d'éthique, créée et financée par le Fonds ANNE FRANK et elle est la directrice de l'Institut d'éthique appliquée et d'éthique médicale à la Faculté de médecine de l'Université de Bâle, en Suisse. Elle est membre du conseil d'administration du Département de santé publique et elle dirige le programme transfacultaire en éthique appliquée de cette même université. De plus, elle a mis sur pied un programme de recherche interdisciplinaire en éthique clinique et elle est impliquée dans des projets sur l'éthique en psychologie et en sciences de la vie (programme de Ph.D. en éthique appliquée et éthique médicale). Stella Reiter-Theil donne entre autres les cours obligatoires d'éthique médicale du programme de formation des futurs médecins. Elle est membre du comité directeur qui dirige le diplôme européen de maîtrise en bioéthique «*Erasmus Mundus Master of Bioethics*» en collaboration avec les Universités de Nijmegen (Pays-Bas), Louvain (Belgique), Padova (Italie) et Bâle (Suisse). Avec l'aide de George Agich, elle a mis sur pied une série de conférences internationales sur l'éthique clinique et la consultation : en 2003, 2005 et 2007. Elle a développé et conseillé plusieurs services de consultation éthique dans plusieurs institutions de santé. De plus, elle a participé à plusieurs comités d'éthique nationaux (*Federal Health Dept./Germany; Senate, Swiss Academy of Medical Sciences*) et internationaux (par ex. CIOMS, OMS). Elle dirige le nouveau programme de formation à distance sur la consultation éthique dans les soins de santé. Site Internet : www.unibas.ch/aeme



Ross Upshur received BA (Hons.) and MA degrees in philosophy before receiving his MD from McMaster University in 1986. After 7 years of rural primary care practice he returned to complete his MSc in epidemiology and fellowship training in Community Medicine and Public Health at the

University of Toronto. He is currently the Director of the University of Toronto Joint Centre for Bioethics and a staff physician at the Department of Family and Community Medicine, Sunnybrook Campus of the Sunnybrook Health Sciences Centre. Dr. Upshur is the

Avant de recevoir son diplôme de médecine de l'Université McMaster en 1986, **Ross Upshur** détenait déjà un baccalauréat et une maîtrise en philosophie. Après sept ans de pratique médicale en milieu rural, il retourna compléter une maîtrise en épidémiologie et une formation (Fellowship) en médecine communautaire et santé publique à l'Université de Toronto. Il est présentement le directeur du *Joint Center for Bioethics* de l'Université de Toronto et il travaille comme médecin à l'unité de médecine communautaire et familiale au *Sunnybrook Campus* du *Sunnybrook Health Sciences Centre*.

Dr. Upshur est titulaire de la Chaire de recherche du Canada sur les soins de première ligne et il est chercheur et professeur agrégé au Département de médecine communautaire et familiale et des sciences

Plenary Speakers / Présentateurs des séances plénières

Canada Research Chair in Primary Care Research and a Research Scholar and Associate Professor, Departments of Family and Community Medicine and Public Health Science and Adjunct Professor at the Institute of Clinical Evaluative Sciences at the University of Toronto. He is a member of The Royal College of Physicians and Surgeons of Canada, the College of Family Physicians of Canada, the University of Toronto Joint Centre for Bioethics and is an Associate Member of the Institute of Environment and Health at McMaster University. He is an affiliate of the Institute of the History and Philosophy of Science and Technology at the University of Toronto.

His research interests include the concept of evidence in health care, medical epistemology, clinical reasoning, public health ethics, ethics and health information, empirical approaches to bioethics, primary care research methods, time series applications to health services research, communicable disease, and environmental epidemiology. He has published peer reviewed studies in each of these domains. At the University of Toronto, he has designed and taught courses in the undergraduate, graduate, and post graduate curriculum in ethics and epidemiology, as well as supervising doctoral and master's candidates and being a clinical supervisor in the post graduate Family Medicine Residence programme. He has served on Advisory Boards for the International Joint Commission, Doctors Without Borders, and Scidev.net, and consulted with the World Health Organization.

de santé publique. Il est également chercheur associé à l'*Institute of Clinical Evaluative Sciences* de l'Université de Toronto. Il est membre du Collège royal des médecins et chirurgiens du Canada, du Collège des médecins de famille du Canada, du *Joint Center for Bioethics*, ainsi que membre associé de l'*Institute of Environment and Health* de l'Université McMaster. Il est aussi affilié à l'*Institute of the History and Philosophy of Science and Technology* de l'Université de Toronto.

Ses intérêts de recherche comprennent des sujets tels que le concept de «donnée probante» (*evidence*) dans les soins de santé, l'épistémologie médicale, le raisonnement clinique, l'éthique et la santé publique, l'éthique et l'information en santé, les approches empiriques en bioéthique, les méthodes de recherche sur les soins de première ligne, les séries chronologiques d'application en recherche et soins de santé et les maladies infectieuses et les épidémies environnementales. Il a publié des recherches, évaluées par des pairs, dans chacun de ces domaines. À l'Université de Toronto, il a conçu et donné des cours en éthique et épidémiologie pour le premier, deuxième et troisième cycle. Il a dirigé des étudiants à la maîtrise et au doctorat, et il a été le superviseur clinique de médecins résidents au programme de médecine familiale. Il a participé aux conseils consultatifs de la commission internationale conjointe, de Médecins sans frontières et de Scidev.net. Il a également été consultant pour l'OMS.

Special Conference Events / Événements spéciaux de la conférence

PLAY

Title: I'm Still Here

Date: Thursday, May 31, 2007—7:30 p.m to 9:00 p.m

Location: Church of the Holy Trinity, 10 Trinity Square



I'm Still Here is a hard-hitting research-based drama about living with dementia, created by ACT II STUDIO (Ryerson University, Toronto) from five studies conducted by nurse-researchers Drs. Gail Mitchell (York University) and Christine Jonas-Simpson (Sunnybrook Health Centre). This research-based drama has been well-received by audiences across North America.

The play will be performed on Thursday, May 31, 2007 from 7:30-9:00 pm at the Church of the Holy Trinity, next door to the conference venue.

Check for ticket availability at the registration desk.

DINNER WITH A VIEW

Date: Friday, June 1, 2007—6:30 to 8:30 p.m

Location: 360 Restaurant, CN Tower, 301 Front St. W.



Join us for dinner at the CN Tower, the World's Tallest Building at 553.33m (1,815 ft., 5 in.), and engineering Wonder of the Modern World. Enjoy award-winning cuisine and breath-taking views of the city lights more than 1,000 feet below and stretching out to the horizon in a gently revolving restaurant overlooking the city of Toronto.

After dinner wander down one flight of stairs to the Look Out and Glass Floor levels. Six high-speed glass-fronted elevators give you a breath-taking view as you travel up and down the tower at 22 kilometres (15 miles) per hour.

Hope you can join us for this unique experience!

Check for ticket availability at the registration desk.

PIÈCE DE THÉÂTRE

Titre: I'm Still Here

Date: mardi, le 31 mai 2007— de 19h30 à 21h

Lieu: L'église Holy Trinity, 10 Trinity Square

I'm Still Here est une pièce de théâtre dramatique à caractère scientifique qui traite de la démence. Cette pièce a été créée par l'ACT II STUDIO (Université Ryerson, Toronto), à partir de cinq recherches menées par les chercheuses en sciences infirmières Gail Mitchell, Ph.D., (Université York) et Christine Jonas-Simpson, Ph.D., (Sunnybrook Health Centre). Cette pièce de théâtre à caractère scientifique a été bien accueillie par les spectateurs d'un bout à l'autre de l'Amérique du Nord.

La pièce sera jouée le jeudi, 31 mai 2007, de 19h30-21h00, à l'église Holy Trinity, située tout près du lieu de la conférence.

Veillez vous adresser au comptoir de l'inscription pour vous procurer des billets.

SOUPER AVEC VUE PANORAMIQUE

Date: le vendredi 1er juin 2007—de 18h30 à 20h30

Lieu: 360 Restaurant, Tour du CN, 301, Front St. W.

Joignez-vous à nous pour le souper à la Tour du CN, le plus haut bâtiment au monde à 553.33m (1815 pi. et 5 po.), et merveille d'ingénierie du monde moderne. Dans ce restaurant tournant surplombant la ville de Toronto, vous apprécierez la cuisine primée du chef et la vue magnifique sur les lumières de la ville qui s'étendent sur l'horizon.

Après le souper, vous pourrez descendre vers les étages où se trouvent le plancher de verre et le point d'observation. Six ascenseurs à grande vitesse avec portes en verre vous offriront une vue magnifique, tout en vous permettant de monter et descendre, à une vitesse de 22 kilomètres (15 miles) par heure.

Nous espérons compter sur votre présence pour cette expérience exceptionnelle!

Veillez vous adresser au comptoir de l'inscription pour vous procurer des billets.

Special Conference Events / Événements spéciaux de la conférence

VISUAL POSTCARD EXHIBIT – ETHICS MATTERS

Date: Friday, June 1, 2007

Location: Grand Ballroom Foyer, Toronto Marriott Downtown Eaton Centre

Please join us for an International Bioethics Visual Postcard Exhibit. Postcards address the question "How does ethics matter to you in the work you do related to bioethics?" Included are submissions from Canada, England, Italy, Turkey, the United States, Australia and Nigeria. The exhibit "Ethics Matter" is an innovative opportunity for community engagement, representing reflective practice and creative expression in the exploration of bioethics.

EXPOSITION DE CARTES POSTALES – L'ÉTHIQUE, C'EST IMPORTANT

Date: vendredi, 1er juin 2007

Lieu: Grand Ballroom Foyer, Toronto Marriott Downtown Eaton Centre

Nous vous invitons à venir assister à une exposition internationale de cartes postales. Les cartes postales soulèvent la question suivante: «Quelle importance l'éthique revêt-elle dans votre travail en bioéthique?» Nous avons reçu des cartes postales du Canada, de l'Angleterre, de l'Italie, de la Turquie, des Etats-Unis, de l'Australie et du Nigeria. L'exposition «L'éthique, c'est important.» est un moyen innovateur et créatif d'expression et d'exploration en bioéthique.

Visual Postcard Exhibitors / Exposants

Moji Adurogbangba	- Nigeria
Bertha Alvarez Manninen	- Phoenix, Arizona, United States
Denise Avard	- Canada
Yen-Yuan Chen	- Ohio, United States
Hanzade Dogan	- Istanbul, Turkey
Margaret Dorazio-Migliore	- Vancouver, Canada
Keira Eades, Peter Isaacs & Eleanor Milligan	- Brisbane, Australia
Karen Faith	- Toronto, Canada
Marin Gillis	- Reno, Nevada, United States
Dianne Godkin	- Toronto, Canada
Christine Harrison	- Toronto, Canada
Peter Isaacs & Eleanor Milligan	- Brisbane, Australia
Rory Jackson	- Brisbane, Australia
Hazel Markwell	- Toronto, Canada
Sue MacRae	- Toronto, Canada
Maria McDonald	- Toronto, Canada
Kay McGarvey	- Toronto, Canada
Kadie McLaren	- Brisbane, Australia
Cynthiane J. Morgenweck	- Wisconsin, United States
Bob Parke	- North York, Canada
Deborah Pape	- Toronto, Canada
David J. Satin	- Minnesota, United States
Barbara Secker	- Toronto, Canada
Marcia Sokolowski	- Toronto, Canada
Antonio G. Spagnolo & Nunziata Comoretto	- Rome Italy
Chrissie Tuck	- Brisbane, Australia
Frank Wagner	- Toronto, Canada
Shawn Winsor	- Mississauga, Canada
Randi Zlotnik Shaul	- Toronto, Canada

Special Conference Events / Événements spéciaux de la conférence

NETWORKING EVENTS

Event: Neuroethics Breakfast and Information Session

Date: Friday, June 1 - 7:45 to 8:45 a.m.

Location: Room Trinity II

Come and join us to learn more about Canadian neuroethics research, neuroethics networks, collaborations, training opportunities, publications and other activities. All are invited to discover more about neuroethics research and ways to get involved, especially those not currently participating in related initiatives.

Event: Canadian Nurses Ethics Interest Group Networking Lunch

Date: Friday, June 1 - 12:00 to 1:00 p.m.

Location: Room Trinity II

Canadian Nurses Interested in Ethics (CNIE) is an emerging group of the Canadian Nurses Association. Our mission is to promote nursing ethics based on the belief that ethics is involved in every moment of nursing. Our primary goal is to build a connected moral community across Canada for Registered Nurses, Nursing Students, and other interested Health Care colleagues.

Event: Clinical Ethics Summer Institute Networking Lunch

Date: Friday, June 1 - 12:00 to 12:50 p.m.

Location: Room Trinity I

This networking lunch will be an opportunity for attendees from CESI 2006 to renew contacts made at the inaugural institute. Those who are interested in attending a future CESI are also welcome to attend, as we will be sharing our vision and plans for CESI 2008 and beyond.

ACTIVITÉS DE RÉSEAUTAGE

Activité: Petit déjeuner d'information sur la neuroéthique

Date: vendredi, 1^{er} juin de 7h45 à 8h45

Lieu: Salle Trinity II

Venez et joignez-vous à nous pour en connaître davantage sur la recherche en neuroéthique au Canada, sur les réseaux en neuroéthique, sur la formation, sur la publication et sur les autres activités dans ce domaine. Tous et toutes sont invités à venir en apprendre davantage sur la recherche en neuroéthique, ainsi que sur les diverses façons d'y participer, surtout ceux et celles qui ne sont pas des initiés.

Activité: Lunch de réseautage du groupe d'intérêt en éthique des infirmières canadiennes

Date: vendredi, 1^{er} juin, de 12h à 13h

Lieu: Salle Trinity II

Les infirmier(ière)s canadien(ne)s intéressé(e)s à l'éthique - *Canadian Nurses Interested in Ethics (CNIE)* est un groupe en émergence de l'Association canadienne des infirmières et infirmiers. Notre mission consiste à faire la promotion de l'éthique infirmière, en s'appuyant sur l'idée que l'éthique se retrouve dans chaque moment de la pratique infirmière. Notre objectif principal vise à construire une communauté morale à travers le Canada pour les infirmières et infirmiers, les étudiants et les autres collègues du domaine de la santé intéressés par l'éthique.

Activité: Lunch de réseautage de l'école d'été en éthique clinique

Date: vendredi, 1^{er} juin, de 12h à 12:50h

Lieu: Salle Trinity I

Ce lunch de réseautage est une occasion, pour ceux et celles qui ont participé à l'école d'été en éthique clinique, de renouer des liens. Les personnes éventuellement intéressées à suivre les cours de l'école d'été sont aussi les bienvenues puisque nous parlerons des orientations futures pour l'école d'été en 2008 et pour les années à venir.

Special Conference Events / Événements spéciaux de la conférence

CBS STRATEGIC PLAN 2020

Please join us Thursday morning, May 31st, from 7:30 to 8:30 a.m. in Trinity II Ballroom, to give the CBS more feedback about this draft strategic plan.

The purpose of the Canadian Bioethics Society (CBS) strategic planning process is to develop a long term strategic plan to 2020 for the Society.

There are four key phases in this strategic planning process. First in phase 1, focus groups involving various CBS members were conducted, where participants were asked to comment on the current mission of the CBS and provide input into a future vision and operational plan for the Society. In phase 2, in December of 2006, the members of the Executive Committee met face-to-face for an all-day strategic planning session where, building on the input received from the membership, the Executive developed a draft mission, vision and strategic operational priorities for the organization. In phase 3, the draft strategic plan will be posted on the CBS website for membership review and comment. In phase 4, the membership will approve a CBS strategic plan 2020 on May 31st, 2007 at the annual general meeting at the CBS conference (Joint Ethics Conference.).

Phase 1: Focus groups with members

Data Collection: Twenty-three tele-conference focus groups were conducted between July 18, 2006, and November 20, 2006. Groups were offered in both English and French. While only two groups were conducted completely in French, a number of Francophones participated in the English groups. Each focus group lasted approximately one hour and was guided by a facilitator. Group members were asked to discuss a series of questions on issues relating to the mission, the vision, the activities, and a logo for the CBS. For the majority of the focus groups, a separate recorder was present. Notes were taken as close to verbatim as possible so specific quotes could be used in the report.

Sample: A total of 90 people participated in the focus groups. Focus groups were comprised of current CBS members, including:

- Academic Bioethicists and fellows
- Practicing Clinical Bioethicists and fellows
- Administrators and directors of ethics programs
- Healthcare and health policy administrators
- Professional practice leaders
- Nurses
- Physicians

SCB PLAN STRATÉGIQUE POUR 2020

Venez vous joindre au comité exécutif de la SCB, le jeudi 31 mai de 7h30 à 8h30 a la salle Trinity II Ballroom, afin de nous soumettre vos commentaires sur le plan stratégique.

L'objectif du processus de planification stratégique de la Société canadienne de bioéthique (SCB) consiste à mettre au point le plan stratégique à long terme de la Société jusqu'en 2020.

Ce processus de planification stratégique comprend quatre phases clés. Au cours de la phase 1, des groupes de discussion comprenant différents membres de la SCB ont été mis en place; il a été demandé aux participants de discuter de la mission actuelle de la SCB et de formuler des suggestions quant à la vision future et au plan opérationnel de la Société. Pendant la phase 2 du mois de décembre 2006, les membres du comité exécutif se sont rencontrés lors d'une session de planification stratégique d'une journée au cours de laquelle ils ont mis au point un avant-projet de la mission, de la vision et des priorités opérationnelles stratégiques de l'organisation en s'appuyant sur les suggestions des membres. Dans la phase 3, l'avant-projet du plan stratégique a été affiché sur le site Web de la SCB afin que les membres puissent le consulter et le commenter. Au cours de la phase 4, un plan stratégique pour 2020 sera soumis au vote des membres à l'occasion de l'assemblée générale annuelle du congrès de la SCB (Conférence conjointe en éthique) qui aura lieu le 31 mai 2007.

Phase 1: groupes de discussion avec les membres

Recueil des données: vingt-trois groupes de discussion ont été organisés par téléconférence entre le 18 juillet et le 20 novembre 2006. Les groupes de discussion étaient proposés en anglais et en français. Seuls deux groupes ont été menés entièrement en français et plusieurs francophones ont pris part aux groupes en anglais. Chaque groupe de discussion encadré par un animateur durait environ une heure. Les membres de chaque groupe ont abordé une série de sujets relatifs à la mission, à la vision et aux activités de l'organisation ainsi qu'à la création d'un logo pour la SCB. Un rédacteur de compte rendu distinct était présent dans la plupart des groupes de discussion afin de prendre des notes aussi complètes que possible permettant d'utiliser des citations précises dans le rapport.

Échantillon: 90 personnes ont participé aux groupes de discussion. Les groupes de discussion comprenaient des membres actuels de la SCB, dont:

Special Conference Events / Événements spéciaux de la conférence

- Long term care and providers
- Spiritual care providers
- Professors
- Students
- Researchers and research ethics officers

Phase 2: Executive Meeting

The second step in the strategic visioning process was the meeting of the CBS Executive for a Visioning Strategic Planning Retreat. This retreat was held on December 3, 2006 in Toronto and facilitated by Dr. Jennifer Gibson, a strategic retreat facilitator. The purpose of the retreat was to develop a draft strategic plan for the society, including mission, vision, and strategic operational priorities. (Logo development was outside the scope of this retreat.) See below.

DRAFT: Revised CBS Mission Statement (2007)

The Canadian Bioethics Society (CBS) is a bioethics* member-driven organization that:

- Fosters interdisciplinary networks of individuals and organizations to collaborate and support each other in bioethical theorizing, research, practice, policy development and public engagement.
- Recognizes and seeks to support different publics (stakeholders) including professional ethics staff, academics, researchers, students, trainees, volunteers committed to ethics work, enablers of ethics work in society, individuals and institutions involved in setting public policy, and people interested in ethics.
- Supports and mentors students and trainees.
- Engages the general public in the discussion, education and public policy development around ethical issues.
- Facilitates the development and dissemination of leading practices, the promotion of excellence in bioethics education, research policy, and capacity-building.
- Promotes an understanding of the unique impact of the Canadian context on Bioethics issues.

*Definition of Bioethics: Bioethics is understood in its broadest sense to include critical descriptive and normative work, theoretical and applied work, and research, professional and practice focused endeavors in areas of clinical, organizational, academic, research, political, environmental, and global arenas.

2020 Vision Statement (DRAFT) *Tagline: Advancing the Wellbeing of Canadians through Bioethics:*

The CBS seeks to advance the health and wellbeing of the Canadian public by supporting and promoting effective work in bioethics through the promotion of:

- leadership and collaboration in bioethics nationally;

- Des bioéthiciens et des chercheurs universitaires
- Des bioéthiciens et des chercheurs cliniciens en exercice
- Des administrateurs et des directeurs de programmes d'éthique
- Des administrateurs en soins de santé et en politiques en matière de santé
- Des chefs d'exercice professionnel
- Des infirmières
- Des médecins
- Des prestataires de soins de santé à long terme
- Des prestataires de soutien spirituel
- Des professeurs
- Des étudiants
- Des chercheurs et des chargés d'étude dans le domaine de l'éthique

Phase 2 : réunion des membres exécutifs

La deuxième étape du processus stratégique de visualisation consistait en une réunion du comité exécutif de la SCB lors d'une journée de réflexion sur la planification stratégique. Cette assemblée s'est tenue le 3 décembre 2006 à Toronto et a été organisée par le Jennifer Gibson, Ph.D., une organisatrice de journées de réflexion stratégiques. L'objectif de cette session consistait à mettre au point l'avant-projet d'un plan stratégique pour la Société, y compris en ce qui concerne sa mission, sa vision et ses priorités opérationnelles stratégiques. (La mise au point du logo n'était pas à l'ordre du jour de cette réunion.) Voir ci-dessous.

AVANT-PROJET: énoncé révisé de la mission de la SCB (2007)

La Société canadienne de bioéthique (SCB) est un organisme de bioéthique* composé de membres qui :

- Encourage le réseautage interdisciplinaire des personnes et des organisations dans un but de collaboration et de soutien mutuel dans l'élaboration de théories bioéthiques, dans la recherche, la pratique, la mise au point de politiques et l'intérêt du public.
- Reconnaît et cherche à soutenir différents groupes publics (parties prenantes), y compris les professionnels de l'éthique, les universitaires, les chercheurs, les étudiants, les stagiaires et les bénévoles réalisant des travaux sur l'éthique, les facilitateurs du travail sur l'éthique dans la société, les personnes et les institutions impliquées dans la mise en place de politiques publiques et les personnes portant un intérêt à l'éthique.
- Soutient et conseille les étudiants et les stagiaires.
- Sensibilise le public à la discussion, à la formation et à l'élaboration de politiques publiques liées aux questions d'éthique.
- Facilite la mise au point et la diffusion de pratiques gagnantes, la promotion de l'excellence dans la formation à la bioéthique, dans les politiques de

Special Conference Events / Événements spéciaux de la conférence

- teaching, education and knowledge dissemination in bioethics;
- inter-professional and inter-disciplinary networks and communities of practice where members can share ideas and collaborate around bioethics education, research, policy development and practice;
- theoretical and practice-based approaches to bioethics;
- respect, tolerance and mutual respect that allows vigorous debate of complex topics without fracturing the community;
- diversity, inclusivity and mutual respect of the rich bioethics perspectives in the Canadian community;

2020 CBS Strategic Operational Priorities (DRAFT):

In its Operational Activities and financial decision-making, the CBS will seek to:

- Continue the annual CBS conference;
- Enhance networking & peer support in bioethics;
- create foray for discussion, reflection and dialogue in bioethics
- create a searchable database of members
- support regional and national community building
- explore partnerships (national/regional/local)
- support less visible sectors e.g., northern Canada
- provide more language and cultural translation for more effective collaboration between Anglophone and Francophone Canadians.
- Promote capacity-building and education in bioethics;
- support academic and professional training in bioethics
- support students at all levels in bioethics
- Support the identification and sharing of leading practices, ideas and approaches in bioethics;
- support research and academic exploration of bioethics topics
- support the sharing & dissemination of practice-based ideas and approaches in bioethics
- examine effectiveness in bioethics practice
- set agenda for bioethics practice in Canada
- promote outreach and dissemination of academic and practice-based work in bioethics
- continue to examine feasibility of Canadian Bioethics Journal
- Support an in-depth examination or research or advocacy on specific issues of interest in bioethics and Canadian society through working groups;
- Enhance communication/connectivity across the society (internally and externally);
- explore website and other technological communication innovations
- Further the examination of professional issues in bioethics;
- Examine credentialing, professionalization, working conditions
- Engage the public in topics related to bioethics

recherche et dans le renforcement des capacités.

- Favorise la compréhension de l'impact singulier du contexte canadien sur les questions de bioéthique.

*Définition de la bioéthique : la bioéthique est prise en compte ici dans son sens le plus large, et comprend le travail descriptif et normatif critique, le travail théorique et appliqué ainsi que les activités de recherche, professionnelles et de pratique dans les domaines clinique, organisationnel, universitaire, de la recherche, politique, environnemental et mondial.

Vision pour 2020 (AVANT-PROJET):

Slogan: améliorons le bien-être des canadiens par le biais de la bioéthique

La SCB a pour objectif d'améliorer la santé et le bien-être des canadiens en soutenant et en encourageant les travaux réalisés dans le domaine de la bioéthique. Dans ce but, elle accorde son soutien aux domaines suivants :

- la collaboration et le leadership nationaux dans le domaine de la bioéthique;
- l'enseignement, la formation et la transmission des connaissances en matière de bioéthique;
- le réseautage et les communautés de pratique interprofessionnelles et interdisciplinaires grâce auxquelles les membres peuvent partager des idées et travailler ensemble sur la formation, la recherche, l'élaboration de politiques et la pratique liées à la bioéthique;
- les approches théoriques et pratiques de la bioéthique;
- le respect, la tolérance et le respect mutuel qui permettent les débats dynamiques autour de sujets complexes sans entraîner la rupture de la communauté;
- la diversité, l'inclusivisme et le respect mutuel des perspectives prometteuses en termes de bioéthique dans la communauté canadienne.

Priorités organisationnelles stratégiques de la SCB pour 2020 (AVANT-PROJET):

Par ses activités opérationnelles et ses décisions financières, la SCB cherchera à:

- Poursuivre la conférence annuelle de la SCB;
- Améliorer le réseautage et le soutien des confrères dans le domaine de la bioéthique;
- créer un environnement enclin à la discussion, à la réflexion et au dialogue relatifs à la bioéthique
- mettre au point une base de données des membres interrogeable
- encourager le développement d'une communauté régionale et nationale
- identifier les partenariats possibles (nationaux, régionaux et locaux)

-soutenir les secteurs moins visibles, p. ex. le Nord du Canada

Special Conference Events / Événements spéciaux de la conférence

Pursue logo development and other strategies for marketing
Continue to find creative funding opportunities to sustain CBS and its activities.

Phase 3: Membership check The purpose of phase 3 was to seek comment from the membership regarding this draft strategic plan using the feedback form provided. Via the CBS Website, members were invited to give feedback on the draft mission, vision, and strategic operations.

Phase 4: Final approval of CBS strategic plan At the Annual CBS Business Meeting on May 31, 2007 at the CBS conference (Joint Ethics Conference) the final strategic plan will be presented for approval by the membership.

-augmenter le nombre de traductions linguistiques et culturelles pour assurer une collaboration plus efficace entre les canadiens anglophones et francophones.
Promouvoir le renforcement des capacités et la formation dans le domaine de la bioéthique;
-soutenir les formations universitaires et professionnelles en bioéthique
-encourager les étudiants de tous niveaux à s'orienter vers la bioéthique
Promouvoir l'identification et le partage des pratiques de pointe, des idées et des approches relatives à la bioéthique;
-soutenir la recherche et l'exploration universitaire des sujets afférents à la bioéthique
-encourager le partage et la transmission des idées et des approches basées sur la pratique dans le domaine de la bioéthique
-étudier l'efficacité de la pratique de la bioéthique
-établir un programme pour la pratique de la bioéthique au Canada
-développer la portée et la diffusion du travail universitaire basé sur la pratique
-poursuivre l'étude de la faisabilité d'un journal canadien de la bioéthique
Encourager un examen en profondeur ou bien une recherche ou un plaidoyer de sujets spécifiques liés à l'intérêt de la bioéthique et à la société canadienne par le biais de groupes de travail;
Améliorer la communication et la connectivité au sein de la Société (en interne et en externe);
-examiner le projet de site Web ainsi que les autres innovations technologiques en matière de communication
Approfondir l'étude des problèmes professionnels de bioéthique;
-Passer en revue la délivrance de titres et certificats, la professionnalisation et les conditions de travail
Sensibiliser le public aux sujets relatifs à la bioéthique
Poursuivre la mise au point du logo et d'autres stratégies de marketing
Continuer à rechercher des possibilités originales de financement afin de soutenir la SCB et ses activités.

Phase 3 : consultation des membres L'objectif de la phase 3 consiste à recueillir les commentaires des membres concernant l'avant-projet de ce plan stratégique à l'aide du formulaire prévu. La date limite d'envoi des commentaires été fixée au 30 MARS 2007.

Phase 4 : approbation finale du plan stratégique de la SCB

Lors de la séance administrative annuelle de la SCB qui se tiendra le 31 mai 2007 au congrès de la SCB (Conférence conjointe en éthique), le plan stratégique final sera présenté aux membres afin d'être approuvé.

Awards and Tributes / Prix et hommages

Canadian Bioethics Society Lifetime Achievement Award

Presentation: Thursday, May 31, 2007 – 4:00 to 4:30 p.m.

The CBS Lifetime Achievement Award is given annually to an individual whose demonstrated scholarship and/or leadership has contributed significantly to health care ethics in Canada.

Criteria for selection include:

- A clear focus on health care ethics in his or her lifetime achievements
- National and international profile in health care ethics
- Outstanding leadership in shaping the field of health care ethics in Canada
- Primary consideration will be given to nominees whose major contributions have occurred in the Canadian context

The committee is pleased to announce that this year's recipient of the CBS Lifetime Achievement Award is

Dr. Susan Sherwin.



Susan Sherwin grew up in Toronto. After completing her BA at York University (1969) and her PhD in philosophy at Stanford University (1974), she spent a year as a Postdoctoral Fellow in the Moral Problems in Medicine Project at Case Western Reserve University; there she co-edited (with Samuel Gorovitz et al.) the first textbook in medical ethics. She has been at Dalhousie University since 1974, currently as a University

Research Professor in the Department of Philosophy and Gender and Women's Studies. Her principal areas of research and teaching are in feminist theory and health ethics with particular emphasis on questions that arise in the intersection of these fields.

Her 1992 book, *No Longer Patient: Feminist Ethics and Health Care*, helped to launch the field of feminist bioethics. In the 1990's she coordinated the Feminist Health Care Ethics Research Network, an interdisciplinary group of Canadian scholars and practitioners, which jointly produced *The Politics of Women's Health: Exploring Agency and Autonomy*.

Prix d'excellence pour l'ensemble des réalisations de la Société canadienne de bioéthique

Présentation: jeudi, 31 mai 2007, de 16h à 16h30

Le prix d'excellence pour l'ensemble des réalisations de la SCB est décerné annuellement à l'individu dont l'érudition et/ou le leadership a contribué de façon importante à la l'éthique en matière de soins de santé au Canada.

Les critères de sélection comprennent :

- une vision claire de l'éthique en matière de soins de santé dans l'ensemble des réalisations;
- un profil national et international en éthique en matière de soins de santé;
- un leadership extraordinaire dans l'élaboration du domaine de l'éthique en matière de soins de santé au Canada;
- une considération particulière sera accordée aux candidats dont les contributions les plus importantes ont été réalisées dans un contexte canadien.

Le comité est fier d'annoncer que la récipiendaire du prix d'excellence pour l'ensemble des réalisations de la SCB de cette année est décerné à **Susan Sherwin, Ph.D.**

Susan Sherwin a grandi à Toronto. Après avoir complété son baccalauréat à l'Université de York (1969) et son doctorat en philosophie à l'Université de Stanford (1974), elle a passé une année postdoctorale à travailler sur les problèmes moraux dans le cadre du projet médical de l'Université Case Western Reserve, où elle coédita (avec Samuel Gorovitz et al.) le premier manuel scolaire en éthique médicale. Depuis 1974, elle travaille à l'Université Dalhousie en tant que chercheuse et professeure au Département de philosophie et au programme d'études féministes. Son domaine principal de recherche et d'enseignement est la théorie féministe et l'éthique de la santé avec une emphase particulière sur les questions qui émergent à l'intersection de ces deux champs.

Son livre *No Longer Patient: Feminist Ethics and Health Care*, publié en 1992, a permis de donner son envol à la bioéthique féministe. Dans les années 1990, elle a coordonné le réseau de recherche sur l'éthique féministe et les soins de santé, un groupe interdisciplinaire de chercheurs et de praticiens canadiens, qui a conjointement produit le livre *The Politics of Women's Health: Exploring Agency and*

Awards and Tributes / Prix et hommages

Her research explores important conceptual and social justice issues associated with various policies within health and health care. She is a Fellow of the Royal Society of Canada. In 2004, she was named Distinguished Woman Philosopher of the Year by the Society for Women in Philosophy (U.S.). She is the winner of the 2006 Killam Prize in Humanities in recognition of her important contributions to health ethics.

Autonomy.

Ses recherches explorent d'importants enjeux conceptuels, qui touchent la justice sociale, et qui sont en lien avec les diverses politiques de santé. Elle est membre de la Société royale du Canada. En 2004, elle a été nommée «philosophe de sexe féminin de l'année» par la *Society for Women in Philosophy* (É-U). Elle a reçu en 2006 le prix Killam en sciences humaines et lettres, pour son important travail et sa contribution en

Awards Committee Members/Les membres du comité de sélection des prix

Daryl Pullman (Chair/Président)
 Paula Chidwick
 Eoin Connolly
 Bernard Keating
 Stacey Page
 Barbara Russell

CBS Student Abstract Competition Winners/ Les gagnants du concours étudiant

The Canadian Bioethics Society congratulates the following winners of the CBS Student Abstract Competition:



Ariella Binik, McGill University



Rose Geransar, University of Calgary



Matthew Hunt, McGill University



Erica Sutton, University of Toronto



Celine Durand, Université de Montréal



Dierdre DeJean, McMaster University



Osimiri Peter, University of Lagos

La Société canadienne de bioéthique félicite les gagnants susmentionnés du concours étudiant.

Awards and Tributes / Prix et hommages

Tribute to Ron Cranford

Date: Saturday, June 2, 2007 – 5:00 p.m.

Ronald Cranford, MD, Professor of Neurology at the University of Minnesota died on May 31, 2006. Ron is known in bioethics circles as one of the leading experts on coma and unconsciousness and as a pioneer in clinical ethics.



In the mid-1970s, Dr. Cranford founded and chaired the Thanatology Committee at Hennepin County Medical Center in Minneapolis, Minnesota to examine and improve end-of-life care. He was a passionate educator and advocate for hospital ethics committees, co-editing one of the first volumes on ethics committees: [*Institutional Ethics Committees and*](#)

[*Health Care Decision Making*](#) in 1984 and was active in the Society for Bioethics Consultation, a predecessor organization of the American Society for Bioethics and Humanities.

Ron worked with families on highly controversial public cases involving persons in a persistent vegetative state. This work and the ensuing court decisions, e.g., Karen Ann Quinlan, Paul Brophy, Nancy Cruzan, and Terri Schiavo, helped to create the legal framework in the United States that allows patients and their immediate loved ones to decide when life support should be used or curtailed.

Ron is sorely missed by his friends and colleagues, and the field of clinical ethics has lost one of its strongest proponents.

Hommage à Ron Cranford

Date: samedi, 2 juin 2007 - 17h

Ronald Cranford, MD, professeur de neurologie à l'Université du Minnesota, est décédé le 31 mai 2006. Ron était reconnu dans le milieu de la bioéthique pour son expertise sur le coma et l'inconscience, et en tant que pionnier en éthique clinique.

Au milieu des années 1970, Dr. Cranford fonda et présida le comité de thanatologie, au centre médical Hennepin County à Minneapolis au Minnesota, afin d'analyser et d'améliorer les soins en fin de vie. Il était un bon pédagogue, passionné pour son métier, ainsi qu'un excellent défenseur des comités d'éthique en milieu hospitalier. D'ailleurs, il a été coéditeur d'un des premiers livres portant sur les comités d'éthique «[*Institutional Ethics Committees and Health Care Decision Making*](#) », publié en 1984. Il a également été très actif au sein de la *Society for Bioethics Consultation*, l'ancêtre de la *American Society for Bioethics and Humanities*.

Ron a travaillé auprès de familles, dans des cas très controversés impliquant des personnes qui étaient dans des états végétatifs permanents. Ce travail, et les décisions des tribunaux, par ex. Karen Ann Quinlan, Paul Brophy, Nancy Cruzan et Terri Schiavo, ont permis de créer, aux États-Unis, un cadre légal qui permet aux patients et à leurs proches de décider quand les traitements en fin de vie devraient être maintenus ou arrêtés.

Ron manquera à ses collègues et à ses amis. Le champ de l'éthique clinique a perdu une de ses figures de marque.

PROGRAM INFORMATION

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INFORMATIONS SUR LE PROGRAMME

Program at a Glance

	Wednesday May 30, 2007	Thursday May 31, 2007	Friday June 1, 2007	Saturday June 2, 2007	Sunday June 3, 2007
All Day	CBS Pre-Conferences	CBS Poster Exhibit	Visual Postcard Exhibit	ICCEC Poster Exhibit	
Early Morning	Global Health & Ethics Children's and Adolescents' Participation in Decision Making: Ethical and Developmental Considerations	7:30 - 9:30 Registration 7:30 - 8:30 am CBS Strategic Planning Meet & Greet <i>Student General Mtg.</i>	7:30 - 9:00 Registration 7:30 - 8:45 <i>Student Mentor Breakfast</i>	7:30 - 9:00 Registration	7:30 - 8:50 CBS Executive Mtg.
Morning		8:55 - 10:00 Plenary Session Chris McDonald 10:00 - 10:30 Break 10:30 - 12:00 Concurrent Sessions	8:55 - 10:00 ICCEC Conference Opening & Plenary Session Ellen Fox 10:00 - 10:30 Break 10:30 - 12:00 Concurrent Sessions	8:55 - 10:00 International Panel Jens Mielke, Robyna Khan, Anant Bhan 10:00 - 10:30 Break 10:30 - 12:00 Concurrent Sessions	9:00 - 10:30 Concurrent Sessions 10:30 - 11:00 Break - Choral Performance by the <i>Miles Nadal Jewish Community Centre Choir</i> 11:00 - 12:00 Closing Plenary Panel George Agich, Stella Reiter-Theil, Ross Upshur
After-noon	3:30 - 5:30 CBS Executive Mtg. 4:00 - 6:00 Registration 5:00 - 6:45 <i>Student Meet and Greet</i>	12:00 - 2:00 Lunch & CBS Business Meeting 2:00 - 3:30 Concurrent Sessions 3:30 - 4:00 Break 4:00 - 4:30 CBS Lifetime Achievement Award 4:30 - 5:30 Plenary Session Ghislaine de Langavant	12:00 - 1:00 Lunch (Networking) 1:00 - 3:30 Concurrent Sessions 3:30 - 4:00 Break 4:00 - 5:00 Plenary Session (Alloway Lecture) Daniel Sulmasy 5:00 CBS Closing Remarks	12:00 - 1:00 Lunch 1:00 - 3:30 Concurrent Sessions 3:30 - 4:00 Break 4:00 - 5:00 Plenary Session Henk ten Have 5:00 Tribute to Ron Cranford	12:00 - 12:30 ICCEC Closing Remarks Invitation to Next Conferences
Evening	7:00 - 8:30 CBS Conference Opening and Public Lecture (AMS/CBS Lecture) Michael Ignatieff 8:30 - 10:00 CBS Reception - Cash Bar Musical Interlude by <i>The Royal Entertainment</i>	5:00 - 7:00 Registration 5:30 - 7:00 <i>Student Dinner</i> 7:30 - 9:00 Play: I'm Still Here (Church of the Holy Trinity)	5:30 - 6:30 Cash Bar Reception at Horizons (CN Tower) 6:30 - 8:30 Dinner with a View (CN Tower)		

Aperçu du programme

	mercredi 30 mai 2007	jeudi 31 mai 2007	vendredi 1er juin 2007	samedi 2 juin 2007	dimanche 3 juin 2007
Toute la journée	SCB Préconférences	SCB - Présentations par affiche	Exposition d'affiches visuels	CIECC - Présentations par affiche	
Tôt le matin	Santé dans le monde et éthique La participation des enfants et des adolescents à la prise de décision: Considérations éthiques et développementales	7h30 – 9h30 Inscription 7h30 – 8h30 Rencontre de la SCB sur le plan stratégique <i>Assemblée générale des étudiants</i>	7h30 – 9h Inscription 7h30 – 8h45 <i>Petit-déjeuner étudiant avec mentors</i>	7h30 – 9h Inscription	7h30 – 8h50 Rencontre du comité exécutif de la SCB
Avant-midi		8h55 – 10h Séance plénière Chris McDonald 10h – 10h30 Pause 10h30 – 12h Séances simultanées	8h55 – 10h CIECC - Présentation d'ouverture Séance plénière Ellen Fox 10h – 10h30 Pause 10h30 – 12h Séances simultanées	8h55 – 10h Panel international Jens Mielke, Robyna Khan, Anant Bhan 10h – 10h30 Pause 10h30 – 12h Séances simultanées	9h – 10h30 Séances simultanées 10h30 – 11h Pause Le spectacle de chorale a été donné par le <i>Miles Nadal Jewish Community Centre Choir</i> 11h – 12h Séance plénière de clôture George Agich, Stella Reiter-Theil, Ross Upshur
Après-midi	15h30 – 17h30 Rencontre du comité exécutif de la SCB 16h – 18h SCB - Inscription 17h30 – 18h45 <i>Activité d'accueil des étudiant(e)s</i>	12h – 14h Dîner & SCB Assemblée générale 14h – 15h30 Séances simultanées 15h30 – 16h Pause 16h – 16h30 SCB - Prix d'excellence pour l'ensemble des réalisations 16h30 – 17h30 Séance plénière Ghislaine de Langavant	12h – 13h Dîner (réseautage) 13h – 15h30 Séances simultanées 15h30 – 16h Pause 16h – 17h Séance plénière (Alloway Lecture) Daniel Sulmasy 17h SCB - Mot de la fin	12h – 13h Dîner 13h – 15h30 Séances simultanées 15h30 – 16h Pause 16h – 17h Séance plénière Henk ten Have 17h Hommage à Ron Cranford	12h – 12h30 CIECC - Mot de la fin Invitation aux prochaines conférences
Soirée	19h – 20h30 SCB - Présentation d'ouverture et séance plénière (Conférence AMS/ CBS) Michael Ignatieff 20h30 – 22h00 SCB Réception, bar à la carte Interlude musicale par <i>The Royal Entertainment</i>	17h – 19h Inscription 17h30 – 19h <i>Souper des étudiants</i> 19h30 – 21h Pièce de théâtre: I'm Still Here (L'église Holy Trinity)	17h30 – 18h30 Réception, bar à la carte au Horizons (Tour du CN) 18h30 – 20h30 Souper à la Tour du CN		

Wednesday, May 30 / mercredi, le 30 mai

3:30 – 5:30 p.m.	CBS Executive Meeting (closed) Dundas	15h30 – 17h30	Rencontre du comité exécutif de la SCB Dundas
4:00 – 6:00 p.m.	Registration Grand Ballroom Foyer	16h00 – 18h00	Inscription Grand Ballroom Foyer
5:00 – 6:45 p.m.	Student Meet & Greet Characters Sports Bar (Marriott)	17h00 – 18h45	Activité d'accueil des étudiant(e)s Characters Sports Bar (Marriott)
7:00 – 8:30 p.m.	CBS Conference Opening & Public Lecture* Grand Ballroom 	19h00 – 20h30	SCB - Présentation d'ouverture et séance plénière* Grand Ballroom 
	Associated Medical Services/ Canadian Bioethics Society Lecture Michael Ignatieff <i>*The presenter will be speaking in English and French.</i>		Associated Medical Services/ Société canadienne de bioéthique Michael Ignatieff <i>*Le présentateur parlera en français et en anglais.</i>
8:30 – 10:00 p.m.	Reception —Cash Bar Grand Ballroom Foyer Musical Interlude by The Royal Entertainment <i>The Royal Entertainment</i> is an ensemble group composed of Indulis and Ilga Suna. The couple were born in Latvia and musically trained at the J. Vitolis Latvian State Conservatory in Riga. They have made Canada their home since 1991.	20h30 – 22h00	Réception —bar à la carte Grand Ballroom Foyer Interlude musicale par The Royal Entertainment Le groupe <i>The Royal Entertainment</i> , est composé de Indulis et de Ilga Suna. Ce couple, né en Lettonie, a été formé au J. Vitolis Latvian State Conservatory de Riga. Ils vivent au Canada depuis 1991.

Thursday, May 31 / jeudi, le 31 mai

7:30 – 9:30 a.m.	Registration Grand Ballroom Foyer	7h30 – 9h30	Inscription Grand Ballroom Foyer
7:30 – 8:30 a.m.	CBS Student General Meeting Trinity I	7h30 – 8h30	Assemblée générale des étudiants Trinity I
7:30 – 8:30 a.m.	CBS Strategic Planning Meet & Greet Trinity II	7h30 – 8h30	Rencontre de la SCB sur le plan stratégique Trinity II
8:55 – 10:00 a.m.	Plenary Session Grand Ballroom 	8h55 – 10h00	Séance plénière Grand Ballroom 
	<i>Real-World Bioethics, Heroic Risks, and the Risks of Heroism</i> Chris MacDonald		<i>La réalité bioéthique, risques héroïques et le risque de l'héroïsme</i> Chris MacDonald
10:00 – 10:30 a.m.	Break & Posters Grand Ballroom Foyer	10h00 – 10h30	Pause et affiches Grand Ballroom Foyer

Concurrent Sessions—10:30 to 12:00 p.m. / Séances simultanées—10h30 à 12h

Room/Salle	Time/Heure	Title/Titre	Author(s)/Auteur(s)
GRAND BALLROOM 	10:30-12:00	WORKSHOP: La valorisation de la recherche universitaire : un regard éthique	Michel Bergeron, Simon Hobeila, and Guillaume Paré
TRINITY I	10:30-12:00	WORKSHOP: Poetry [like Bioethics] Resists Easy Answers	Jeff Nisker, Cathie Watson, and Diane Westerhoff
TRINITY II	10:30-11:00	Ethics Programs in the Era of LHINs: Planning for Success	Shawn Winsor, Paula Chidwick, Michael Coughlin, Andrea Frolic, Laurie Hardingham, Abbyann Lynch, and Robert S. Williams
	11:00-11:30	Pay-for-Performance: The United States Can Learn From Britain and New Zealand	David J. Satin
	11:30-12:00	Postgraduate Bioethics Education: Answering the Call to Action	Alex Levin
TRINITY III	10:30-11:00	Access to Medicines and the Role of Corporate Social Responsibility: The Need to Craft a Global Pharmaceutical System with Integrity	Jillian Clare Cohen & Patricia Illingworth
	11:00-11:30	Rationing Vaccines in a 1918-type Influenza Pandemic: An Ethical Framework for a State	Dorothy Vawter, Karen G. Gervais and Eline Garrett
	11:30-12:00	Transnational Justice and Caregiving for the Elderly	Lisa A. Eckenwiler
TRINITY IV	10:30-11:00	Strengthening National Capacity for What? The Means, Ends & Ethics of Emerging International Public Health Law	Christopher W. McDougall
	11:00-11:30	When Does Bioethics Matter to U.S. Judges?	Bethany Spielman
	11:30-12:00	Ethical Dilemmas and Expert Medical Evidence in the Criminal Justice System: The Case for Sexual Assault Nurse Examiners	Anna Zadunayski, Glenys Godlovitch, Rose Geransar and Isabelle Chouinard
TRINITY V	10:30-12:00	WORKSHOP: Working Conditions for Bioethicists Task Force	Paddi Rodney, Paula Chidwick, Eoin Connolly, Andrea Frolic, Laurie Hardingham, George Webster

Thursday, May 31 / jeudi, le 31 mai

12:00 – 1:00 p.m.	Lunch Grand Ballroom Foyer	12h00 – 13h00	Dîner Grand Ballroom Foyer
12:00 – 2:00 p.m.	CBS Business Meeting Grand Ballroom	12h00 – 14h00	SCB Assemblée générale Grand Ballroom



Concurrent Sessions—2:00 to 3:30 p.m. / Séances simultanées—14h à 15h30

Room/ Salle	Time/Heure	Title/Titre	Author(s)/Auteur(s)
GRAND BALLROOM 	2:00-3:30	WORKSHOP: L'autonomie et la réflexion critique: des compétences essentielles pour une formation en éthique	Isabelle Ganache, Danielle Laudy, Véronique Besançon, et Michel Bergeron
TRINITY I	2:00-2:30	Teaching Ethics in a Home Care Program	Dorothy Irvine and Ranjit Uppal
	2:30-3:00	An ethical analysis of the Alternate Level of Care Issue at the Atlantic Health Sciences Corporation in Region 2 of New Brunswick	Timothy Christie, Dora Nicinski, Eileen MacGibbon, Margaret Melanson, and Terry Livingstone
	3:00-3:30	Development of a Community-Based Ethics Framework	Kerry Bowman and Anita Jacobson
TRINITY II	2:00-2:30	Researching Polymorphisms in Indigenous Populations: Developing New Ethical Guidelines Encouraging Greater Scientific Responsibility in Research Design and the Dissemination of Results	Dana Wensley
	2:30-3:00	Surviving the Health Canada Inspection- What does that have to do with research ethics?	Suzette Salama
	3:00-3:30	Rethinking the notion of risk in social science and humanities research	Nancy Walton
TRINITY III	2:00-2:30	Deciding to Use Complementary and Alternative Medicine with Children: Legal, Ethical and Clinical Issues	Joan Gilmour, Christine Harrison, and Sunita Vohra
	2:30-3:00	How Much is that Prozac in the Window: Big Pharma and the Made-to-Order Patient	Anna Gotlib and Soraya Gollop
	3:00-3:30	The Placebo Complex	Lynette Reid

Thursday, May 31 / jeudi, le 31 mai

Room/ Salle	Time/Heure	Title/Titre	Author(s)/Auteur(s)
TRINITY IV	2:00-2:30	Excessive Expense of Treatment and Disproportionate Burden: To what extent is the relationship an ethical basis to forego life-sustaining treatment?	Mark Repenshek, Micheal Panicola and Bridget Carney
	2:30-3:00	US Medicare Part D: What NOT to do in Canadian Pharmacare	Laura Shanner
	3:00-3:30	Ethics in Conditions of Disaster and Deprivation: Learning from Health Workers' Narratives	Lisa Schwartz, Chris Sinding, Laurie Elit, Lynda Redwood-Campbell and Michelle Li
TRINITY V	2:00-2:30	Data and Decision Making regarding the Disclosure of Financial Conflicts of Interest in Research	Jeremy Sugarman, Kevin P. Weinfurt, Mark. A. Hall, Micheala A. Dinan, Venita DePuy, Joëlle Y. Friedman, and Jennifer S. Allsbrook
	2:30-3:00	The Ethics of Sham Surgery Arms in Randomized Clinical Trials	Patrick McDonald
	3:00-3:30	Is there a place for the pharmaceutical sale representative in the doctor-patient relationship?	Marie-Chantal Fortin and Delphine Roight
3:30 – 4:00 p.m.	Break Grand Ballroom Foyer	15h30 – 16h00	Pause Grand Ballroom Foyer
4:00 – 4:30 p.m.	CBS Lifetime Achievement Award Grand Ballroom 	16h00 – 18h00	SCB - Prix d'excellence pour l'ensemble des réalisations Grand Ballroom 
4:30 – 5:30 p.m.	Plenary Session* Grand Ballroom <i>Ethics in policy-making: Where there is a will there is a way</i> Ghislaine de Langavant <i>*The presenter will be speaking in French.</i>	16h30 – 17h30	Séance plénière* Grand Ballroom <i>L'éthique dans l'élaboration des politiques publiques: quand on veut, on peut</i> Ghislaine de Langavant <i>*La présentatrice parlera en français.</i>
5:00 – 7:00 p.m.	Registration Grand Ballroom Foyer	17h00 – 19h00	Inscription Grand Ballroom Foyer
5:30 – 7:00 p.m.	Student Dinner Mr. GreenJean's (Toronto Eaton Centre)	17h30 - 19h00	Souper des étudiants Mr. GreenJean's (Toronto Eaton Centre)
7:30 – 9:00 p.m.	Play – I'm Still Here Church of the Holy Trinity	19h30 - 21h00	Pièce de théâtre: I'm Still Here L'église Holy Trinity

Friday, June 1 / vendredi, le 1er juin

7:30 – 9:00 a.m.	Registration Grand Ballroom Foyer	7h30 – 9h00	Inscription Grand Ballroom Foyer
7:30 – 8:45 a.m.	Student Mentor Breakfast Trinity I	7h30 – 8h45	Petit-déjeuner étudiant avec mentors Trinity I
7:30 – 8:45 a.m.	Neuroethics Breakfast & Information Session Trinity II	7h30 – 8h45	Petit déjeuner d'information sur la neuroéthique Trinity II
8:55 – 10:00 a.m.	 ICCEC Conference Opening & Plenary Session Grand Ballroom	8h55 – 10h00	 CIECC - Présentation d'ouverture et Séance plénière Grand Ballroom
	Integrated Ethics at the US Veterans Health Administration Ellen Fox		Intégrer l'éthique au US Veterans Health Administration Ellen Fox
10:00 – 10:30 a.m.	Break & Posters Grand Ballroom Foyer	10h00 – 10h30	Pause et affiches Grand Ballroom Foyer

Concurrent Sessions—10:30 to 12:00 p.m. / Séances simultanées—10h30 à 12h

Room/Salle	Time/Heure	Title/Titre	Author(s)/Auteur(s)
BALLROOM C & D 	10:30-11:00	De l'éthique clinique à l'éthique de la recherche clinique	Pierre Boitte, Jean-Philippe Cobbaut et A. de Bouvet
	11:00-11:30	Recherche chez les enfants très malades ou en soins palliatifs : normes et enjeux éthiques	Thérèse St-Laurent-Gagnon, Franco Carnevale, et Michel Duval
	11:30-12:00	Les citoyens et le concept d'éthique en science et technologie	Marianne Dion-Labrie, Céline Durand, Isabelle Ganache, et Hubert Doucet
TRINITY I	10:30-11:00	Ethical challenges in psychiatry: a clinical ethics process in the field of early identification and treatment of psychoses	Didier Caenepeel
	11:00-11:30	Developing Clinical Ethics in Psychiatry for Medical Residents at the University of Nevada School of Medicine	Marin Gillis and Steven Zuchowski
	11:30-12:00	End-of-Life Decision Making in the Context of Mental Illness	Barbara Russell and Lynne Peters
TRINITY II	10:30-11:00	Characterizing the PGD Embryo: A Review of Recent Policy Positions	Estair Van Wagner, Roxanne Mykitiuk, and Jeff Nisker
	11:00-11:30	The Ethics of Imperfect Cures	Monique Lanoix
	11:30-12:00	Security or Survival? Prenatal Diagnosis and Justice for Affected Communities	Timothy Krahn
TRINITY III	10:30-11:00	Creating a Community of Practice in Clinical Ethics	Laurie Hardingham, Dianne Godkin, Paula Chidwick, and Karen Faith
	11:00-11:30	Informal ethics consultation: hindrance or help?	Samia A. Hurst and Marion Danis
	11:30-12:00	On the Role of Emotions During Ethical Consultations	Kurt W. Schmidt

Friday, June 1 / vendredi, le 1er juin

Room/Salle	Time/Heure	Title/Titre	Author(s)/Auteur(s)
TRINITY IV	10:30-11:00	Role of Media in Promoting Ethics in Health Research	Afrina Rizvi
	11:00-11:30	Walking the Line: Ethical and Educational Concerns for Therapist Self-Disclosure	Bryn A. Robinson and Mary Ann Campbell
	11:30-12:00	Health Technology Assessment in Argentina: Social and Ethical Aspects	Carolina Martin
SIMCOE	10:30-11:00	Implementing Clinical Moral Deliberation Processes	Bert Molewijk and Guy Widdershoven
	11:00-11:30	Distance Teaching and Clinical Ethics Consultation - Contradictio in Terminis?	Stella Reiter-Theil and Ralf J. Jox
	11:30-12:00	Beyond Clinical Ethics: A Qualitative Case Study of Organisational Ethics and Clinical Ethicists	Diego S. Silva, Jennifer L. Gibson, Robert Sibbald, Eoin Connolly, and Peter Singer
BALLROOM A & B	10:30-12:00	WORKSHOP: Difficult Consultations that Haunt Us	Paul J. Ford, Denise Dudzinski, Stuart G. Finder, Alissa Swota, Joseph DeMarco, and Mary Beth Foglia
KING	10:30-11:00	Why Do We Do What We Do? The Goals and Objectives of Ethics Consultation	Martin L. Smith and Kathryn L. Weise
	11:00-11:30	Capacity assessment as an integral part of ethics consultation	Jeffrey Philip Spike
	11:30-12:00	Clinical Ethics and Public Health Ethics: Where Does One End and the Other Begin? A Case Discussion	Deborah Pape, Ross Upshur, and Karen Sasaki
CARLETON	10:30-12:00	WORKSHOP: Neuroenhancement for Sustainable Well-Being	Françoise Baylis, Walter Glannon, Eric Racine, and Jason Scott Robert
BAY	10:30-11:00	Evaluating Ethics Consultation: Does the Design of Randomized Control Trials Work?	Yen-Yuan Chen
	11:00-11:30	Geographies of Dying in Intensive Care Units	Joan Liaschenko and Cynthia Peden-McAlpine
	11:30-12:00	Clinicians' evaluation of clinical ethics consultations in Norway: a qualitative study	Reidun Førde, Reidar Pederson, and Victoria Akre
YORK A	10:30-11:00	Quality Improvement and Clinical Impact of Ethics Consults on Patient Care	John F. Tuohey, Helene Anderson, Ann Bryant, and Marsha Williams
	11:00-11:30	Emergency department staff perceptions of family member presence during resuscitations: A Canadian perspective	Jeanette E. Boyd, L.S. Montgomery, I. Mitchell, & T.J. Sakaluk
	11:30-12:00	Thinking on the Street: Ethics and Harm Reduction	Bernadette Pauly
YORK B	10:30-11:00	Health for Some: An Examination of Global Health Discourses	Ronald Labonte, Reidar Pedersen, and Victoria Akre
	11:30-12:00	Corporate Governance Mechanisms as Tools for Ensuring the Bioethics of Health Industry Business in Least Developed Countries	Anita M. Huntley
	12:00-12:30	Evidence and Ethics in Studying Globalization and Health	Ted Schrecker

Friday, June 1 / vendredi, le 1er juin

12:00 – 1:00 p.m.	Lunch Grand Ballroom Foyer	12h00 – 13h00	Dîner Grand Ballroom Foyer
12:00 – 12:50 p.m.	Clinical Ethics Summer Institute Networking Lunch Trinity I	12h00 – 12h50	Lunch de réseautage de l'école d'été en éthique clinique Trinity I
12:00 – 12:50 p.m.	Canadian Nurses Ethics Interest Group Networking Lunch Trinity II	12h00 – 12h50	Lunch de réseautage du groupe d'inté- rêt en éthique des infirmières cana- diennes Trinity II

Concurrent Sessions—1:00 to 3:30 p.m. / Séances simultanées—13h à 15h30

Room/Salle	Time/ Heure	Title/Titre	Author(s)/Auteur(s)
BALLROOM C & D 	1:00-1:30	L'expérience du théâtre interactif, les enjeux éthiques des avancées de la génomique et la communication citoyenne	 Celine Durand, Isabelle Gareau, Marianne Dion-Labrie, Isabelle Ganache et Hubert Doucet
	1:30-2:00	The dangers of industry-sponsored medical research: Perspective of industry sponsors and academic researchers	Wayne Rosen
	2:00-2:30	REB Review and Aboriginal Community Values	Kathleen Cranley Glass and Joseph Kaufert
	2:30-3:00	Encadrement juridique et éthique de la recherche biomédicale en Afrique Noire	Marius N. Kêdoté et Danielle Laudy
	3:00-3:30	Les chercheurs sont-ils des sujets éthiques vulnérables ?	Guillaume Paré
BAY	1:00-1:30	Legal and ethical issues of MRI research involving children: An issue scoping overview	Jocelyn Downie, Matthais Schmidt, Nuala Kenny, Ryan D'Arcy, Michael Hadsakis, and Jennifer Marshall
	1:30-2:00	Consent for future research on DNA samples and information	Barry F. Brown
	2:00-2:30	Ethics in Pandemic Planning: Getting to the nitty gritty	Bashir Jiwani
	2:30-3:00	Planning for Research Endeavours during a Public Health Emergency: Learning from SARS	Catherine Tansey, Margaret Herridge, and Jim Lavery
	3:00-3:30	Ethical considerations in the prioritization of children for pandemic influenza vaccine	Caroline Alfieri
CARLTON	1:00-1:30	The Genetics Outcomes Study: Empirical results and an ethics framework for understanding	Michelle A. Mullen, Heather E. Howley, Natasha O'Reilly, Judith E. Allanson, Wendy S. Meschino, Christine Kennedy, and Brenda J. Wilson
	1:30-2:00	Analysis of the Decision-Making Process in Stem Cell Transplantation: Empirical Findings and Ethical Implications	Tatjana Weidmann-Huegle, Hanna Siegwart, Kyrill Schwegler, and Urs Schanz
	2:00-2:30	Genetic Justice after the Human Genome Project	Timothy F. Murphy
	2:30-3:00	Ethics in Canadian Health Technology Assessment: A Descriptive Review	 Dierdre DeJean and Mita Giacomini
	3:00-3:30	Expanded Newborn Screening: Informed Consent for the Public's Health	 Erica Sutton

Friday, June 1 / vendredi, le 1er juin

Room/Salle	Time/Heure	Title/Titre	Author(s)/Auteur(s)
KING	1:00-1:30	Deep-Brain Stimulation & the Brain-Computer Interface: Trials & Travails	Sheri Alpert
	1:30-2:00	Autonomy, Public Health and Prenatal Genetic Testing: Too many to tango?	Victoria Seavilleklein
	2:00-2:30	Just Regionalisation: Rehabilitating care for people with disabilities and chronic illnesses	Barbara Secker, Maya J. Goldenberg, Barbara E. Gibson, Frank Wagner, Bob Parke, Jonathan Breslin, Alison Thompson, Jonathan R. Lear, and Peter A. Singer
	2:30-3:00	What matters to the most vulnerable of the vulnerable – patients dying of brain cancer: A qualitative study in neuroethics	Mark Bernstein, Nir Lipsman, Jonathan Kimmelman, and Abby Skanda
	3:00-3:30	'Genohype' and the Discourses of Disability	Elisabeth Gedge
SIMCOE	1:00-1:30	Obesity, Ethics, and Public Health	James Dwyer
	1:30-2:00	The Big Patient Problem. Ethical issues in the organization and delivery of care for obese (bariatric) patients	Rick Singleton and Elaine Warren
	2:00-2:30	Case Studies and Consultations in Public Health Ethics: Why Not?	Barry N. Pakes, Nataly Farshait, and Bob Parke
	2:30-3:00	Ethical Dilemmas for Nurses in Protecting the Public's Health	Kathleen Carlin, Betty Burcher, and Louise R. Sweatman
	3:00-3:30	Social Determinants of the Health of Embryos and Implications for Children	Roxanne Mykitiuk and Jeff Nisker
TRINITY I	1:00-1:30	Being Kind Is Its Own Reward: Anonymous Living Organ Donation	Linda Wright, Diego Silva and Kelley Ross
	1:30-2:00	Living Anonymous Directed Organ Donation	Kelley Ross and Linda Wright
	2:00-2:30	Whose Decision Making Authority should be Privileged Post-mortem When Affirmative Wishes to Donate are Known?	Jeff Kirby
	2:30-3:00	Issues of Informed Consent in Public Umbilical Cord Blood Banking: Canadian Parents' Perspectives	 Rose Geransar, Isabelle Chouinard, Anna Zadunayski, and Glenys Godlovitch
	3:00-3:30	How Health Professionals Experience Ethics in Humanitarian Assistance and Development work: A Qualitative Study	 Matthew R. Hunt
TRINITY II	1:00-1:30	The Charter of Principle of the North Italy Transplant: a New Model of Medicine	Mario Picozzi
	1:30-2:00	Organ Donation after Cardiocirculatory Death	Alister Browne
	2:00-2:30	Donor advocacy programs for parental living liver donors : An ethical alibi?	Véronique Fournier and Emma Beetlestone
	2:30-3:00	TBA / à confirmer	
	3:00-3:30	Is renal transplantation a right or a privilege?	Delphine Roigt and Marie-Chantal Fortin

Friday, June 1 / vendredi, le 1er juin

Room/Salle	Time/Heure	Title/Titre	Author(s)/Auteur(s)
TRINITY III	1:00-1:30	On the Viability of a Pluralistic Bioethics	Chris Durante
	1:30-2:00	On The Banality of Ethics	Brendan Leier
	2:00-2:30	Enacting justice in health care practice in a diverse and inequitable society: Ideological fault-lines of egalitarianism and multiculturalism	Sannie Tang, Annette Browne, and Paddy Rodney
	2:30-3:00	Autonomy, Paternalism and the Impact Bias	Nada Gligorov
	3:00-3:30	Transcending the Paternalistic Model of Behavioural Healthcare: Allowing Middle-Ground Patients to Exercise Autonomy	John Holmes and John Tuohey
TRINITY IV	1:00-1:30	The Ethics of Evidence-Based Psychiatry	Mona Gupta
	1:30-2:00	Observations of a human research subject	Leigh Hayden
	2:00-2:30	TBA / à confirmer	
	2:30-3:00	Communicable Disease Control in The New Millennium: A Qualitative Inquiry on the Ethical Use of Restrictive Measures	Cécile Bensimon and Ross Upshur
	3:00-3:30	Clinical Ethics in the Service of Clinical Research: Another Kind of Clinical Consultation	Stuart Finder and Mark J. Bliton
BALLROOM A & B	1:00-1:30	Clinical Ethics and the Faith Factor	Robert D. Orr
	1:30-2:00	It's not all about Decision-Making: The Importance of Discernment and Spirituality in Clinical Ethics	Jim Huth and Deborah Pape
	2:00-2:30	Caring Approaches in Health Governance	Katherine Duthie
	2:30-3:00	The Case for Dignity	Nora Jacobson
	3:00-3:30	The Perceived Role of Islam in Western Muslim Medical Practice	A.I. Padela, N. Chin, J. Greenlaw, H. Shanawani, H. Hamid, and M.Aktas

Friday, June 1 / vendredi, le 1er juin

Room/Salle	Time/Heure	Title/Titre	Author(s)/Auteur(s)
YORK A	1:00-1:30	Doing Right in Difficult Settings: Medical leaders' moral quandaries	Suzanne Shale
	1:30-2:00	Evaluating the Success of Priority Setting	Shannon Madden, Ross Upshur, Peter Singer, and Douglas Martin
	2:00-2:30	ECWeb: A Quality Improvement Database Tool for Standardizing, Documenting, Assessing, and Reporting on Ethics Consultations	Mary Beth Foglia, Kenneth Berkowitz, Barbara Chanko, Raymond Frazier, and Ellen Fox
	2:30-3:00	Citizen Science for Safer Health Care: A Five Year Program of Research	Patricia Marck, Glenda Coleman-Miller, Beth Horsburgh, and Rene Day
	3:00-3:30	Harmless Worries? Error and the Ethics of Disclosure	Ann Munro Heesters
YORK B	1:00-1:30	Ethical Lessons to be Learned from a Diverse and Dispersed Population: Quaternary Level Developmental Assessment in British Columbia	Elizabeth Bredberg
	1:30-2:00	Organizational Ethics in Healthcare: Issues, Strategies, Indicators of Effectiveness	Jennifer L. Gibson, Eoin Connolly, Robert Sibbald, and Peter A. Singer
	2:00-2:30	Is Pharmacogenomics the Science for Global Justice?	Catherine Olivier and Byrn Williams-Jones
	2:30-3:00	Organizational Ethics: The Example of Business Development	Robert W. Sibbald, Jennifer Gibson, and Peter Singer
	3:00-3:30	"Ethics on the Move": Reflections on Three years of Capital Health Ethics Support	Mary McNally, Christy Simpson, Jeff Kirby, David Burke, and Cathy Simpson
3:30 – 4:00 p.m.	Break Grand Ballroom Foyer	1530 – 1600	Pause Grand Ballroom Foyer
4:00 – 5:00 p.m.	Plenary Session Grand Ballroom 	1600 - 1700 	Séance plénière Grand Ballroom
	Alloway Lecture <i>Is there a moral obligation to address spiritual needs of patients and their caregivers?</i> Daniel Sulmasy		Conférence Alloway <i>Y a-t-il une obligation morale de prendre en compte les besoins spirituels des patients et de leurs proches?</i> Daniel Sulmasy
5:00 p.m.	CBS Closing Remarks Grand Ballroom	1700	SCB - Mot de la fin Grand Ballroom
5:30 – 6:30 p.m.	Cash Bar Reception at Horizons CN Tower	1730 – 1830	Réception, bar à la carte au Horizons Tour du CN
6:30 – 8:30 p.m.	Dinner with a View at the CN Tower 301 Front Street West	1830 - 2030	Souper avec vue panoramique à la Tour du CN 301 Front Street West

Saturday, June 2 / samedi, le 2 juin

7:30 – 9:00 a.m.	Registration Grand Ballroom Foyer	7h30 – 9h00	Inscription Grand Ballroom Foyer
8:55 – 10:00 a.m.	International Panel Grand Ballroom 	8h55 – 10h00	Panel international Grand Ballroom 
	Reflections/experiences from the developing world: clinical ethics beyond the ethics of clinical research Jens Mielke, Robyna Khan, & Anant Bhan		Réflexions et expériences des pays en émergence: l'éthique clinique au-delà de l'éthique de la recherche clinique Jens Mielke, Robyna Khan, & Anant Bhan
10:00 – 10:30 a.m.	Break & Posters Grand Ballroom Foyer	10h00 – 10h30	Pause et affiches Grand Ballroom Foyer

Concurrent Sessions—10:30 to 12:00 p.m. / Séances simultanées—10h30 à 12h

Room/ Salle	Time/Heure	Title/Titre	Author(s)/Auteur(s)
GRAND BALLROOM 	10:30-12:00	WORKSHOP: Get It Together: a practical workshop on planning, building and sustaining an effective clinical ethics consultation team	Andrea Frolic and Leigh Hayden
TRINITY I	10:30-11:00	Globalizing Human Experimentation: A Re-examination of the Moral Issues	 Osimiri Peter
	11:00-11:30	Clinical and Psychological Issues in Survivors of Torture	John Perry and Ezat Mossallanejed
	11:30-12:00	Risky Measures: Objectivity and Interpretation in the Science and Methods of Public Health	Suze Berkhout
TRINITY II	10:30-11:00	Clinical Ethics Consultations in a Society with Family-Centred Decision Making	Alireza Bagheri
	11:00-11:30	Complementary and Alternative Medicine (CAM) in the Hospital Setting: The Controversy and Challenge of Developing a CAM Policy	Maya Goldenberg and Paula Chidwick
	11:30-12:00	Sharing Responsibility For At-Risk Children & Youth: Finding Morally Credible Solutions Within Constrained Services	Cheryl Williams
TRINITY III	10:30-11:00	Health Care Ethics and Clinical Ethics in Ireland	Heike Schmidt-Felzmann
	11:00-11:30	Family Will – An Indian perspective	Jameela George
	11:30-12:00	Developing Ethical Oversight in El Salvador: Perspectives from the Field	Jonathan W. Camp, Amanda J. Young, Miguela D. Caniza, Raymond Barfield, Ruthbeth Finerman, and Alicia Rodriguez

Saturday, June 2 / samedi, le 2 juin

Room/ Salle	Time/Heure	Title/Titre	Author(s)/Auteur(s)
TRINITY IV	10:30-11:00	To Treat or not to Treat: Medical Aid for Children and Adults in Developing Countries faces Allocation Problems	Klaus Kobert and Christine Möhle
	11:00-11:30	Reflections on 'False' Hope: Letting Our Emotions Do the Work?	Christy Simpson
	11:30-12:00	Moving towards Clinical Ethics Consultation in Italy	Antonio G. Spagnolo and Nunziata Comoretto
TRINITY V	10:30-11:00	Implementing Clinical Ethics in German Hospitals: Content, didactic methods and evaluation of a nationwide training program	Gerald Neitzke, Andrea Dörries, Alfred Simon, and Jochen Vollmann
	11:00-11:30	Clinical Ethics in Nigeria: A Critical Appraisal	Ayodele Samuel Jegede, A.O. Adejumo, and T. Ogundiran
	11:30-12:00	Medical Professionalism in Japan and Britain: A Cross-Cultural Dialogue	Gregory Plotnikoff and Suzanne Shale

12:00 – 1:00 p.m.

Lunch

Grand Ballroom Foyer

12h00 – 13h00

Dîner

Grand Ballroom Foyer

Concurrent Sessions—1:00 to 3:30 p.m. / Séances simultanées—13h à 15h30

Room/ Salle	Time/ Heure	Title/Titre	Author(s)/Auteur(s)
GRAND BALLROOM 	1:00-1:30	A Feminist Argument for Incorporating a "Meaning-Making" Intervention into Routine Cancer Patient Care	Jennifer Bell
	1:30-2:00	Resolving Conflicts Over Life-Sustaining Treatment: Views of the Public	Jonathan Breslin, Eoin Connolly, Sue MacRae and Alireza Bagheri
	2:00-2:30	Why Ethics Matters; One Family's Perspective	Barbara Farlow
	2:30-3:00	Front Line Nurses Perceptions of Enacting Patient Centred Care	Billie Hilborn, Karen Faith, and Lisa Rougas
	3:00-3:30	UK Clinical Ethics Support: The Challenge of Patient Access	Ainsley J. Newson
TRINITY I	1:00-1:30	Re-reading Dax's Case	Giles R. Scofield
	1:30-2:00	The wish to hasten death among ALS patients in a palliative care program	Ralf J. Jox, Sigrid Haarmann-Doetkotte, Maria Wasner, and Gian Domenico Borasio
	2:00-2:30	Responding to Trust: Perspective of Surgeons on Informed Consent	Martin McKneally and Douglas Martin
	2:30-3:00	Withholding and Withdrawing Life-sustaining Care in a Rehabilitation Centre	Jenny Young, Alister Browne, and Bill Sullivan,
	3:00-3:30	End of Life Models in Practice: Why Consistency Matters for Patient Care	Helene Anderson, Ann Bryant, Bronwyn Evenson and Marsha Rice

Saturday, June 2 / samedi, le 2 juin

Room/ Salle	Time/Heure	Title/Titre	Author(s)/Auteur(s)
TRINITY II	1:00-1:30	Assisted suicide knocking at Swiss hospital doors: Establishing recommendations on how to deal with inpatients seeking assistance in suicide at the Zurich University Hospital	Georg Bosshard and Nikola Billar-Andorno
	1:30-2:00	Ethics of Palliative Sedation: Clinical and Practical Guidelines	Marcia Sokolowski and Michael Gordon
	2:00-2:30	The Curious Case of the Recalcitrant Defibrillator	Daryl Pullman, Kathy Hodgkinson, and Rick Singleton
	2:30-3:00	Justice for incompetent patients?	Annie Janvier, Isabelle Leblanc, and Keith Barrington
	3:00-3:30	Advance Directives, DNR Bracelets and Suicide Attempts	Arthur Derse and Cynthiane J. Morgenweck
TRINITY III	1:00-1:30	Improving Transparency: The ODBP and the Transparent Drug Systems for Patients Act (2006)	Oliver Klimek
	1:30-2:00	Rounding as a Clinical Ethics Consultation Service	Nneka O. Mokwunye and Daria C. Grayer
	2:00-2:30	The Ethics of Bioethics: Some Elements of Code Development	Kenneth Kipnis
	2:30-3:00	Are ethical issues being overlooked whilst encouraging reflection within academic nursing study?	Ruth Todd
	3:00-3:30	Becoming an Ethics Consultant: The Experiences of Health Professionals as they take on the Role of Ethics Consultant	Michael D. Coughlin and Andrea Frolic
TRINITY IV	1:00-1:30	Making ethics matter to Clinicians: First do not harm to each other	Anne Moorhouse and Hilda Swirsky
	1:30-2:00	Inter-professional Values and Practices : Considerations in IP Negotiation and Dialogue	Michele Chaban
	2:00-2:30	Linking the Political to Ethical Clinical Practice: Impacts on Knowledge and Identities for Nurses Who Advocate for Lesbian Health	Judith A. MacDonnell
	2:30-3:00	Certification Revisited: Is Now the Time to Formalize Professional Training in Clinical Ethics?	Gary Goldsand and Neil Elford
	3:00-3:30	On professionalism and ethics in healthcare: A report from the Expertise Center for Ethics and Care, University Medical Center Groningen	Menno J. de Bree, E.E. Feenstra, E.L.M. Maeckelberghe, and M.A. Verkerk
TRINITY V	1:00-1:30	Charity Care - What are our obligations to the Uninsured?	Eoin Connolly, Jennifer Gibson, Robert Sibbald, and Peter A. Singer
	1:30-2:00	Privacy and Informed Consent: The challenge of new technologies in the workplace	Glenys Godlovitch, Barry Baylis, Stacey Page, and Bill Ghali
	2:00-2:30	Ethical Implications of an Exploration of Technology Adoption in Healthcare	Suzanne Craig
	2:30-3:00	TBA / à confirmer	
	3:00-3:30	Innovating a Process for Innovations in Patient Care	Randi Zlotnik Shaul and Maria Macdonald

Saturday, June 2 / samedi, le 2 juin

3:30 – 4:00 p.m.	Break Grand Ballroom Foyer	15h30 – 16h00	Pause Grand Ballroom Foyer
4:00 – 5:00 p.m.	Plenary Session Grand Ballroom 	16h00 – 17h00	Séance plénière Grand Ballroom 
	Global Bioethics – The Ethics Program of UNESCO Henk ten Have		Bioéthique globale : le programme éthique de l'UNESCO Henk ten Have
5:00 p.m.	Tribute to Ron Cranford Grand Ballroom	17h00	Hommage à Ron Cranford Grand Ballroom

Sunday, June 3 / dimanche, le 3 juin

10:30 – 11:00 p.m.	<p>Break Grand Ballroom Foyer</p> <p>Choral Performance by the Miles Nadal Jewish Community Centre Choir The Miles Nadal Jewish Community Centre Choir is an auditioned community choir with members ranging in age from 21 to 80. Under the direction of Harriet Wichin, this choir sings a wide variety of music including jazz, international, classical, rhythm and blues, Hebrew and Yiddish tunes.</p>	10h30 – 11h00	<p>Pause Grand Ballroom Foyer</p> <p>Spectacle de chorale par le Miles Nadal Jewish Community Centre Choir Le Miles Nadal Jewish Community Centre Choir est une chorale dont les membres sont âgés de 21 et 80 ans. Pour faire partie de cette chorale, les choristes doivent, au préalable, passer une audition. Harriet Wichin dirige cette chorale qui chante dans une variété de styles musicaux, tels que le jazz, le rhythm and blues, la musique du monde et des chansons en hébreu et en yiddish.</p>
11:00 – 12:00 p.m.	<p>Closing Plenary Panel Grand Ballroom</p>  <p>Challenges for Clinical Ethics as It Develops Internationally George J. Agich, Stella Reiter-Thiel, & Ross Upshur</p>	12h00 – 12h00	<p>Séance plénière de clôture Grand Ballroom</p>  <p>Les défis de l'éthique clinique dans son développement international George J. Agich, Stella Reiter-Thiel, & Ross Upshur</p>
12:00 – 12:30 p.m.	<p>ICCEC Closing Remarks Invitation to Next Conferences Grand Ballroom</p>	12h00 – 12h30	<p>CIECC - Mot de la fin Invitation aux prochaines conférences Grand Ballroom</p>

CBS Poster Exhibit /Présentations par affiche de la SCB**Thursday, May 31 / jeudi, le 31 mai**

Title/Titre	Author(s)/Auteur(s)
Trainee Selection for Research Bioethics Training in a Developing Country (Bangladesh)	Harun Ar-Rashid
Cesarean Section: Jewish Ethical Requirements	Marianne L. Burda
Dignifying Canadian Biomedical Policy	Lawrence Burns
Teaching and Assessing Professionalism and Ethics in an Undergraduate Medical Program	Eugene. C. Cameron and Alister Browne
Development of Donation after Cardiac Death Policy, Essential Involvement of the Institutional Ethics Committee	Annette Carron, Ernest Krug, Diane Morgan and Barb Cottrel
The relationships of moral distress, ethical climate, and intent to turnover among critical care nurses	Karla M. Fogel
The Dilemma of Consent giving in Clinical Drug Trial in Zambia: A Conflict Between Rights and Culture	Kaona A.D. Frederick and Mary Tuba
Fair Allocation of Health Resources: A Qualitative Investigation of Responses to a Quantitative Survey	Mita Giacomini, Jeremiah Hurley, and Deirdre De-Jean
Dying from Respiratory Disease: Constructed Reality and the Interpretive Repertoires of ICU Nurses	Donna Goodridge, W. Duggleby and S. Ellis
A Survey of the 'Ethics Climate' in Hong Kong Public Hospitals	Edwin C. Hui
Inclusivity and Engagement: Challenges in Using Theatre as Novel Method of Health Policy Development	Magdalena Kazubowski-Houston, Susan M. Cox, and Jeff Nisker
Exploring Ethical Risk Communication in a Health Context	Holly Longstaff
Congestive Heart Failure Offering Individualized Choice Evaluation Study (CHOICES)	Jane MacIver and Heather Ross
Using Technology & Partnerships to Enhance Ethics Knowledge & Build Ethics Capacity in Northern Ontario	Maureen McLelland, Karen Longlade, Allison Cline-Dean, and Rachel Haliburton
Do-Not-Resuscitate Ordering Patterns Between Physician Specialties	Eric Douglas Morrell, B.P. Brown, K.E. Drabiak, A.Q. Pong and P.R. Helft

CBS Poster Exhibit / Présentations par affiche de la SCB**Thursday, May 31 / jeudi, le 31 mai**

Title/Titre	Author(s)/Auteur(s)
Is the Global Rationing Debate a Non-Debate? Contesting Some Uncontested Claims in the Current Health Care Rationing Literature	Janne Nikkinen
Implications éthiques des biotechnologies appliquées à l'agriculture. Analyse du discours de la presse écrite de l'Argentine	Mariana Nunez
An Audit of Health Products and Services Marketed on Chiropractic Websites in Alberta and Consideration of these Practices in the Context of Chiropractic Codes of conduct and Ethics	Stacey A. Page
Currents of Hope: Bioethics and International Print Media Coverage of Neurostimulation Techniques	Nicole Palmour and Eric Racine
Centering the 'Human Subject' in Health Research: Understanding the Meaning and Experience of Research Participation	Nina Preto, Susan Cox, Michael McDonald, Pat Kaufert, Joe Kaufert, Catherine Schuppli, Kim Taylor, Natasha Damiano and Lisa Labine
Biotechnology Innovation and Health System Sustainability: An Ethical Approach to Priority Setting	Zahava R.S. Rosenberg-Yunger, Peter A. Singer, Abdallah S. Daar, and Douglas K. Martin
Informed Consent and Stimulant Medication: Adolescents' Preferences for Information and Understanding of Information	Debbie Schachter and Irwin Kleinman
Ethical Issues of Qualitative Health Research: Patients and Practitioners as Subjects and Gatekeepers or Contextual Contributors?	Anne Townsend and Susan Cox
The Cascade Education Campaign: An Effective Bioethics Education Program	Davidicus Wong
Attitudinal Barriers Towards Medical Students with "Disabilities"	Adelicia Yu, Janet Malowany, Bruce Weaver and Jeffrey Nisker
Ethical Challenges of New Advances of Biotechnology and Islamic Views in Iran	Farzaneh Zahedi and Bagher Larijani

ICCEC Poster Exhibit /Présentations par affiche de la CIECC

Saturday, June 2 / samedi, le 2 juin

Title/Titre	Author(s)/Auteur(s)
Resolving Conflict Through Bioethics Mediation	Armand H. Matheny Antommara, and Edward B. Clark
Experiences of Genetic Discrimination Among Presymptomatic Huntington Disease Mutation Carriers	Yvonne Bombard, Elizabeth Penziner, Joji Decolongon, Mary Lou Nicolson Klimek, Susan Creighton, Oksana Suchowersky, Mark Guttman, Jane S. Paulsen, Joan L. Bottorff, and Michael R. Hayden
The Effect of the Routinization of Medical Care on Patients Informed Consent	Melissa Constantine
Approche éthique des stratégies décisionnelles dans une situation d'incertitude et d'urgence d'accident vasculaire cérébral grave	Sophie Crozier, Christine Pires, et Yves Samson
Clinical Ethics Consultation Relevant to Cardiovascular Surgery: A Turkish Experience in Istanbul	Hanzade Dogan
Getting Ethics into Action. A Practice Based Approach to Implementing Ethics into a Healthcare Organization	Enne Feenstra
Sedation in Palliative Medicine	Hans-Jurgen Flender, Klaus Kobert, and Fritz Mertzluft
« Quelle utilité de l'éthique clinique pour l'évaluation des pratiques ? » Réflexions à partir d'une étude des déterminants éthiques dans la prise en charge du cancer colorectal chez les patients âgés.	Nicolas Foureux, Catherine Brezault, Vered Abitbol, Marianne Gaudric, Mahut Leconte, et Véronique Fournier
Can an Ethics Committee Contribute to Reducing Bureaucracy in Managed Care?	Ofra Golan, Basil Porter, and Joshua Shemer
Does Ethics Education Influence the Use of Ethics Resources by Practicing Nurses and Social Workers?	Christine Grady, M. Danis, K. Soeken, P. O'Donnell, C. Taylor, A. Farrar, Y. Fang, and C. Ulrich
Moving Ethics Forward by Building Community Health-care Capacity	Karen Longlade, Maureen McLelland, Allison Cline-Dean, and Rachel Haliburton
Implementation of an Ethics Service in Mental Health and Addictions Services in the Calgary Health Region	Connie E. Mahoney
Outil méthodologique d'analyse des mécanismes décisionnels en éthique clinique: Place des émotions	Perrine Malzac, Pierre Le Coz, et Jean-Robert Harle
Revisiting Patient Responsibilities: The Other Side of Patient Rights	Maria McDonald

ICCEC Poster Exhibit /Présentations par affiche de la CIECC**Saturday, June 2 / samedi, le 2 juin**

Title/Titre	Author(s)/Auteur(s)
Surgeon-Patient Communication: Precept and Practice	Temidayo O. Ogundiran and Clement A. Adebamowo
Ethics: It's All About the Journey	Catherine Petch and Glenn Yaffee
Epilepsy Surgery as an Example for Ethical Consideration in Elective Interventions	Margarete Pfaellin, Klaus Kobert, and H.W. Pannek
Être consultant en soins palliatifs pédiatriques: dilemmes éthiques rencontrés dans la pratique quotidienne	Suzanne Plante
A Qualitative Study of Prognostication and End-of-Life Decision-Making in Critically-Ill Neurological Patients	Eric Racine, Maarten Lansberg, Marie Josée Dion, Judy Illes, and Christine Wijman
End of Life (EOL) Communication: What do Intensivists document?	Mohana Ratnapalan, Andrew B. Cooper, D.C. Scales, T. Sinuff, and R. Pinto
Ethical Decision-Making in Patients who Cannot Communicate: Problems Arising in a Long-Term Ventilation Unit	Joerg Stockmann
Ethics Rounds or Ethics Consultation in Sweden? How Much Input Should the Ethicist Have? - Nurses' and Physicians' Experiences	Mia Svantesson, R. Löfmark, H. Thorsén, K. Kallenberg, and G. Ahlström
A Case of Organ Transplantation from Istanbul: Would Ethics Consultation Change the Coercion or Voluntariness?	Elif Vatanoglu and Hanzade Dogan
Enhancing Patient and Family Care Through Clinical Ethics Consultation	Cathy Walls, Kathy McKay, Christy Simpson, and Jeff Kirby
The Functioning of a Clinical Ethics Committee in an Acute Care Hospital	Elaine Warren and Alice P. Gaudine
Bioethics and Primary Healthcare: An Approach for Principlism, Virtue, Casuistry or Care?	Elma Zoboli

**ABSTRACTS:
Workshop & Paper
Presentations**

**RÉSUMÉS:
Ateliers &
présentations
orales**

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Disintegration of medical ethics by means of clinical reasoning

Although the medical profession has deep moral foundations, clinicians often find it difficult to recognize how theories of bioethics are relevant for their daily work. Even if you realize that medicine is replete with ethical aspects, it is not evident where the moral issues arise from the medical ones in daily clinical work. So where did ethics go?

I am currently undertaking a study where I seek to disclose how physicians handle the diverse moral aspects of medicine that arise through their regular working day. My findings suggest that physicians' systematic approach to clinical situations affects their ability to recognize the ethical issues. Irrespective of their field, physicians use a similar technique in their approach to clinical questions. In order to handle multifaceted, diffuse and often troubling clinical encounters, physicians separate the problems into lesser, more manageable fragments. They also seek to concretize the issues, categorize the patients' complaints to fit medical definitions, and accordingly delimit medicine's area of responsibility.

This informal method of clinical reasoning is intended to simplify the problem at hand and improve the physicians' ability to make required decisions in a complex reality. The benefit of this process is not only simplification of the clinical problem, but fragmentation of the inherited values. The concept of human dignity is deprived of meaning when the patient is divided into organs, physiological functions and subjective suffering, and otherwise difficult value laden questions seemingly disappear. Physicians' practical approach to clinical issues thus actively and systematically disperses medical ethics.

Susan Albersheim, Liisa Holsti, Vincent Arockiasamy

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The Experience of Fathers in the Neonatal Intensive Care Unit

Introduction: Having a critically ill newborn is extremely stressful for both parents. Fathers are important participants in the care of their babies, and the bonding of fathers with their children is crucial for optimal development. Little is known about the experiences of fathers in the Neonatal Intensive Care Unit (NICU), and no studies have examined Canadian fathers' experiences.

Objective: To understand the experience of fathers of very ill babies.

Methodology: In this qualitative study, one male interviewed 16 fathers of very ill newborns, who had been in the NICU for more than 30 days. Fathers were asked about their babies, focusing particularly on concerns regarding communication and accessing of information, as well as more general perceptions of their experience in the NICU. Interviews were audio-taped and transcribed, with ongoing analysis to determine sampling. Coding was by content analysis, with validation of themes by three researchers.

Results: The over-arching theme for fathers was the importance of control or sense of lack of control, from which coping strategies were developed. The themes important in the development of coping strategies were communication, relationships, information, roles, world views, and personal diversions.

Discussion: Fathers experience a sense of lack of control when they have an extremely ill baby in the NICU. Coping strategies help fathers regain control, in order to fulfill their various roles of protectors, fathers, partners, and breadwinners.

Speculations: Helping fathers develop coping strategies in the NICU will improve their early experiences, their relationship with the health care system, and enhance bonding with their babies.

Caroline Alfieri

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Ethical considerations in the prioritization of children for pandemic influenza vaccine

The debate over the child's place in priority ranking lists for pandemic influenza vaccine distribution is still unresolved. The Canadian Pandemic Influenza Plan has placed children last in its vaccine allocation scheme. This was based on the observation that children have not been among the most critically affected populations in past pandemics. A rigorous ethical process for establishment of the priority groups must take into account the goals of pandemic planning which are to minimize overall morbidity and deaths, and to reduce societal disruption, in the event of an influenza pandemic. Since pandemic flu preparedness is a public health endeavour, the fact that children are efficient transmitters of respiratory infections would promote the reasoning that vaccinating them first should help protect the health of the entire population. This is in line with the framework of public health ethics, whereby concerns for the aggregate are favoured over individual interests. The question is whether this rationale is sufficiently robust—when balanced against the rationales used for prioritizing other groups—to grant children higher priority in the ranking scheme. Another approach in favour of raising the priority status of children invokes the 'fair innings' argument which bases calculations of resource allocation on the number of quality years remaining in a person's lifespan. The presentation will propose various scenarios to help guide pandemic planners in establishing priority lists for vaccine distribution. The arguments presented may also be useful when planning public forums on vaccine allocation issues.

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Deep-Brain Stimulation and the Brain-Computer Interface: Trials and Travails

Neuroscience research and technologies have rapidly become more invasive in recent years. For instance, Deep Brain Stimulation (DBS), which uses electrodes implanted in the brain to deliver electrical current, is being studied to determine its efficacy for helping those with treatment-resistant depression and obsessive-compulsive disorder. In contrast to DBS, Brain Computer Interfaces (BCI) use brain signals sent to a computer to either activate external devices, like a paralyzed or prosthetic limb, or translate brain signals generated through eye movement into movement of a cursor across a computer screen. Both these technologies/techniques are in the investigational stage of testing. While they may hold great promise, one of the primary ethical concerns associated with these particular devices is the claim that they can have a fundamental, potentially irreversible, impact on a patient's personality and his/her ability to function.

Given the potentially transforming nature of these devices, it is especially troubling to consider the 2004 Auditor General's report on Health Canada's (HC) regulation of medical devices. The report identified several weaknesses in the entire approval process, from lack of regulatory authority to conduct proactive inspections in the investigational testing phase for medical devices to HC's alleged laxity in exercising post-market oversight of devices. These weaknesses may be putting human research subjects in peril. I provide an overview of DBS and BCI, the current regulatory framework for medical devices (pre- and post-market phases) in Canada, and suggest changes to the medical devices regulations to more fully protect human research subjects and potential device recipients.

Helene Anderson RN, BA, CCRN; Ann Bryant, MSW, LCSW; Bronwyn Evenson, RN, BSN, CCRN, MD; Marsha Rice, RN

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End of Life Models in Practice: Why Consistency Matters for Patient Care

Providence St. Vincent Medical Center (PSVMC) is an academic teaching hospital in Portland, Oregon. It is part of Providence Health and Services the largest health care system on the West coast. End of life protocols used as a guideline for the inpatient health care team ensure consistency with practice and patient care delivery. The protocols are designed to reduce risk, ensure the delivery of quality care, support the ethical decision making process and to create an atmosphere of ethical direction. Sample protocols include the Physician Orders for Life Sustaining Treatment (POLST), advanced directives, withdrawal of mechanical ventilation, brain death and organ donation.

The outcomes are measured by an analysis of information collected from The End of Life Family Survey. This survey is mailed to all families of patients who die in PSVMC. It helps measure family satisfaction with this important inpatient experience. The satisfaction data can then be linked to practice standards reinforced by the protocols for end of life care. Providence St. Vincent was awarded the national 2003 Circle of Life Award for exemplary delivery of end of life care.

When end of life protocols for practice are followed by trained staff, care plans can be more easily developed for a variety of unique situations which can be laden with difficult ethical issues. Patients and families are more likely to develop confidence in the care team because of the consistency that is enhanced by the utilization of these protocols.

Alireza Bagheri

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Clinical Ethics Consultation in a Society with Family-Centered Decision Making

The family-centered healthcare decision-making model is a culturally accepted ethical norm in Asian and Hispanic societies, among others. This differs significantly from societies such as North America and some parts of Europe where patient autonomy and confidentiality are key values. In the latter, patients may prefer to make ultimate decisions on their own. However, in most parts of Asia for example, patients may prefer to include family members during medical visits and also leave healthcare decision-making to someone else in the family.

This paper examines how providing ethics consultation in a society where healthcare decision making is family-centered differs from a clinical setting in which patients prefer to have the authority in making decisions. The paper highlights the challenges in providing ethics consultation in a multi-cultural society where patients from different cultures seek medical intervention.

Françoise Baylis, Walter Glannon, Eric Racine, and Jason Scott Robert

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Neuroenhancement for Sustainable Well-Being

Developments in the neurosciences are giving us new and better treatments for old diseases. Moreover, as evidenced by recent advances in neural prosthetics, experimental neurosurgery, and psychopharmacology the domain of neuroscience is expanding dramatically. According to some, these advances 'promise' (and according to others, they 'threaten'), to transform the very meaning of what it is to be human. This potential transformation has significant implications for how we understand sustainable well-being.

What if, for example, social ills that result from contingent limitations of the human brain could be addressed through bioengineering, chemical manipulation or neuro-environmental changes? Is it reasonable (even, praiseworthy) to push for or against such "treatment" or "enhancement"? On the basis of what interests and what values might such interventions be embraced? At an individual level, assuming choice is an option, what are the implications of taking control of the brain, and choosing to enhance certain capacities (for attention, memory, language, consciousness and so on) while suppressing others? What are the challenges and implications of "volitional cognition" – where our brains choose how our brains are to work? And, what about the less volitional aspects of cognitive transformations as when the marketplace "chooses" how our brains are to work? More generally, how does this all fit with the view that "progress is to be thought of in terms of improving the human condition"?

This Panel presentation is by researchers on the CIHR New Emerging Team "States of Mind: Emerging Issues in Neuroethics" led by Françoise Baylis.

Jennifer Bell

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A Feminist Argument for Incorporating a "Meaning-Making" Intervention into Routine Cancer Patient Care

Recent studies in psychosocial oncology that seek to address the social, psychological, emotional, and functional impacts of cancer, report positive findings for "meaning-making" interventions designed to help cancer patients cope with their illness experience. These interventions are successful in decreasing cancer patient depression and increasing life satisfaction, self-esteem, physical functioning, and optimism. By extension these interventions may help patients regain or retain their autonomy following diagnosis. Despite these positive findings, however, and the great potential these interventions hold for increasing patient autonomy, meaning-making interventions and, more generally psychosocial care, are not well incorporated into routine cancer patient care.

In this paper I argue that a feminist ethical framework of relational autonomy morally obligates healthcare professionals and institutions specializing in oncology to incorporate the intervention into patient care. Relational autonomy is a significant improvement on the more traditional conception of patient autonomy, which requires patients to possess an independent rationality to make informed choices and judgments. Often under the traditional account patients' experience of pain, suffering, shock, and trauma are seen as obstacles to patient autonomy. These affective states, in other words, are conceptualized as impairments, limiting patients' ability to make informed and carefully reasoned treatment choices.

Instead of viewing emotions as an obstacle to autonomy, relational theory appreciates them as part of patients' coping with life-altering information, not least because reliance on others in order to cope is seen as unproblematic from this perspective. Consequently, if we are in fact committed to supporting patient autonomy, where autonomy is conceptualized in relational terms, we are morally obligated to incorporate meaning-making interventions into routine cancer patient care.

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Communicable Disease Control in the New Millennium: A Qualitative Inquiry on the Ethical use of Restrictive Measures**STATEMENT OF PURPOSE/PROBLEM**

When public health decision-makers invoked quarantine during the recent SARS epidemic, it raised difficult questions about the legitimacy and acceptability of restrictive measures to achieve public health goals. While public health interventions have traditionally been justified on utilitarian grounds, this project aims to establish an empirical basis for public health action. It investigates how individuals perceive the use of restrictive measures as a means to control the spread of communicable diseases and seeks to characterize their views on the justifiability of such measures.

METHODS

The authors employed qualitative methodologies to gather lay and expert perspectives. They conducted personal interviews with 62 participants consisting of 23 health care providers, 16 members of the public, 13 community and/or spiritual leaders from the Greater Toronto Area as well as 6 public health officials and 4 regulators at local, provincial or federal levels of jurisdiction. Participants' views were analyzed and organized into themes.

RESULTS

The views of participants on the use of restrictive measures to control the spread of communicable diseases were organized according to six themes: common good; varieties of quarantine; compliance; reciprocity; uncertainty; and communication.

CONCLUSIONS/IMPLICATIONS

This project contributes to the emerging field of public health ethics. Combining empirical research with conceptual scholarship, the authors develop a novel framework for ethical decision-making in the implementation and enforcement of restrictive measures during infectious disease outbreaks within the context of a Habermasian model of communicative action that brings public health ethics and human (individual) rights into dialogue.

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La valorisation de la recherche universitaire : un regard éthique

Au cours des dernières années, le rôle sans cesse grandissant de vecteur économique dévolu aux établissements d'enseignement supérieur et de recherche a considérablement modulé les structures de la recherche universitaire au Canada. Sous le paradigme omniprésent de l'économie du savoir, la valorisation des résultats de la recherche, l'innovation et le transfert de connaissances sont devenus les nouveaux chevaux de bataille des universités canadiennes.

Alors que les volontés gouvernementales et institutionnelles d'accroître le rôle des universités dans le processus national d'innovation semblent répondre tant à des impératifs économiques qu'à un souci de justice sociale en prônant un retour d'investissements sur les fonds publics, les conséquences de ces politiques sur la recherche universitaire et particulièrement celle impliquant des sujets humains demeurent en grande partie inconnues. Pourtant, l'intensification et l'orientation de la recherche universitaire n'est pas sans soulever d'importants enjeux éthiques.

Les universités peuvent-elles répondre simultanément de la recherche désintéressée et de la recherche du profit? Quels sont les effets de cette double orientation sur l'intégrité, les questions de conflits d'engagement et d'intérêts auxquelles font face, entre autres, les chercheurs, soumis à des exigences multiples et souvent contradictoires? Quelle est la visée éthique de la valorisation et ses implications institutionnelles? Faut-il aller jusqu'à valoriser tout matériel de recherche, tel que les banques et les sous-produits? À quel prix?

C'est à ces questions que cet atelier tentera de répondre démontrant qu'à toute phase du processus de recherche « l'éthique, c'est important ! ».

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Risky Measures: Objectivity and Interpretation in the Science and Methods of Public Health**Issue:**

Concerns related to the field of public health are increasingly attended to within bioethics; these are not simply a matter of competing claims of individual rights and the social good. In this paper, I consider how, within the context of HIV, the relationship between epidemiology and public health enables the perpetuation of problematic and harmful social identities.

Approach:

Drawing from a range of philosophical literature, including that of Charles Taylor, Foucault, and from contemporary discussions of public health ethics, I give an analysis of a particularly challenging metaphysical and ethical problem related to the predominant scientific methods of public health.

Key Points:

Reductionist models of epidemiology presuppose a clear distinction between description and evaluation, contributing to an understanding of social reality as consisting of brute data. This ultimately misconstrues modes of social relations as individual actions or behaviours. When we consider this issue in the context of HIV, an ethical problem emerges. Describing individual actions as "data," or "fact," constructs and reinforces transgressive social identities. Given that stigmatization is itself part of the risk context for HIV and adverse health outcomes, the reliance of public health on methods that unreflexively interpret human action is ethically problematic.

Conclusions:

Epidemiology has a fundamental and foundational relationship with public health. Understanding this relationship in the context of HIV suggests that difficulties located within the scientific underpinnings of public health cannot be overlooked. These problems, metaphysical and ethical, may be resolved through an understanding of epidemiology as an essentially hermeneutical science.

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**What matters to the most vulnerable of the vulnerable – patients dying of brain cancer:
 A qualitative study in neuroethics**

Background: Much money and energy has been spent on the study of the molecular biology of malignant brain tumours. As well, numerous randomized controlled studies have been done and have found no or minimal improvement in survival. However, little attention has been paid to the wishes of patients afflicted with these incurable tumours, and how this might influence treatment considerations.

Methods: The authors undertook a qualitative study using semi-structured interviews with terminal brain cancer patients and/or their family members. Transcripts were subjected to modified thematic analysis by five reviewers. REB approval was obtained, participation was voluntary, and informed consent was obtained.

Results: Thirty brain cancer patients and/or their family members were studied over an 18-month period. Analysis of the interviews yielded several themes. Most patients value independence and quality of life over longevity. Most would be willing to make some trade-offs for longer survival, but not major ones. For example, hemiplegia would be accepted for 3 months additional survival but not cognitive impairment to gain 6 months additional survival. Gaining information about their illness was deemed important in patients' ability to cope. Most families of deceased patients favoured the option of assisted suicide, but the loved ones of living patients had more mixed feelings.

Conclusions: Understanding what values and priorities are important to brain cancer patients and their loved ones can help clinicians care better for these vulnerable patients. Qualitative research in neuroethics can augment and support concepts, and can help answer questions quantitative methodology cannot.

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Minimal Risk Revisited: The Ethics of Clinical Research with Children

One of the central problems concerning research with children is the delineation of appropriate levels of exposure to risk. The US Code of Federal Regulations developed the concept of "minimal risk" as an anchoring measure for allowable risk in clinical research involving children. By restricting research with healthy children to no more than "minimal risk" and research with children with a disease or disorder to no more than a "minor increase over minimal risk", the regulations sought to promote a balance between scientific advances in pediatric research and the protection of children's vulnerable status. In spite of the guideline's definition of minimal risk, as procedures in which "the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life, or during the performance of routine physical or psychological examinations or tests," research ethics boards and the medical community espouse a multitude of varying opinions regarding what procedures classify as minimal risk. Without a uniform understanding, the federal guidelines have been interpreted in different ways, with more recent research demonstrating a trend toward the inclusion of children in higher risk research.

This presentation documents an escalation of risk in pediatric research as the result of ambiguities in the federal guidelines. Informed by ethical theory, law, and guidelines governing pediatric research, the analysis will evaluate the increase in risk in pediatric research, call for a reassessment of the concept of minimal risk, and recommend a modified theory of casuistry as the most practical method of risk classification.

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Neonatal brain death – Case report on the background of German law

We will present the exceptional situation of a neonatal brain death in an only 10-day-old baby after a huge intracerebral bleeding. The parents themselves raised the question of organ explantation in their daughter. After fulfilling the catalogue of criteria for brain death, her heart could successfully be donated to a young baby with a severe congenital heart defect.

The conditions of the German transplantation law concerning babies will be presented on the background of the discussion about organ explantation in patients being not strictly brain dead, like in heart beating donors or anencephalic babies.

In Germany brain death in neonates has to fulfil the same preconditions and the same completed list of missing brainstem reflexes, whereas the proof of irreversibility is even stricter than in all older age groups. Brain dead babies of less than 37 wks of gestation are not allowed to be organ donors at all in Germany.

But neonates very seldom reach these strict criterions with all clinical and technical signs, because in cases of cerebral edema or other forms of swelling, their brain is not restricted to the defined volume of the cerebral cavity.

On the other side the emotional background of the parents losing their loved and newly welcomed baby stands in great contrast to the request for organ donation.

So explantation in newborn babies, although they are the group of children with the highest mortality rate, does not really take place in Germany.

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« De l'éthique clinique à l'éthique de la recherche clinique »

Depuis la première moitié des années 1990, le Centre d'Ethique Médicale de l'Université Catholique de Lille a développé une méthode d'éthique clinique de type rétrospectif visant à analyser avec des équipes de soins des récits de situations cliniques ayant posé problème à cette équipe.

Cette démarche cherche à faire apparaître la moralité à l'œuvre dans les processus de décision et de s'appuyer sur celle-ci pour envisager la meilleure manière d'agir dans ce genre de situations. A travers ce processus réflexif, le groupe se structure progressivement comme un sujet moral et développe une créativité éthique à l'égard des problèmes qu'il rencontre.

L'objectif essentiel que poursuit cette méthode est de faire émerger au cœur du développement de la médecine contemporaine des acteurs capables de développer un questionnement critique à propos de leur action et une créativité éthique basée sur une meilleure compréhension des questions soulevées par le soin.

Ces dernières années, la recherche clinique est devenue un objet de questionnement de plus en plus fréquent pour les équipes. Ce besoin de recherche prend corps au sein même de la pratique clinique et soulève des questions tant à l'égard de la détermination de l'objet des recherches à mener, que des conditions de leur réalisation et, notamment, l'enrôlement des patients.

La présente communication visera donc à présenter les premières réflexions de notre équipe visant à adapter cette méthodologie d'éthique clinique à la réflexion concernant la recherche clinique. En effet, l'accompagnement éthique à la réflexion concernant la recherche clinique demande une étude spécifique du contexte d'intervention (qu'est-ce qu'une équipe de recherche clinique ?), de l'objet de la réflexion (la recherche clinique elle-même) ainsi que d'une méthodologie adaptée pour aborder cet objet spécifique.

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Assisted Suicide Knocking at Swiss Hospital Doors: Establishing Recommendations on How to Deal with Inpatients Seeking Assistance in Suicide at the Zurich University Hospital.

According to the Swiss Penal Code Art. 115, assistance in suicide is not illegal in Switzerland for anyone as long as there are no motives of self-interest. Against this open legal background, the Swiss practice of assisted suicide developed from the early 80s as sort of a civil right movement where right-to-die societies such as Exit or Dignitas play a crucial role. The Swiss Academy of Medical Sciences still upholds its statement that "assistance in suicide is not part of a physician's activity" but today accepts involvement in assisted suicide as "a doctor's personal decision of conscience".

Until the early 2000s there was a common understanding that assisted suicide is not allowed within hospital facilities, although there were only a few specific regulations on either the level of institutions (hospitals) or health law (Cantons). In December 2005 however, after a two year decision-making process, the Lausanne University Hospital came out with a regulation allowing right-to-die societies onto their premises to help terminally ill patients die. The other University Hospital in the French-speaking part of Switzerland, the Geneva University Hospital, followed suit in September 2006.

At the Zurich University Hospital, a task force started to deal with the subject of inpatients seeking for assistance with suicide in February 2006. The positions held by a number of task force members and by several hospital professionals reflected the fact that the German-speaking part of Switzerland generally lays more stress than its French-speaking counterpart on the separation of assisted suicide and health care. This paper presents the task force's recommendations and describes their efforts to find a balance between the respect for the patient's autonomy and the institution's interest that any conflict of roles for health care professionals and any potential for tensions within the team of caregivers be minimised.

* Georg Bosshard is the chair of the Zurich University Hospital's task force "Assisted suicide and hospital".

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Development of a Community-Based Ethics Framework

Community health care delivery has been a topic of increasing attention in recent years. Health care administrators and politicians are focusing on the merits of this model of health care delivery. While community care presents unique challenges not faced by hospital or institutional health care workers, Bioethics literature is virtually silent on questions in this domain. These challenges include major shifts in authority within the health care worker-client relationship (notably with Personal Support Workers) and client misperceptions of the role of the worker. Cultural differences are brought into sharper contrast as the client's home becomes a "cultural microcosm", making the need for cultural awareness and understanding more urgent. Finally, questions related to worker safety, duty to care, and respect for high risk, autonomous choices of the client frequently emerge.

To handle these challenges, the Scarborough CCAC has developed a "ground-up" community-based ethics program that raises ethical awareness within the organization, helps staff recognize an ethical dilemma, and provides an avenue for staff, managers and administrators to report, consult on and analyze ethical dilemmas. Specific initiatives in this program include an educational program for staff, management and the Board of Directors in clinical and organizational ethics, the development and training of a clinical ethics committee, a formal process for referring cases to the clinical ethics committee, and the development of one of the first Research Ethics Boards in the community health care context. This presentation will describe the unique nature of community health care ethics and the development of this program.

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Emergency department staff perceptions of family member presence during resuscitations: a Canadian perspective.

BACKGROUND: The question of whether and how families should be allowed to witness resuscitation attempts has been much debated in both the popular media and the medical literature. A number of investigators have demonstrated the desire of family to be present during the resuscitative process and the benefits to be gained from their presence. Yet despite the growing body of evidence supporting the practice, and the increasing acceptance of family member presence in the UK, few hospitals in North America have policies to facilitate the process. Researchers have attempted to identify some of the factors that prevent many emergency department staff from accepting family members in the resuscitation room, but few have done more than suggest possible areas of concern based on personal anecdotes – and none have examined the issue from a Canadian perspective.

DESIGN: Nine emergency department staff (staff physicians, and RNs) were identified through a nominated/network sampling process. Through qualitative descriptive interviews the staff described their experience of family member presence during resuscitations. Interviews were conducted until data saturation was felt to be reached.

FINDINGS: Staff perceived four main areas that family witnessed resuscitation (FWR) might impact: the patient, the patient's family, the resuscitation team, and the general administration of the emergency department. Although nurses and physicians perceived FWR as being beneficial for both the family and the patient, all cited potential detrimental effects that FWR might have if not managed carefully. Despite this, all respondents felt that FWR should become departmental policy. Notably, the responses to our interviews exhibited several differences from similar data gathered in American hospital contexts.

CONCLUSIONS: This study demonstrated a clear feeling on the part of staff that FWR should be common practice. The barriers to such a policy are outlined and possible solutions suggested.

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Ethical Lessons to be Learned from a Diverse and Dispersed Population: Quaternary Level Developmental Assessment in British Columbia

An initiative for diagnosis and support for children with "complex developmental and behavioural conditions" (CDBC's) has been undertaken by British Columbia's ministries of Health and of Child and Family Development. Centres in each of the Province's six regional health authorities have been established to provide multi-disciplinary tertiary assessment for children suspected of having a variety of conditions, including autism spectrum disorders, fetal alcohol spectrum disorders, and other developmental disorders.

A further, quaternary, level of clinical expertise will be available to supplement the regional centres. Children referred by the regional clinicians will travel to Vancouver for assessment and evaluation.

The cultural diversity and geographic dispersion of this quaternary patient population combines with its diagnostic complexity to pose a distinctive set of ethical challenges: Geographic and cultural variance may affect equity of access both to diagnosis and to needed interventions. The highly urbanized group of clinicians in Vancouver may have a limited grasp of resources available to caregivers in remote areas, and risk making unrealistic recommendations regarding supports and schooling. A balance must be found between recognizing limitations and advocating for needed supports. A meaningful set of criteria, applicable across settings and diagnoses, must be found for evaluation of this new program.

These challenges pose a unique challenge to the capacity of ethical reflection in tertiary and quaternary paediatric care in British Columbia, which to date has largely addressed questions concerning acute care. This paper will discuss possible approaches to these issues and their potential to broaden ethical discourse in this setting.

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Resolving Conflicts Over Life-Sustaining Treatment: Views of the Public

This presentation will report on findings from a pilot study using information and communication technologies (ICT) to engage members of the community in the Greater Toronto Area (GTA) regarding their views on resolving conflicts over life-sustaining treatment. A recent study of clinical bioethicists in Toronto revealed that disagreements over treatment decisions is the top ethical issue facing the public in health care, the most common example of which is conflict over the appropriate use of life-sustaining treatments. Preliminary results from a study on the organizational ethics issues facing health care organizations, which involved interviews with Board members, senior managers, middle managers, and bioethicists at various Toronto hospitals, has found that disagreements over life-sustaining treatment is one of the most pressing ethical issue from an organizational perspective. To date, attempts to resolve this issue in Canada have taken a largely top-down approach, with individual hospitals and health professionals developing their own policies, which are then imposed on the public. To our knowledge, however, there has been no attempt to elicit the views of the public on how to resolve this issue in Canadian hospitals.

In this paper, we will report quantitative and qualitative results from a pilot 21st Century Town Hall event with members of the GTA community. The results from this pilot project will help to inform the development of a larger engagement project with members of the public from across Canada. We believe the knowledge gained from both the pilot and proposed larger projects will have a significant positive impact in establishing a more patient centered approach to the resolution of conflicts over life-sustaining treatments.

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Consent for Future Research on DNA Samples and Information

Research Ethics Guidelines such as the Tri-Council Policy Statement and the RMGA Statement set out the requirements for consent forms for future research on blood and tissue samples containing DNA. This research may be very restricted in scope, or it may be very open-ended and general. Model consent forms which present options have been developed and published. It is assumed that the consent thus gained will be ethically and legally acceptable. However, recent reflections on this matter have challenged this assumption on the grounds that the consent cannot be legally effective because it cannot be sufficiently informed with respect to contingent possibilities that are not yet known.

This position appears to take as a paradigm the consent forms for clinical trials, in which the consent form deals with research that will take place in the immediate or near future, are often very long, and contain extensive details. However, in many areas of life and in bioethics, effective consent may be considerably less informed about future possibilities. For example, in blood donation, the donor typically does not know who the unknown stranger to whom the blood will be given is. It might go to a person that the donor would not approve of, such as a convicted terrorist in prison. In this, as in several other areas of life and health, we often give consent under a "veil of ignorance" (to borrow from Rawls).

Some proponents of this position nevertheless hold that if true consent is not possible, *permission* for open-ended research can be given. However, they also hold that such permission must be informed. What then is the difference between an informed consent and an informed permission? Is it purely verbal, and thus it does not make any difference whether the authorization is called consent or permission? The informed nature of consent may simply be a matter of degree.

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Organ Donation after Cardiocirculatory Death

The current main source of transplantable organs is patients who have suffered neurological death. But the demand for organs far outstrips the supply, and these patients are not the only potential donors. The aim of the Canadian Council for Donation and Transplantation (CCDT) in its recent report, *Donation After Cardiocirculatory Death: A Canadian Forum* (2005), is to expand the donor pool by devising criteria which would allow patients who have suffered cardiocirculatory death to be organ donors. My paper will examine the recommendations of that report from an ethical point of view.

Two of the most asked questions about DCD programs are: "Is my loved one really dead?", and "Will he or she feel any pain?" It is reasonable to suppose that any satisfactory program must be able to guarantee these can be answered with "Yes" and "No." I will argue, first, that DCD programs set up on the recommendations of the CCDT will not automatically yield those answers, and hence that the "minimum criteria to proceed with organ donation" that the council provides are inadequate. I will then argue that in order for those criteria to become satisfactory, the council must require greater disclosure about the nature of cardiocirculatory death and give more direction in the selection of a pain-protocol. These changes will make the recruitment of organ donors more complex and intrude into the medical practices of individual ICUs and hospitals, but without them we cannot have reasonable assurance that DCD proceeds with consent.

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Ethical challenges in psychiatry: a clinical ethics process in the field of early identification and treatment of psychoses

Early intervention in psychosis appears to be a field of exploration particularly interesting and fertile to probe the evolution of modern psychiatry at the epistemological level. We will examine this issue through an ethical analysis of the questioning issued by the clinicians and researchers practicing in this particular field of medicine. In this approach, we use a method of reflexive and critical clinical ethics. This method has for starting point the narratives and the discourses that the clinicians and researchers carry on their practices.

Initially, we will expose the ethical questioning arising with the development of clinical and research practices in the field of prodromal and early intervention for psychoses. Then we will examine its inscription and extent at the level of an ethics of care. We will show that the ethical questioning relates as much to the subject and object of care as it does to the significance and meaning of the act of "caring" in preventive psychiatry. Clinical research in the field of the first psychoses therefore points towards a clinical field "in research" which has as a horizon an ethics of care. We will show that the early psychoses domain offers a paradigmatic field interrogating the frames and assumptions of contemporary psychiatry, especially through its definitions of concepts, choices of approaches and elaborations of methods.

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Developing Ethical Oversight in El Salvador: Perspectives from the Field

PROBLEM: One of the most significant ethical challenges of research involving human subjects in low-income countries is available infrastructure for local ethical oversight. The absence of ethical oversight in the form of trained ethics committees often restricts or prevents the very collaborations needed for clinical progress in low-income countries.

OBJECTIVE: The purpose of this preliminary research was to gain perspectives from Salvadoran ethics committee members regarding the current state of human research subjects protections in El Salvador, to uncover obstacles to compliance with international guidelines for research oversight in El Salvador, and to establish next steps for further collaborative efforts

METHOD: We formed an interdisciplinary collaboration between The University of Memphis, St. Jude Children's Research Hospital in Memphis, and Hospital de Niños Benjamín Bloom in El Salvador. In this paper we report findings on our preliminary focus group research in El Salvador with members of the newly-formed National Ethics Committee as well as members from two newly-formed institutional ethics committees.

RESULTS: Our analysis of the focus group transcripts reveals the following emergent themes:

- Informed Consent (legal issues, process, and documentation)
- Ethics Committees (roles, composition, training, networking, and financing)
- Context (political, socio-economic, and cultural)
- Legislation (national and international guidelines; law)
- Research Teams (compliance, international collaboration, and sponsorship)

CONCLUSION: By soliciting and respecting the perspectives of key bioethics stakeholders in El Salvador, we believe our preliminary efforts will contribute toward a model of international collaboration for developing sustainable ethical oversight in other low-income countries.

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Title: Ethical Dilemmas for Nurses in Protecting the Public's Health

One of the characteristics of a self-regulating profession is the development of standards of practice, based on the values of the profession. For nurses in Canada, these values are articulated in the Canadian Nurses Association (CNA) *Code of Ethics for Registered Nurses* (2002) and are grounded in our professional relationships with individual clients. The Code of Ethics and most health-care codes are based on the autonomy of the individual and honour their informed choices. While the current code does state that the scope of nurses' responsibilities includes families, community and society, it is unclear how to apply the code's values when the individual's choices or interests may put the broader community at risk. During a pandemic or other community health emergency, this ethical dilemma of protecting the rights of individual patients versus protecting the rights of the community or "the public" will be central for health-care practitioners. Public health nurses, because of their distinct focus on both the individual and population already experience this unique challenge (Haugh & Mildon, 2005; Williams, 2004). The CNA has created *Public Health Nursing Practice and Ethical Challenges* (2006), an *Ethics in Practice* web-based illustration to support public health nurses working through these ethical challenges. This presentation will use the CNA *Code of Ethics* (2002), the web-based illustration and the recent Joint Centre for Bioethics pandemic planning document (2005) to systematically analyze these ethical tensions to support health-care practitioners' decision making and practice in a health emergency.

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Inter-professional Values and Practices : Considerations in IP Negotiation and Dialogue

There are a number of venues in which inter-professional practice is observable. This can include patient care rounds, team, education, research and management meetings. There are certain assumptions made about how these processes will unfold. What happens when the basic tenants of IP practice are not realized. For example, what happens when one profession dominates discussion or tries to determine another's practice, or when team members are discouraged from practicing according to their professional college's practice guidelines? What methods do we have for conflict resolution, mediation? Whose responsibility is it to initiate and ensure these processes-the individual, the team, or the organization? When all else fails should mediation be mandatory?

If there is a power differential, who ensures that further intimidation will not be used during the mediation process. These are issues facing inter-professional practice. Using case based examples, this presentation will consider the issues before us, the approaches and pitfalls integral to our commitment to IP practice.

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Evaluating Ethics Consultation: Does the Design of Randomized Control Trials Work?

Ethics consultations, while a relatively new strategy to resolve conflicts, are widely utilized with increasing frequency by different moral stakeholders in clinical setting. Empirical evidence of effectiveness, provided by randomized control trials, has lent authority to the argument that ethics consultations can improve the cares of patients by promoting patient satisfaction, reducing the use of life-sustaining treatments and days of ICU stay without shortening patients' survival. Randomized control trials are the gold standard for evaluating effectiveness in clinical medicine. In the literature, four randomized control trials have been conducted to provide empirical evidence to evaluate the effectiveness of ethics consultations. I will argue that the design of randomized control trials to evaluate the effectiveness of ethics consultations is not achievable and not ethical. Randomized control trials are not feasible if the variable, such as ethics consultations, cannot be manipulated. A patient/surrogate cannot be randomly assigned to receive an ethics consultation or not to receive an ethics consultation. Additionally, the nature of ethics consultations may hamper random allocation and blinded control, which are both strictly required in the design of randomized control trials.

In order to better evaluate the effectiveness of ethics consultations, propensity score matching, a design of non-randomized control trials, will be introduced. I will discuss how propensity score matching works and why it is a better research design than a randomized control trial to evaluate the effectiveness of ethics consultations. Furthermore, the limitations to apply propensity score matching will also be discussed.

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An ethical analysis of the Alternate Level of Care Issue at the Atlantic Health Sciences Corporation in Region 2 of New Brunswick

Background: Alternate level of care (ALC) refers to patients who have been medically discharged and no longer require acute care services, who are still in the hospital consuming scarce resources because the community cannot accommodate their needs. These patients do not require acute services but they do require less intense care that is not available elsewhere.

Objective: The objective of this paper is to determine the ethical probity of providing ALC patients acute care services.

Methods: We conducted an observational study of health care resource utilization by ALC patients, a systematic literature review, and an ethical analysis using the principles of fiduciary obligations and justice.

Results: ALC patients contribute to Emergency Department overload, the cancellation of scheduled surgeries, and other utilization problems. They receive acute services at the expense of other patients who are either denied appropriate care or their access to services is severely limited. The primary reason that ALC patients receive preferential treatment is because of the tradition of patient advocacy resulting from the fiduciary relationship between professionals and patients. However, our ethical analysis demonstrates that these reasons do not justify the preferential treatment of ALC patients. In this case, the principle of justice supersedes the fiduciary obligations of individual health care professionals.

Conclusion: It is unfortunate that the community does not have the services that ALC patients need but it is not unjust. However, denying or restricting access for patients with acute care needs because they are being consumed by ALC patients violates the principle of justice.

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Access to Medicines and the Role of Corporate Social Responsibility: The Need to Craft a Global Pharmaceutical System with Integrity

Access to essential medicines is a fundamental human right explicitly stated in the Universal Declaration of Human Rights and covenants. The right to essential medicines, especially in developing countries, has raised questions as to the roles and implications for pharmaceutical organizations, their shareholders, and their stakeholders. Corporate social responsibility is the obligation of corporations to contribute to the community. Meeting the needs of the developing world to essential medicines thus constitutes a window of opportunity for pharmaceuticals. Many pharmaceutical companies have failed to seize this opportunity to meet their duties to the community. There are startling global inequities with respect to access to medicines between developing and developed countries; while developing countries represent about 80% of the global population, they speak for only 20% of the global pharmaceutical market. We argue that pharmaceutical companies are morally obligated to provide essential medicines to people in developing countries. This obligation is predicated on three considerations: 1) pharmaceutical companies have duties of justice because they benefited in the past from the harm inflicted on those in the developing world and they are in a position to deliver effective aid; 2) human rights trump profits; and 3) those involved indirectly in healthcare such as pharmaceutical companies have a responsibility in virtue of the medical mission. It is necessary to reassess the incentives inherent in profit maximization principles in order to respect rights and facilitate duties.

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Charity Care – What are our obligations to the Uninsured?

'Charity care' is the term often used to describe uncompensated medical treatment provided to patients who for one reason or another do not have the financial resources to access the medical treatment they need. Since 2000, one health care organization providing 'charity care' in Toronto had 7000 visits by 2000 patients from 85 different countries. However, with the increasing cost of medical treatment, 'charity care' is a dilemma not only in Canada but also internationally, with the United States, France and the United Kingdom all struggling to provide health care to uninsured patients.

In Canada, only 'insured persons' are legally entitled to health care treatment. However, the colleges of most health care professionals expect their members to bring about social change in the areas of human rights and poverty, and not to discriminate against a patient based on their ability to pay. Moreover, excluding certain groups of patients based on their insurance status is potentially troublesome for some religiously based health care organizations that uphold a 'preferential option for the poor'. The increasing demand on financial and human resources combined with the professional obligations to provide treatment has nurses, physicians, and hospital administrators struggling to determine their obligations to these patients.

This presentation will report the findings of a qualitative study on "charity care" involving interviews of Chief Executive Officers, Vice Presidents, Directors, Board Members, Managers, Program Leaders and Bioethicists in health care organizations. The presentation will describe the ethical issues associated with "charity care" as well as identify strategies used to address these ethical issues, and provide indicators to evaluate the effectiveness of these strategies.

MaryTherese Connors, DHCE; Adam Duhl, MD*; Janet Grover, MA, ABD; Valerie Satkoske, MSW, ABD***; Jennifer Shaw, MA, ABD******

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Ethics Consults as a Teaching Tool for Resident Physicians; Phase Two

For the past three years, there has been a unique collaborative effort between Duquesne University of Pittsburgh, Pennsylvania and Mercy Hospital of Pittsburgh. Graduate students in the Health Care Ethics Program of Duquesne University have embarked on a successful effort to assist resident physicians in satisfying the Professionalism Competency requirement of the Accreditation Council for Graduate Medical Education (ACHME).

Students in the doctoral programs of Duquesne's ethics program are required to spend four semesters in the clinical medical arena. As their Clinical Supervisor, with the assistance of Adam Duhl, M.D., Chair of the IEC of Mercy Hospital, the ethics residents have been placed in each of the seven medical specialties at Mercy.

The ethics residents accompany the teaching rounds of each service on a continuing basis as a part of the treatment team. During these rounds and in formal sessions held at least three times a year (more frequently in the larger specialties) ethics students and resident physicians participate in ethics case discussions.

As a workshop session, we propose to present: Adam Duhl, M.D. who will present rationale and origin of the program; Jennifer Shaw, MA, ABD a senior ethics student, who will present the health care ethics graduate student experience; Valerie Satkoske, MSW, ABD an experienced social worker and ethics resident who will give a report on the success of our program; Janet Grover, MA, ABD a senior ethics student who will give the perspective of the collaboration of the two institutions; and MaryTherese Connors, DHCE will suggest a model to use when ethics students are not available as resources in the education program.

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Becoming an Ethics Consultant: The Experiences of Health Professionals as they take on the Role of Ethics Consultant

A recent study of ethics consultation in the US reveals that those providing consultation services come from a wide variety of professional backgrounds, with physicians, nurses, social workers, chaplains, and administrators making up over 97% of consultants (Fox, 2002). A similar previous Canadian study found that over 53% of those providing ethics consultation did so in addition to their other professional roles (Coughlin & Watts, 1994). Thus, most ethics consultants juggle multiple roles, duties and methods. To date, little is known about the experiences of ethics consultants who have other professional roles in a healthcare organization. For example, how do they take on the identity of an ethics consultant? How do their colleagues perceive this new role? How do they balance their professional accountabilities as an ethics consultant with their other clinical duties? How do they keep their roles straight? This paper addresses these issues.

This report arises from the collective experiences of a small volunteer team of health professionals, including physicians, nurses, social workers and administrators, who recently trained together to provide ethics consultation. It draws together the group's reflections on the process of becoming ethics consultants, as captured in conversations throughout the training process and the first year of consultation practice.

The paper will address the following issues:

- The process of taking on a professional identity as an ethics consultant;
- How this group of health professionals perceive their unique roles and accountabilities as ethics consultants;
- Situations in which role confusion commonly occurs and ways to avoid this confusion;
- Strategies to help clarify the role of ethics consultants in policy and practice.

This study will be of particular interest to ethicists and educators who train students or ethics committee members to participate in ethics consultation.

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Drawing the Line on Drawing a Line: Canadian Perspectives on the Development of Health Policy on Pre-implantation Genetic Diagnosis

In 2005, Canadians in three cities attended the play *Orchids* (written by JN) as part of a novel process of public engagement in the development of health policy on preimplantation genetic diagnosis (PGD). The goals of this CIHR and Health Canada funded study were to: i) offer Canadians the opportunity to learn about and discuss social, ethical and health policy issues arising from PGD, ii) describe and analyze diverse Canadian perspectives on PGD and, iii) provide these perspectives to Health Canada to inform the development of health policy on PGD.

Sixteen workshop performances of the 70 minute play occurred in Vancouver, Toronto, and Montréal (in French, with collaborator Hubert Doucet) engaging 741 attendees. All attendees were invited to participate in a large audience or simultaneous focus group discussion held immediately after each performance. Both formats were taped and transcribed.

In this paper, we describe the range of concerns expressed by audience members with regard to the development of policy on PGD in Canada. In particular, we examine the reluctance of many audience members to engage in drawing a line between acceptable and unacceptable uses of PGD. As our analysis demonstrates, there is little consensus on what constitutes 'suffering'. Moreover, Canadians are uncomfortable with the task of defining when we ought to allow or disallow PGD in order to prevent suffering. Citizens who contribute to public engagement fora such as this must, therefore, be granted sufficient autonomy to (re)frame key policy questions as a fundamental aspect of their participation.

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Ethical Implications of an Exploration of Technology Adoption in Healthcare

Communication gaps between healthcare providers have been linked to adverse events and untimely deaths. Technology can facilitate the timely exchange of critical data, but high rates of technology rejection indicate factors determining technology adoption, specifically in relation to how it impacts communication patterns and information flow, are poorly understood.

A hand-held telecommunication technology was implemented in a large, Toronto hospital in an effort to improve communication between nurses, patients and other healthcare workers. A preliminary study revealed inconsistent levels of adoption of the technology among nurses despite an increased risk to patient safety.

The aim of this study was to explore factors influencing the adoption of communication technology in healthcare organizations, with the objective of developing an evaluation framework that will guide future applications of technology in the healthcare environment.

To accomplish this, its affect on the communication patterns and work practices of nurses was examined.

Findings indicate that a combination of individual, social and organizational factors influence technology adoption behaviour. The implications for practice are that change in the form of innovative information technology in a complex environment such as a healthcare organization without fully understanding the impact may be costly, and introduce unforeseen and avoidable risk to performance and quality of care. The purpose of this presentation is to present the ethical implications of behaviour that emerged from an exploration of technology adoption by nurses and discuss the use of an evaluation framework to minimize risks to performance and the delivery of quality care.

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On professionalism and ethics in healthcare: a report from the Expertise Center for Ethics and Care, University Medical Center Groningen.

Our Center works from the perspective that ethics should be considered as an integral part of quality of care. Three central elements of our theoretical framework are: *care ethics* (our ethical perspective), *reflective professionalism* (the idea that professional caregivers should be competent to address both the technical and moral aspects of their work), and care practices as *practices of responsibility*, (in which (moral) responsibilities are not pre-set, but result from negotiation and deliberation).

In this presentation we will show the practical implications of this framework, by presenting three of our projects:

An example of our *education programmes for residents*: 'Reflective Professionalism', a continuous running series of workshops focusing on normative aspects of health care, covering training needs in the field of the CanMEDS-role 'professional'.

An example of our *research*, entitled 'Ethics and Identity in a Multicultural Care Center'. This qualitative research project focuses on the question how to deal with religious and cultural diversity (of both caregivers and care-receivers) in a care center for people with intellectual disabilities. The results form the basis of a training module.

An example of our activities in the field of *ethics in organisations*: a course in which an ethics program is developed in collaboration with an ethical steering group. Members of this group participate in research in which they reflect on questions as what ethics can be, what kind of ethics is appropriate for their organisation and what possibilities there are for doing ethical reflection upon daily practice.

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Ethics in Canadian Health Technology Assessment: A Descriptive Review

Health technology assessment (HTA) examines the medical, social, ethical, and economic implications of the development, diffusion, and use of health technology. Despite the comprehensive goal to consider all implications of a health technology, an increasing number of studies indicate that HTA reports often emphasize the epidemiologic and economic aspects, and omit social and ethical considerations. This study answers the question of *how* ethical issues are incorporated into HTA when they are addressed and how these approaches compare to existing guidelines for the ethical assessment of health technologies. What sorts of ethical issues are addressed? What strategies do agencies use for including ethical issues in HTA? How does the inclusion (or exclusion) of ethical issues vary (across types of health technologies, years, agencies)?

This project is a descriptive review of ethical issues in Canadian HTA reports published from 1997-2006. We characterize the sorts of ethical issues that are addressed in the reports, both explicitly and implicitly. We describe how ethical considerations are presented; for example, through the brief identification of an ethical issue without further inquiry, or with elaborate discussion and analysis. We also examine the strategies used to gather and synthesize ethically relevant evidence, such as literature reviews, qualitative surveys and interviews, and/or the inclusion of an ethicist on the research team. Using an existing framework for the ethical assessment of health technologies, we note the strengths and discrepancies in the ethical analysis of health technologies in practice. Finally, we offer recommendations for when and how ethical considerations can be more successfully incorporated into the assessment of health technologies.

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Advance Directives, DNR Bracelets and Suicide Attempts

Do Not Resuscitate (DNR) orders and advance directives were promulgated to promote patient autonomy, but not to permit patient suicide. A Wisconsin statute allows individuals to wear a DNR bracelet under specified conditions. This bracelet signals Emergency Medical Technicians and Emergency Department personnel that there is a physician order limiting pre-hospital treatment for the patient. Although the bracelet is for the purpose of restricting unwanted medical care, it potentially prevents care that would reasonably be expected to be given after a suicide attempt, such as intubation, the use of a ventilator and vasoactive medications to support blood pressure. This new dilemma has caused bioethicists to struggle to develop proper advice for guiding medical care in such circumstances.

Three cases will be discussed that present the dilemma of honoring DNR bracelets and advance directives or providing seemingly prohibited interventions after attempted suicide. All three patients were resuscitated in direct contradiction to their advance directive or DNR bracelet. In two cases, family members requested interventions despite being aware of the patient's preferences. In one case the patient expressed deep anger after being brought to the Emergency Department and receiving treatments that were contrary to his previously articulated wishes. How should we think about these cases? Do these cases highlight the concept of rational suicide? The authors will propose a framework for deliberation.

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Les citoyens et le concept d'éthique en science et technologie

Le mot éthique et ses dérivés représentent sans doute des concepts phares de notre époque. Dans de nombreux documents, l'éthique est présentée comme la réponse aux défis que pose le développement des sciences et des technologies. Peu d'études s'intéressent au sens et au rôle que lui donnent les citoyens. Ces derniers sont-ils d'accord avec ces conceptions de l'éthique? Une portion d'une étude qualitative portant sur l'évaluation de deux mécanismes de communication citoyenne réalisés de 2002 à 2006 par le GREB abordait cette question. L'exposé présentera, en première partie, le contexte de la recherche et la méthodologie utilisée. La deuxième partie comprendra deux éléments. Elle examinera la signification que les citoyens donnent à l'éthique, les synonymes qu'ils utilisent et les domaines qu'ils y associent. Ensuite elle rendra compte des fondements utilisés pour légitimer leurs positions éthiques et les obligations qui s'ensuivent. La troisième partie analysera le lien entre l'éthique et la citoyenneté. Pour les citoyens, les deux dimensions sont inséparables. L'éthique, dans le secteur des sciences et des technologies, ne peut se réduire à la seule protection de l'individu. Elle a une dimension proprement collective. Cette partie comparera, entre autres, les documents officiels parlant d'éthique et la pensée des citoyens. En conclusion, la présentation discutera de diverses interprétations des citoyens. Ces derniers reconnaissent la banalisation de l'éthique tout en l'acceptant. Ils définissent également l'éthique comme un questionnement et une discussion en vue de parvenir à des décisions engageant toute la collectivité. Une telle vision est-elle réalisable dans un contexte bureaucratique?

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Legal and ethical issues of MRI research involving children: An issue scoping overview

This presentation reviews various aspects of legal and ethical issues regarding magnetic resonance imaging (MRI) research involving children. It aims to provide a clear description of the landscape of paediatric MRI research and to motivate further work toward the development of ethically and legally sound frameworks, policies, and practices in three priority areas.

We first examine the issue of respectful involvement of children in relation to consent as well as privacy and confidentiality. For example, decision-making around MRI research participation should include children as it is an endeavour not without risk. However, can we expect children to be able to understand the nature of MRI research and its complex types of risks? Paediatric research participants should also be afforded privacy on enrollment and researchers should be careful not to elicit personal information from children that their parents need not know in order to make a determination about participation. But, how is this to be achieved and what, if any, are appropriate limits on privacy?

We then explore issues relating to unexpected findings such as consent, review of scans, and disclosure of findings. An unexpected finding can be particularly devastating if a child's future is potentially affected. Clear guidelines on how to manage unexpected findings could benefit both the researcher and the research participant.

Finally, we explore ethical issues concerning advances in functional MRI (fMRI) in paediatric research participants. We discuss ethical concerns such as, the potential for misinterpretation and misuse of fMRI research results.

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L'expérience du théâtre interactif, les enjeux éthiques des avancées de la génomique et la communication citoyenne

Les défis posés par les développements des biotechnologies et de la génomique ont récemment favorisé la mise en place de mécanismes de dialogue citoyen, tels que les conférences de consensus et les jurys de citoyens. Le théâtre, instrument classique de vie citoyenne, a cependant été peu utilisé malgré sa remarquable capacité de rejoindre les émotions des participants tout en permettant la distanciation face aux problématiques. Quelle valeur le théâtre peut-il avoir encore aujourd'hui comme moyen de communication citoyenne et à quelles conditions? Le Groupe de recherche en bioéthique de l'Université de Montréal (GREB) a voulu répondre à ces questions en réalisant, en collaboration avec une troupe de théâtre professionnelle, une pièce de théâtre qui traite des enjeux éthiques que soulèvent les avancées de la biologie humaine à l'ère de la génomique et en invitant l'auditoire à la discussion après chaque représentation. La discussion était évaluée, autant le point de vue de l'auditoire que celui des créateurs. La présentation discutera des résultats de la recherche portant sur ce mécanisme comme mode de délibération citoyenne concernant les enjeux suscités par la génomique. Elle examinera autant les forces et les faiblesses de la formule que le regard que les participants portent sur la génomique et ses enjeux à la suite de la pièce. Quelques questions seront privilégiées. La pièce pose-t-elle des questions inédites aux différents participants? Quel type d'écoute et de prise de parole favorise-t-elle? En comparaison à d'autres mécanismes, quelle est sa contribution propre?

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On the Viability of a Pluralistic Bioethics

Scientific progress has enabled the creation of new medical technologies and the achievement of great accomplishments throughout a variety of medical fields. However, along with the benefits of medical advancements come new and unforeseen ethical dilemmas. In addition to dealing with strictly 'medical' issues, such as diagnosis and treatment, clinicians are confronted with the multitude of ethical positions held by patients. Often such ethical positions stem from the religious beliefs and cultural backgrounds of patients, potentially creating confusion and possibly leading to disagreement in the clinical setting.

Emerging from a plethora of backgrounds, both religious and secular, numerous bioethicists have attempted to resolve these moral conflicts. However, despite the abundance of work that has been done thus far, the religious pluralism which pervades our society and the diverse modes of moral reasoning which enter into the clinical arena are often inadequately addressed in the theoretical realm of biomedical ethics.

Therefore, exploring the origins of divergent ethical claims which arise in medical settings, a comparative analysis of a Theravada Buddhist's and an Orthodox-Christian's perspectives on the biomedical issue of 'brain death' will be put forth. This comparison will demonstrate the similarities and differences between each author's mode of moral reasoning, the religiously diverse values and beliefs which come to bear on such reasoning, and their respective conclusions. The aim of this analysis will be to enable a method of understanding religiously pluralistic ethical perspectives as they arise in clinical settings and for the purpose of incorporating them into bioethical theorizing.

Finally, a methodological model, which I am calling a "Pragmatic Perspectivism", will be set forth as a potential conceptual framework in which a bioethical theory for a secular yet religiously pluralistic society may be forged. Seeking to lay the foundations of a pluralistic bioethics the aim of this study is to explore the viability of such an endeavor and provide suggestions on how we can go about doing so rather than postulating a conclusive theory. It is the hope of this author that this project will foster further dialogue on initiating new ways of engaging the issue of religious pluralism in bioethical theory and in clinical practice.

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Caring Approaches in Health Governance

This paper explores whether a modern ethics of care approach, which treats context and relationships of dependency as salient in moral deliberations, can and perhaps ought to inform the organization and behaviour of governments overseeing the delivery of health care.

Governments have a relationship with the citizens they serve. In the context of health governance organizations, like provincial ministries of health, aspects of this relationship can be very immediate, where physicians and other health professionals paid by the government provide care to citizens. But the public – including but not limited to those in care – have a more indirect relationship with government in so far as they have an expectation that certain health services will be made available, and are dependent on the government to organize and deliver these services. These health systems attend to and meet needs of particular others for whom the governments of the area have taken a degree of responsibility. According to Virginia Held, relationships based on need and dependency are the central focus of the ethics of care. In line with recent developments in ethics of care literature, such as those put forth by Held and others, this paper contends that the relationship between a population and the health ministry serving it can be also be conceived in such a way.

This application is not only reasonable but valuable. If caring approaches can reasonably be incorporated into governance activities, they can offer a lens or mode of thinking about responsibilities of governance that is, if not more sophisticated and meaningful, at least novel, offering a new perspective on problems that remain unsolved using existing paradigms.

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Obesity, Ethics, and Public Health

To begin, I give an overview of the problem of obesity. I describe how the rates of obesity, especially among children, are increasing not only in North America and Europe, but also in many developing countries. I note the association between obesity and type-2 diabetes, heart disease, stroke, and some types of cancer. But I also note how genuine health concerns become enmeshed with aesthetic norms about beautiful bodies, unexamined beliefs about social status, and moralistic judgments about self-control. After describing the public health concerns, I focus critical attention on the philosophy of individual responsibility that dominates thinking about obesity. I try to avoid retrospective and metaphysical issues about individual responsibility because I want to shift attention to prospective and political issues about the values that are implicit in various approaches and responses. I point out the gender and class biases that are embedded in the emphasis on individual responsibility. I also note how this emphasis neglects the important role that social and built environments play in population health. In the dominant mode of thinking, freedom tends to be equated with a superficial kind of consumer choice, not real democratic control over environments and norms. In closing, I note how the public health problem of obesity raises deep ethical questions about the kind of society we should strive to construct and the kind of people should we strive to become.

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Transnational Justice and Caregiving for the Elderly

There is increasing concern on the part of many countries, including the US and Canada, over how best to address the needs of their aging populations and provide care for the dependent elderly, a population whose numbers are burgeoning and who, on all accounts, currently receive sub-optimal care. There is also growing attention to the problem that governments, the for-profit sector, international lending bodies and others may operate in a way that creates and sustains injustices against those who serve as caregivers – paid and unpaid – including women who migrate from developing countries in search of work as nurses, nurse assistants and home health aides.

My paper will first explore the value of an epistemological orientation known as “ecological knowing” for understanding the ethical and policy issues involved in caregiving as it concerns the transnational movement of capital, people and services, the transnational effects of government policy related to health, labor, and immigration, and the practices of corporate bodies, lenders, non-governmental organizations, and other agencies that cross borders. I will go on to argue for a conception of justice that takes account of economic and other relations that link these agents, or collectivities, transnationally. This conception holds that obligations to promote justice for the elderly and their caregivers should be distributed among the multiple agents involved with caregiving according to their skills, resources, and powers. I will conclude by offering specific prescriptions for governments, international organizations and lending bodies, trade unions, employers, and industry groups.

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(Sponsored by the Canadian Patient Safety Institute, a WHO initiative of the World Alliance for Patient Safety)

Why Ethics Matters; One Family's Perspective

The International Clinical Ethics and Consultation Conference would be well served and rounded by the submission of a patient story which illustrates that ethics most definitely matters.

The author tells the story of her 3 month old daughter Annie's tragic death in the intensive care unit of a world class children's hospital. Her experience emphasizes the essential requirement of the medical team to respect and employ the services of the Bioethics Department for two important reasons;

Ethics consultation enables the family to make the optimal decision for their loved one which minimizes future agony of self doubt of critical decision making. Ethics consultation ensures, for the sake of the physician, that decision making involves full comprehension and discussion of relevant facts and is consistent with professional codes of ethics.

Annie was a child with genetic disabilities and despite the fact that hindsight reveals a patient/physician conflict in perceived quality of life, there was no request for ethical consultation. Annie's death involved lack of properly informed consent. The result was unnecessary anguish and suffering for the family. In addition, the hospital and staff endured the stress of a Coroner's investigation as well as the risk of litigation and reputation.

While the story is very sad, it is not told in an adversarial manner. The author has made the decision to transform the energy of righteous anger into affecting awareness of the importance of clinical ethics and of the respect for the rights of individuals.

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Clinical Ethics in the Service of Clinical Research: Another Kind of Clinical Consultation

The aim of clinical ethics consultation has been conceived in a variety of ways. In our own case, it is the moral experiences of those directly involved in patient care decision making that directs our clinical ethics practice. In light of the methods and skills we have developed in this practice, on three separate occasions over the past decade we have been asked to develop and implement a "counseling" process to help potential research subjects decide whether or not to enroll in innovative clinical research protocols. The explicit aim of this process has been to ensure that the decisions made by potential subjects are adequately informed by, reflective of, and responsive toward their own set of moral commitments and values. In this paper, we first outline the core features of our clinical ethics practice and the reasons for having moral experience serve as the primary focus and concern. Next, after brief overviews of the different research projects in which we have been involved and the designs of the "counseling" process, we discuss how the process has been overwhelmingly judged to be beneficial by both potential subjects and their families as well as by the researchers. Nonetheless, there are limitations and problems which arise when engaging in this "other kind" of clinical ethics consultation, which we also explore. Of primary interest is a core question applicable to conventional ethics consultation as well: Can individuals refuse to engage in moral reflection, and if so, what legitimates ethics consultants pursuing such matters in the first place?

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ECWeb: A Quality Improvement Database Tool for Standardizing, Documenting, Assessing, and Reporting on Ethics Consultations

Assuring the quality of ethics consultation is a challenge for health care institutions. Our Ethics Center is spearheading an initiative to improve the quality of ethics consultation in our medical centers nationwide. A central part of this effort is the development of ECWeb - a secure, Web-based software program designed to: standardize ethics consultation processes; provide an electronic method of documenting, storing, evaluating, and retrieving ethics consultation data; and generate statistical reports for purposes of quality improvement.

ECWeb consists of two tracks.

- The Case Consultation Track is for consultations related to active patient cases. This track promotes consistent ethics consultation practices by assuring that a standardized set of process steps, activities, and information are documented. ECWeb generates a summary note for entry into the patient's health record.
 - The Non-Case Consultation Track is used to document ethics consultations that are not directly related to an active patient case, e.g., comments on an ethics topic, policy interpretation, document review, analysis of a hypothetical or historical case.
- Other features of ECWeb include:
- Secure access to authorized users through our system's Intranet
 - Ability to designate certain consultation records as quality improvement reviews with special legal confidentiality protections
 - Automated (e-mail) reminders of planned consultation activities
 - Automated (e-mail) notification of consultation referrals
 - Ability to attach electronic documents to records e.g., Word documents, PDF files, etc.
 - Ability to search records by key word
 - Categorization of consultations into standardized content ethics domains and topics

The presentation includes data from a 38 facility field-test and a demonstration of ECWeb.

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Difficult Consultations that Haunt Us

Experienced ethics consultants can be haunted by particularly difficult cases. We discover personal and professional frailties as cases unfold and the memories of these persist. These difficult cases prompt us to reflect on ourselves and our practice. Moral distress or regret may be experienced by the consultant during or after such cases often due to missteps, second guessing, and perceived or actual powerlessness. We interactively explore the personal difficulties of addressing cases that remain vivid in our minds. After a short framing of the discussion, several first person accounts of cases will be presented which examine ways that ethics cases can disturb and inform. These cases have strong affective components related to the practice of ethics consultation. Conference attendees will be invited to discuss these cases and to give brief accounts of their own cases. Final summary comments will be made suggesting various processes that can be used in approaching these cases.

The workshop will include:

- Introduction and Review of Moral Distress, Integrity, and Regret
- Four Short Case Narratives (four different consultants):
 - + Is a Broken Jaw a Terminal Condition?
 - + Feuding Surrogates, Herbal Remedies, and a Dying Patient
 - + Only Three Days
 - + Resident Moonlighting
- Open discussion, sharing, and critique
- Observation for future improvement

The objectives of this workshop are to explore selected affective challenges faced by ethics consultants, provide a time for sharing difficult consultations, and articulate strategies for improving good practice in spite of difficult experiences.

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Clinicians' evaluation of clinical ethics consultations in Norway: a qualitative study

Clinical ethics committees have existed in Norway since 1996. By now all hospital trusts have such a committee. An evaluation of these committees' work was started in 2004. This paper presents results from an interview study of eight clinicians who evaluated six committees' deliberation of ten clinical cases. The study indicates that the clinicians found the clinical ethics consultations useful and worth while. However, a systematic approach to case consultations is vital. Procedures and mandate of the committees should be known to clinicians and patients in advance to secure that they know what to expect. Equally important is bringing all relevant facts, medical as well as psychosocial, into the discussion. A written report from the deliberation is also important for the committees to be taken seriously by the clinicians. This study indicates that the clinicians want to be included in the deliberation, and not only in the preparations or follow-up. Obstacles for referring a case to the committee are the medical culture's conflict aversion and its anxiety for being judged by outsiders. The committees were described as a court by some of the clinicians. This is a challenge for the committees in their attempt to balance support and critique in their consultation services.

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Is there a place for the pharmaceutical sale representative in the doctor-patient relationship?

Recently, the transplant team of the Centre Hospitalier de de l'Université de Montréal (CHUM) was approached by a pharmaceutical sale representative asking about its interest in offering a "clinical preceptorship". This activity would include observation sessions with the physician and team during transplantation rounds and transplantation outpatient clinic. The aim of this activity is, according to the sale representative, to enhance his understanding of all the transplantation process. In exchange for the participation of the team to this "clinical preceptorship", the pharmaceutical company would give a certain fee for each day of participation. The transplantation team felt awkward and submitted this as problematic to the Clinical Ethics Committee (CEC).

The uneasiness felt by some transplant physicians may partially be explained by the mixed representations of the pharmaceutical industry roles in the clinical setting, potential of conflict of interests and the perceptions of the patient-doctor relationship. We will present the ethical framework we used and the results of the CEC deliberations on the issue of pharmaceutical sale representatives' "clinical preceptorship".

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Donor advocacy programs for parental living liver donors: an ethical alibi?

Since March 2003, the Cec has been meeting with parental candidate to living liver donation that are sent to adult surgeons by a referent pediatric team for children needing a liver transplantation.

The Cec meets the parents at the request of their colleagues who remained preoccupied by the ethical issues surrounding living donation. The objectives of the Cec participation is to provide the donor with the opportunity to consider in a neutral place the freedom of his/her choice, to enrich the pre-donation assessment of the donor in checking for example the quality and validity of informed consent and to participate in the teams' reflections about the ethical issues relative to the LDLT whole process. Therefore, the Cec offers something very similar to what is regularly called in the literature "a donor advocacy program".

After three years of collaboration, we are wondering if our programs can really meet their announced objectives. Aren't they a sort of "ethical alibi"? Based on a review of the 70 cases that we already worked on, the paper will argue our hypothesis of feeling to provide teams with an "ethical alibi" while not providing the donors any benefit but rather some supplementary stress.

Then, we will defend that "a donor advocacy program" could still be defended and should be very useful once not built on the same objectives. If it is a specific role for ethics teams to assume such renewed programs will be further discussed.

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Get It Together: a practical workshop on planning, building and sustaining an effective clinical ethics consultation team

It is no longer enough to "mean well" as an ethics consultant; consultants are now expected to possess core knowledge, skills and character. Most ethics consultations in the US are performed by groups, either small teams or full committees, yet one recent study reveals that over 95% of providers of ethics consultation in the US have not completed a fellowship or graduate program in bioethics, and that (Fox, 2002). How can a health care organization ensure the competency of its ethics consultants, when so few will have access to formal training? How does a hospital go about creating (and sustaining) a group of employees to provide effective consultation services? What are the challenges faced by ethics consultation teams and what tactics can maximize the advantages of a team model?

This interactive and pragmatic workshop presents practical strategies, concrete tools and key lessons from one Canadian hospital's experience in creating and sustaining an ethics consultation team that meets core competencies. The goal is to provide inspiration and practical tools to enable participants to improve their consultation team at any stage of development. Upon completion of this workshop, participants will be able to:

- Identify and implement practical steps to build a consultation service that meets ASBH *Core Competencies*.
- Evaluate the capacity of their current ethics consultation service and devise a concrete a plan to improve its effectiveness.
- Understand the foundational elements of a sustainable ethics consultation team.
- Utilize a key educational technique to improve ethics consultation competence: simulated clinical ethics consultations.

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L'autonomie et la réflexion critique: des compétences essentielles pour une formation en éthique

Depuis son émergence au début des années 1970, la bioéthique n'a jamais fait face à une demande aussi importante de formation au Québec. En éthique de la recherche, l'entrée en vigueur de nouveaux cadres normatifs, les exigences de formation posées par certaines institutions universitaires, les besoins manifestés par différents groupes d'acteurs et la carence de formateurs compétents posent des défis importants. Pour sa part, l'éthique clinique voit apparaître une multiplicité de questions fortement tributaires d'enjeux et de problématiques issus du développement des connaissances et de leur application en clinique. Enfin, la collaboration croissante d'acteurs de différents secteurs de la société et la valorisation du savoir fait surgir des questions d'intégrité, de conflits d'intérêts et de conflits d'engagement. Devant ces problématiques, devant les contraintes de temps, de distance, de nombre et de diversité de participants, ainsi que pour répondre aux situations concrètes et aux demandes pressantes, des questions émergent.

Comment rejoindre les futurs chercheurs, les chercheurs actuels, les membres de comités d'éthique, comment guider les cliniciens dans le développement d'une réflexion éthique autonome et critique qui s'intègre à leur travail quotidien ?

Quelles sont les approches pédagogiques qui favoriseraient le développement des compétences d'autonomie et de pensée critique, des habiletés cognitives de haut niveau et des habiletés d'ordre social des apprenants afin de répondre aux compétences professionnelles?

Cet atelier abordera ces questions en présentant différentes initiatives de formation offertes à l'Université de Montréal qui utilisent une méthode pédagogique centrée sur l'apprenant pour favoriser l'apprentissage de l'éthique de la recherche et clinique.

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'Genohype' and the Discourses of Disability

In her introduction to *Ethics of the Body: Postconventional Challenges* (Cambridge, 2005), Margrit Shildrik claims that bioethics is out of touch with bodies (as they are implicated in self-identity), out of touch with the contribution of postmodernism to the reduction of binary thinking, and out of touch with postmodern culture in general, which views with a skeptical eye claims of certainty about universal, abstract goods. A troubling example of binary thinking that arises in much genetics discourse is the construction of disabled identity as deviant (Taylor and Mykitiuk, 2001). Disabilities rights advocates have argued that in the reproductive context this discourse - 'genohype' (Caulfield, Burgess et al, 2001) - sends a message that persons with disabilities are unwelcome and of lesser worth than those who are 'normal' (Asch, 2000). This is known as the expressivist argument.

In this paper I analyse the expressivist argument, and consider various responses to it. While critics of expressivism succeed in showing that the ambiguity of individual reproductive choices undermines the expressivist claim (Nelson, 2000), I argue that a social practice version of expressivism succeeds. In light of this troubling conclusion, I consider the suggestion by Scully (2005) that molecular biology, although currently appropriated by 'genohype,' has the potential to offset the dichotomized understanding of health ('normal' / 'deviant') that gives rise to the devaluing of the disabled. Molecular biology, argues Scully, has a history of valuing variation for its own sake, not to pathologise. Furthermore, the availability of multiple interpretive models in the discipline can form the basis for demanding an ethical and political justification for one's favoured interpretation, and such a demand can be sensitive to the claims of expressivists. Molecular genetics might then provide a discourse to challenge the ideal of normality and celebrate difference.

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Family Will- An Indian Perspective

Introduction: India is a country with diverse ethnic, socio economic, religious and cultural fabric. This country has not only a disease burden of communicable diseases but also those that are life style dependent. The majority of the population does not have health insurance.

Current practices: In India religious beliefs, affordability, the nature of the disease, age, sex, availability or non availability of health care facilities, distance of one's home from these facilities play a part in decisions regarding end of life issues. These decisions are those relating to withholding or withdrawing life sustaining treatment, ordinary and extra ordinary treatment use of sustenance technologies or medical technologies, stopping treatment or continuing treatment etc. In the case of the elderly the family makes the decision taking into account the wishes of the person. These are communicated orally.

Family Will: A living will, medical power of attorney, Ethics Committee or by the court of law has been suggested in western countries to make decisions. In India, in accordance with the current family relationships, appropriate family members, knowing the wishes of the person under consideration, could document a "Family Will".

Conclusion: In spite of the diversity in India, decision regarding health care of an individual is a family decision. As death is a reality for each individual who is alive a Family Will can give clear guidance especially for end of life management. This will avoid panic among relatives when quick decisions have to be made; avoid assault on medical practitioners and litigations against them.

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Issues of Informed Consent in Public Umbilical Cord Blood Banking: Canadian Parents' Perspectives

Human umbilical cord blood (UCB) has attracted a great deal of public and private interest in recent years due to the discovery that it is a rich source of hematopoietic progenitor cells (HPCs), which have many current and potential niches in both research and therapy. UCB is readily available and relatively non-controversial compared to other stem cell sources. Canada is currently taking steps to develop a national public cord blood bank, a project that may utilize some of Canada's existing public and private cord blood bank infrastructure. In this context, informed consent is a salient issue in the collection, storage, and use of UCB, and has ramifications on confidentiality, privacy, access, and equity. Questions regarding whose consent is necessary and sufficient for UCB donation, the timing of consent, and what constitutes 'sufficiently informed' parents, are debatable. In Canada, there has been no evaluation of the informed consent process in UCB banking from parents' perspectives, yet such work is crucial in the development of protocols that are parent- and donor-centric. This study uses a collective case study approach involving public UCB banks in Canada to evaluate the current informed consent protocols for research and therapy, both theoretically and from the perspectives of parents who have donated their child's cord blood. It explores how the underlying notion of autonomy plays out in the context of UCB donation. The findings will be used to arrive at recommendations for informed consent protocols within a national cord blood bank.

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Organizational Ethics in Healthcare: issues, strategies, indicators of effectiveness

Organizational ethics is an emerging area in health care management. Hospital decision-makers are calling for more guidance on organizational ethics issues in their organizations. Recent emphasis on ethics in hospital accreditation seems to be reinforcing this trend. Although there is an increasing interest in organizational ethics among bioethicists, there remain significant gaps in understanding about what ethical issues health care managers are facing, what strategies they are using to address these issues, and how effective these strategies and mechanisms are in resolving organizational ethics issues.

We conducted a large qualitative study to bridge these gaps in understanding and to begin identifying good practices in organizational ethics. The study involved approximately 160 one-on-one interviews of board members, CEOs, senior managers, middle managers (clinical and administrative), and staff clinical ethicists in 13 health organizations in the General Toronto Area. These organizations represent a broad cross-section of health services (acute, rehabilitation, long-term and continuing care, and community-based services) across the life span (children, adult, senior adult) in both urban, inner-city and suburban settings.

In this interactive case-based session, we present key findings of the study, including: a) the organizational ethics issues faced by these organizations, b) the strategies and mechanisms used to address these issues, and c) participants' perceptions of the ethical effectiveness of these strategies and mechanisms.

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Developing Clinical Ethics in Psychiatry for Medical Residents at the University of Nevada School of Medicine

Psychiatry is a particularly value-laden discipline and as such ethical considerations regularly influence clinical decisions, for example, when the value of individual autonomy must be weighed against the value of involuntary treatment. To be sure many such issues are faced by other healthcare practitioners, but while most medical specialties are concerned with areas of human experience and behavior where the values of practitioners and patients are largely shared, this is not always the case in psychiatry and as a result, relationships between provider and patient can be more adversarial. Ethics in psychiatry is wider in scope than traditional bioethics and has deeper philosophical issues including personal identity, rationality, and determinism. Consequently, as has been often argued in the literature, clinical problem solving in psychiatric ethics required sharper thinking skills than in other areas of bioethics. In this presentation, Marin Gillis, a philosopher and Director of the Division of Ethics and Medical Humanities, and Steven Zuchowski, M.D. and Residency Director of Psychiatry and Behavioral Sciences, will report on the challenges and the successes of their team-approach to a new initiative in the psychiatry residency at the University of Nevada School of Medicine in Reno, including resident surveys and comments.

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Deciding to Use Complementary and Alternative Medicine with Children: Legal, Ethical and Clinical Issues

In this paper we report the findings of a project undertaken by an interdisciplinary team with expertise in law, bioethics, paediatrics and epidemiology, in collaboration with the Canadian College of Naturopathic Medicine and funded by the SickKids Foundation. Use of CAM practices and products in children raises specific legal, ethical and clinical concerns, because of the vulnerability of the paediatric population, and because most often, children cannot decide for themselves about treatment.

1. While many of the same legal, ethical and clinical principles apply to CAM and conventional treatment, CAM raises some unique treatment and liability issues.
2. Limited research on CAM's efficacy and safety, especially in children, means that decisions must frequently be made in conditions of uncertainty. Even when risks and benefits are known, people may weigh them differently. Guidance and intervention principles are crucial.
3. Case scenarios can effectively act as a practical "anchor" to explore CAM policy issues, illustrating the application of and shortcomings in existing guidance and intervention principles.

The issues raised by the case scenarios we have developed include: If physicians are obligated to disclose CAM alternatives; If hospitals are obligated to provide access to CAM therapies; Natural health product interactions with conventional medications; Physicians' referrals to CAM practitioners; Parents who reject potentially life-saving medical treatment for CAM; Parents who choose not to immunize their children; The 'mature minor' who prefers CAM to conventional treatment against his parent's wishes; A delay in medical diagnosis for a patient who is seeing a CAM practitioner.

We will conclude with some recommendations regarding education, policy development and clinical practice.

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REB Review and Aboriginal Community Values

Contemporary research ethics review boards have developed for the most part within an established academic or health care institutional framework, with shared cultural, methodological and ethical perspectives on the conduct of research involving humans. Most research ethics policies and guidelines place great weight on individual autonomy and focus on enabling "subjects" to be self-determining participants. A highly individualistic decision-making process in medical practice and research has developed around the principle of autonomous choice on the assumption that the best protection for patients or research participants lies in their ability to make competent, voluntary, informed choices, evaluating the risks and benefits from a personal perspective.

Over the past two decades, Aboriginal communities in North America and International Indigenous communities have identified key issues ignored by most institutional or university based REBs. Many Aboriginal researchers, policy makers and community members have not only critiqued the current structure, they have made proposals for changes on a variety of levels in an attempt to develop more community sensitive research ethics review processes. In doing so, they have emphasized recognition of collective rights including community consent. Critics see these proposals involving alternative policy guidelines and community based review bodies as not only challenging the current system of ethics review, but also as reflecting fundamental differences in values.

In this presentation, we explore the political, legal and ethical frameworks that have informed REB review, looking at their process and content and asking how this contrasts with emerging Aboriginal proposals for community based research ethics review. We follow this with recommendations on how current REB review models might accommodate the requirements of both communities and REBs.

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Autonomy, Paternalism and the Impact Bias

Autonomy is often regarded as one of the primary values in medical ethics. An outcome of the respect for autonomy is the patient's right to choose between medical options, or to refuse care. Patients with capacity are expected to deliberate about the choices presented to them, and reach a decision using their own moral values and ideas about quality of life. One of the considerations used to decide could include the effect of the medical procedure on the patient's long-term emotional well-being after the intervention.

This paper will present some current research in psychology that supports the hypothesis that people's ability to predict future levels of happiness or unhappiness is hindered by a pervasive error – the impact bias. People tend to overestimate the positive impact of good events as well as underestimate their ability to cope and recover from negative events. Applying this result to the field of medical ethics, could challenge the respect that is accorded to patients' decisions involving refusal of treatment in cases where the impact bias estimations are constitutive of the patient's decisions to accept or refuse treatment. This paper will attempt to draw out the implications of impact bias on the respect for autonomy and the justifications for paternalism.

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Privacy and Informed Consent: The challenge of new technologies in the workplace

The Foothills Medical Centre in Calgary has an acute care unit that goes beyond the traditional ward, co-locating a multi-disciplinary research laboratory with a patient care ward to carry out innovative healthcare research. This research agenda incorporates nanotechnology and smart technology: studies currently range from examination and analysis of the physical functional dynamics of knowledge and information transfer at shift-change, video-monitoring of rooms for electronic collection of individual patient data, computational mathematical modeling of locomotion within the unit and the management of the physical space.

Effectively the ward itself has become the subject of study. The goal is to redesign healthcare delivery. Research methodologies include observational investigation of daily activities. Those observed are patients, health care professionals, visitors, hospital maintenance and security staff and hospital management. While detailed personal information is not the object, it comes into the picture at nearly every step. The benefits of this research are being evaluated but remain unproven. Ethical research in this venue requires close consideration of health and other personal privacy protection law. Current law is largely framed at the individual level, but its reach is systemic with a potential for conflict. This research scenario requires the comparative examination of the role of individual consent: avoiding conflicts of interest; and difficulties in ensuring respect; versus the potential or real public good that may arise.

The authors will report on issues identified to date, the steps they have taken to address them and the proposed method of ensuring ethical research in this complex environment.

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**Complementary and Alternative Medicine (CAM) in the Hospital Setting:
The Controversy and Challenge of Developing a CAM Policy**

Implementation of a Complementary and Alternative Medicine (CAM) policy into the Canadian hospital setting poses unique challenges. The values of patient choice, multiculturalism, and the reality that patients may covertly be using CAM anyway must be balanced against the concerns of liability and potential harm to patients associated with unorthodox treatment plans. The CAM literature reveals a very polarized and frequently polemical debate that fails to alleviate, and may even exacerbate, the boardroom tensions.

Drawing from our own experiences in developing a CAM policy at a Canadian hospital, we discuss the conceptual and practical challenges that make such a policy so contentious. We propose that neither the dismissive regard of CAM as unscientific nor the romanticisation of CAM's "ancient wisdom" provide an appropriate theoretical framework for confronting CAM in the hospital setting. Both positions problematically contain an implicit wholesale evaluation of the efficacy and safety of *all* CAMs, which is unsupported in light of the variety of techniques, modalities, and healthcare philosophies that fall into the category of "CAM". These hyperbolic positions are also unsuitable starting points for policy debate. We recommend instead a policy that supports the open and deliberative process rooted in the notion of informed consent take place between patients and their healthcare team regarding the use of CAM. To illustrate support for such a procedural method, we present a demonstrative case that arose in a hospital setting where the CAM policy is in development. Drawing from that case, we offer a general framework for CAM policy.

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Certification Revisited: Is Now the Time to Formalize Professional Training in Clinical Ethics?

Over 10 years ago, the Network on Health Care Ethics Consultation decided that, instead of typical certification practices, health ethics consultants should adopt "...a less formal, more open-ended approach to establishing standards of training and practice." (Sherwin 1994) This advice seems to have been well-heeded by practitioners and teachers of hospital ethics in Canada, which remains unregulated.

Sherwin's balanced appraisal of the pros and cons of certification is reconsidered in light of 12 years of growth, a growing well of experience among ethics practitioners, the evolution of professional identity among ethicists and many allied health care workers, and the experiences of the Canadian Association for Pastoral Practice and Education, which regulates the certification of hospital chaplains after similar discussions years ago. (Dr. Elford is a former CAPPE president)

Sherwin feared that formal certification of clinical ethicists would lead to some unhealthy uniformity of thinking, to a loss of the diversity of backgrounds that currently characterize the field, to turf battles, and in appropriate presumptions of expertise. While these are possible, our experience to date suggests they are unlikely. Rather, we are persuaded that certification is likely to "...make the field more attractive to talented students who will be encouraged to participate in a more clearly established practice." (Sherwin 1994). We argue that such practice is now sufficiently established, and observe that there exists substantial need for both ethics consultation (which normally results in informal ethics education), and dozens of skilled consultants to deliver services. We also suggest that core knowledge and skills that ethicists from any background require for clinical practice are readily identifiable and theoretically teachable. Site-based programs could last from 12 – 48 months.

We need to certify and professionalize to attract talented people into clinical ethics. True inter-disciplinarians are not common and we need to show young students and current health professionals a viable career choice with fair remuneration and relative seniority. We need to give them much front line experience. Sherwin and the Network suggested that the time for certification may arrive, and we suggest in various ways that serious discussion be initiated about this now.

1. Susan Sherwin, "Certification of Health Care Ethics Consultants: Advantages and Disadvantages," in Françoise Baylis, The Health Care Ethics Consultant (Humana Press: Totowa, NJ, 1994), pp. 11-24.

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How Much is that Prozac in the Window: Big Pharma and the Made-to-Order Patient

Amongst industrialized countries, the United States and New Zealand are the only two that permit direct-to-consumer (DTC) advertising of prescription medicines. Currently, New Zealand is considering a ban on the practice, while, following the *Vioxx* debacle, the United States is engaged in a debate about its ethical and medical implications. In this paper, we argue that DTC is both ethically troubling and medically suspect, for it (1) focuses on expensive, least-tested drugs that over time are too often proven unsafe for all or part of a target population, (2) pathologizes certain symptoms that are within the normal range of functioning, (3) undermines public health messages about diet, mental well-being, and exercise by marketing putative silver bullets, and (4) misrepresents to the public the "normal" range of physical and psychological experience while misleading the already vulnerable about potential solutions. Crucially, we argue, all of these problems are generated by the underlying conflict between the profit-making imperative of pharmaceutical corporations (or the *business* of medicine), and the fundamental ethical presuppositions of medical *practice*. We specifically address the cases of *Sarafem* (*Prozac*) as a treatment for Premenstrual Dysphoric Disorder (PMDD) and *Lunesta* as a treatment for insomnia. Both are examples of DTC that call for an ethical re-evaluation of the relationship between medicine and commerce. We believe that the actual and potential harm presented by DTC to the patient, the physician-patient relationship, and to the enterprise of medicine makes clear the centrality of ethics to both the business and practice of medicine.

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The Ethics of Evidence-Based Psychiatry

Evidence-based medicine (EBM) is a concept that has come to dominate the medical literature in the last fifteen years. The phrase 'EBM' was coined in 1990 at McMaster University. Since then, EBM has become highly influential in clinical practice, medical education, and health policy. Along with this widespread dissemination, there has been considerable debate about EBM. This debate has focused on the scientific quality of much research data, the veracity of EBM's epistemic claims, and the professional power of those who control what counts as 'evidence.' Nevertheless, there has been limited discussion about the ethical content of EBM, even while it presents itself as ethically obligatory. In fact, it is this ethical mandate that gives EBM its force. No practitioner wants to be perceived as practicing contrary to evidence, as this could violate his/her ethical duties towards patients.

EBM has received particularly enthusiastic endorsement from psychiatry, to which it offers the promise of greater acceptance through scientific credibility. The memory of harmful, or even abusive, interventions continues to undermine psychiatry as a legitimate medical discipline. Implicitly, advocates of evidence-based psychiatry (EBP) aim to bolster psychiatry's ethical acceptability by using evidence to protect patients from incompetence or worse, the ill-intent of individual practitioners. This paper will explore the normative content of EBP and address the underexamined ethics of EBM. It will argue that EBP cannot provide the ethical substantiation sought by psychiatry. This failure results from EBM's attempt to ground all legitimate clinical decision-making in narrowly-defined, consequentialist reasoning.

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Cesarean Section on Demand – Ethical Concerns and Global Health Disparities

Cesarean section rates are at their highest globally than ever before. At the same time fetal-maternal health and mortality has not improved for the majority of the world's women. While cesarean sections have increased in part due to changes in clinical management of labor, it is also increasing due to a new phenomenon of women requesting the surgery without medical reasons.

Cesarean section on demand has become the most fiercely debated topic in contemporary obstetrics. Like many issues in bioethics, caesarean section on demand, is as much a social issue as it is a medical one. While c-section on demand does not fulfill beneficence, non-maleficence or justice based considerations it is being performed at an increasing rate with the justification that patient choice, autonomy, is the paramount concern. Choice, or respect for autonomy, has been central to this debate in the Western world.

Proponents of the procedure argue that in a free society, we do not put constraints on what people can have done to their own bodies. Even if this was true, we certainly do not pay for all procedures to be done – especially those without clinical benefit. The only area where we do allow patient autonomy to trump other ethical considerations is in the area of cosmetic surgery. Although framing the debate in terms of 'cosmetic cesarean section, may seem more an issue of semantics, it is an important distinction for a variety of reasons. Firstly, the title 'elective cesarean section', 'patient-request cesarean section' etc. make it seem as though it is a medically viable option. Framing the option as 'cosmetic cesarean' may serve to take away the sense of legitimization patients may otherwise feel about the procedure. If cesareans are being performed only based on preference, this is an unethical use of public resources. If the option of cesarean section for non-medical reasons is to be carried out, it is absolutely unethical for it to be covered in a public system where other non-medical (cosmetic) procedures are not covered. Patients should have to pay for the procedure. Included in costs must be increased hospital stay, use of antibiotics/blood products solely related to the procedure, hospital bed costs and nursing fees.

While this issue has been discussed in ethical literature, few if any have argued the importance of framing the debate in terms of cosmetic surgery. This paper will argue the importance of this distinction not only in the West but in the context of global health ethics and resource distribution.

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Creating a Community of Practice in Clinical Ethics

"Teamwork is the ability to work together toward a common vision. The ability to direct individual accomplishments toward organizational objectives. It is the fuel that allows common people to attain uncommon results." (Andrew Carnegie)

In this paper, the experiences of one successful and productive community of practice are described. As defined in the literature, a community of practice is a group of individuals who are informally bound by a shared practice to a set of problems. This particular community of practice is comprised of four full-time clinical ethicists working in both community and academic hospitals who came together as individuals who were making the transition from clinical ethics fellows to newly-employed clinical ethicists.

The benefits accrued for members of this community of practice include reduced moral distress, a decreased sense of isolation, feeling supported and energized in their work, cross-fertilization of ideas, enhanced knowledge and skills, and sharing of resources. This community of practice has generated several scholarly publications and presentations for its members and this past year was instrumental in the development and implementation of a Clinical Ethics Summer Institute that utilized a community of practice framework. Developing a community of practice is not without its challenges and several of these such as determining membership, maintaining momentum, and setting priorities will also be discussed.

Creating a community of practice is one innovative approach to connect and engage healthcare professionals who share an interest in supporting clinical ethics activities and building ethics capacity within or across healthcare organizations.

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Observations of a human research subject

Much of the literature on the experiences of human research subjects is based on aggregate data and does not include the narrative aspects of being a human research subject. Focusing on these narrative aspects of human research subjects' experiences helps us explore how research ethics principles get enacted. In this paper I present my preliminary findings from my ethnographic research about the experiences of human research subjects, including my own. In my study I interviewed approximately 30 people enrolled in 3 different trials (2 drug trials and 1 metabolic trial) and enrolled myself into one of the trials. In this paper I describe my own experiences, including: completing the informed consent process, evaluating the study's risks and benefits, and feeling apprehension regarding pain and medical evaluation. I also describe my relationships with the principal investigators, the research coordinators, and the other participants. I discuss how participation in a medical trial impacted my perspectives and understandings of scientific medicine and the larger research industry. I also explore how it felt to be a "human guinea pig" and the embodied experience of participating in and contributing to medical research. I compare and contrast my own experience with those of other research subjects' in my study to show the variation in experience and to place my experiences within a broader context. This paper will inform research ethics board members and ethicists about participants' perceptions of common ethical concerns in medical research, including the informed consent process and issues of coercion and transparency.

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Harmless Worries? Error and the Ethics of Disclosure

At least in the hospital environment, discourse on the topic of medical error has been dominated by a desire to replace a climate of "shame and blame" with one that recognizes the importance of the structures (and strictures) that are the reality of clinical work. Analogies are made with industry and experts speak frequently of systems, latencies, and root cause analysis. While there is much to recommend this approach – particularly if it can deliver on a promise to quash the "epidemic" – there is also something deeply dissatisfying about it. I will argue that discussions of medical error could be vastly improved if we paid attention to the needs of some missing persons: *i.e.* our patients and their providers. Sensitive disclosure can be facilitated; moreover, in an environment that recognizes a role for "moral luck" (a concept first explored by the philosophers Bernard Williams and Thomas Nagel). At first blush, moral luck may seem excessively theoretical, oxymoronic, and, worse yet, an attempt to elide responsibility. It can be demystified, however, and put in the service of a renewed effort to promote accountability without the exploitation of counter-productive emotions such as devastation, humiliation and anguish. On my view, an essential part of that exercise would be to explore the content of what might simply be called "role related responsibility."

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Ethics Education in the NICU: Sharing Ideas and Resources

Numerous ethical issues arise in the care of infants in the Neonatal Intensive Care Unit (NICU). The manner in which these issues are managed is an important component of healthcare professionals' training and experience. An interdisciplinary group has been developing an educational resource, a Neonatal Ethics Education Directory (NEED), to aid staff deal with the ethical issues in this clinical context. The objective is to develop readily usable, web-based material on the more common neonatal issues so as to facilitate ethics teaching and learning for all the health care professionals in NICU settings. Facilitating discussion and exploration of the ethical components of neonatal care is anticipated to promote the management of these issues in a coherent, sensitive and ethically appropriate manner.

At this workshop the work to date will be presented: participants will share and discuss the results of a needs assessment regarding ethics education in the NICU; be able to view one topic focused chapter and give input on materials in development, and propose their own ideas and strategies that may facilitate ethics teaching and learning in this environment.

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Front Line Nurses Perceptions of Enacting Patient-Centred Care

It is essential that the voice and experiences of front line nurses working in health care settings that have made an organizational commitment to patient-centered care values be heard and understood. This exploratory qualitative study will determine whether or not there is a difference between the theoretical concept of patient-centred care, the values associated with this approach, and what front line nurses experience in their daily practice. Themes identified in this study will help to enhance a professional understanding of how patient centred ideals or values measure against the experiences of those nurses who are practicing, or attempting to practice, patient-centred care. Increased understanding will help guide the development of ethics education, in addition to policies or protocols for healthcare practitioners. As this will be the first study to examine the perceptions of front line nurses regarding patient-centred care, publication of the results of this study will enhance the nursing and ethics literature related to the concept of patient-centred care. Implications for practice and recommendations for future research will be discussed.

Our presentation will describe the background to this study, progress to date, and future plans.

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Transcending the Paternalistic Model of Behavioral Healthcare: Allowing Middle-Ground Patients to Exercise Autonomy

Patients with a mental or behavioral disorder represent a challenging middle ground between patients who have only recently lost decision-making capacity due to illness, and those patients who have never been capable of making decisions due to severe mental disability or retardation. These middle-ground patients often have the capacity to make decisions regarding some spheres of their lives, and often appear to develop coping regimens that allow them significant ability to manage most of their daily life activities. No matter how much these patients lack decision-making capacity for a specific clinical issue, their development of coping skills suggests that healthcare providers cannot simply treat them as if they have little or no say in their care plan.

When it comes to caring for those who lack capacity for a specific clinical issue due to mental/behavior disorders, healthcare providers often employ a paternalistic model of care-giving that attempts to balance curing on the one hand (beneficence) and protection (nonmaleficence) on the other. The authors of this workshop propose to assist healthcare providers by offering a much wider range of care options than simply curing or protecting by re-appreciating the autonomy of these patients. It is possible to view the patient's behavioral disorder as an aspect of autonomy, rather than merely part of the patient's overall diagnosis. Through a series of cases drawn from the experiences of ethics consult teams, the authors show how a less paternalistic model of care-giving provides for better outcomes within this vulnerable middle-ground patient population.

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How health professionals experience ethics in humanitarian assistance and development work: a qualitative study

Canadian health professionals are involved in humanitarian assistance and development work in many regions of the world. They participate in primary health care, immunization campaigns, feeding programs, clinic- and hospital-based care, and rehabilitation services. Many of the health professionals involved in this type of work have not received training in international health settings and may struggle to adapt to new cultural and clinical realities. In the course of this work clinicians are frequently exposed to complex ethical issues and may experience unfamiliar moral dilemmas in the provision of care to patients. For some, these complex ethical issues can lead to moral uncertainty and distress. This paper examines how health workers experience ethics in the course of humanitarian assistance and development work. A qualitative study was conducted to consider this question. Five core themes emerged from the data, including: tension between respecting local customs and imposing outside values, obstacles to the provision of basic care, differing understandings of health and illness, questions of identity for health workers, and issues of trust and distrust. Recommendations are made for organizational strategies that could help non-governmental organizations (NGOs) better support and equip their staff as they respond to ethical issues.

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Corporate Governance Mechanisms as Tools for Ensuring the Bioethics of Health Industry Business in Least Developed Countries

Business, including the business of health, has been heralded as a means for the reduction of poverty in least developed countries. That said, business arrangements by pharmaceutical, biotechnology and other health industry companies in and with least developed countries raise a host of complex challenges for bioethics, e.g., in the case of benefit sharing ventures and public-private partnerships. Bioethical criticisms have been launched against many of these endeavors, pointing to conflicts of interest that, real or perceived, call into question the very integrity of the science and business involved. Improperly addressed, ethical dilemmas can have dire consequences not only for least developed countries, but for health industry companies and their stakeholders -- directors, officers, shareholders and experts. Are these companies equipped to be accountable for the bioethics of their activities? An analogy may be drawn to recent financial reporting scandals in the United States that have been addressed by the institution of corporate governance mechanisms to protect stakeholders, while ensuring that officers, directors and experts have the right information and support to make ethical decisions. Properly conceived, a corporate governance framework could also help ensure the bioethics of health industry activities in least developed countries. Directors, officers and experts would be apprised of better information and evaluation tools to make bioethical choices. Shareholders would be educated to judge the bioethics of a company's activities in least developed countries and empowered to have a say. In the result, least developed countries would benefit from participating in informed bioethical analysis at all stages of business engagement.

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Informal ethics consultation: hindrance or help?

Background: Informal ethics consultation is criticized on several grounds, but may also hold opportunities for developing formal ethics consultations services.

Methods: Based on national surveys of US and European clinicians, we explore the advantages and disadvantages of informal ethics consultation.

Results: Informal ethics consultation takes several forms, leading to occasional difficulties in distinguishing formal and informal services. Ethics advice originating outside a formally labeled "ethics" structure is available to 24% of internists from Norway, Italy, Switzerland, and the UK. Additionally, those performing formal ethics consultation in the US and Europe often lack formal training in ethics. Moreover, 30% of consultations performed by formal ethics support were "curbside" consultations. Critics of informal ethics services have raised the concerns that they would exclude non-clinicians, may merely reflect a clinical perspective, and thereby be likely to reinforce the requestor's values. They also worry that informal services promote a misunderstanding that questions of value are questions of technical expertise and that medical experience confers the capacity to make difficult moral decisions. Furthermore, informal consultation may be less thorough, careful, and accountable than formal consultation. Physicians, however, use informal services and the obstacles to their use may be different from those hindering formal services.

Conclusion: While informal ethics support lacks uniform quality, it offers sufficient value to warrant integration with, rather than replacement by, formal services. This could increase diversity and representation within ethics consultation, enhance availability of ethics support, and enable better accountability in the formal and informal components.

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It's not all about Decision-making: The Importance of Discernment and Spirituality in Clinical Ethics.

Clinical ethics at times has been characterized by quandaries and dramatic cases that are reduced to mere problems to be solved. Despite the intended focus of clinical ethics being the patient, it can be argued that the practice of clinical ethics itself is not patient-centred. Its interest is often on the application of principles, such as autonomy, beneficence, nonmaleficence and justice, in an attempt to resolve ethical challenges in medicine.

Those involved in ethical quandaries need to have knowledge not only of ethical principles and theories, but also an understanding of narrative epistemology, which pertains to what is important to the life and care of the patient. What clinical ethics does not always contemplate is the spiritual—what gives meaning, purpose and value to a person's life. This focus calls for a rich description of a person's narrative and for imaginative discernment in addressing ethical quandaries.

The presentation will address not how to solve ethical dilemmas. Such a task, which involves decision-making, can lead to an over-emphasis on the decision as being an end to itself. This in turn can create an environment in which moral residue can easily surface for persons who are troubled about how decisions are made or why certain values and principles are allowed to "trump" others. Instead, the presentation will concentrate on how to "dissolve" problems, which entails an ethic of care. Such an ethic is not situational but is person specific and engages clinicians and others in a dialogue that discerns what is important for the patient.

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Teaching Ethics in a Home Care Program

Not only are new advances in biotechnology and biomedical science confronting health care professionals with ethical dilemmas, but health professionals working in community settings are additionally faced with ethical decision making in providing care to community based clients. With an increase in the aging population there is more demand for increased health care services. Many clients wish to remain in their own home and many are living at risk, which results in ethical dilemmas and moral distress for many health professionals.

When the Calgary Health region, Home Care Program established an Ethics Committee in 2003 a survey was carried out to determine the staff's knowledge of bioethics, identify gaps and learning needs. Analyses of the data provided information on the diversity of levels of knowledge and understanding of bioethics. As a result a sub-committee was struck to develop an educational program to prioritize and meet the identified learning needs of the Home Care staff members.

As client care needs become more complex and the number of clients assigned to each staff member increases, staff spend more time assessing needs, problem solving, providing care, and driving between client visits, and resulting in less time available during their work day for staff development. Educational sessions needed to meet staff convenience with regard to location, adequate parking facilities, be held on a variety of days and at different times during the work time. The orientation program for all staff new to Home Care was revised to include an introduction to bioethics. Basic bioethics sessions were then offered for all staff members, including managers, to obtain an understanding of the ethical principles. Case studies were used to generate discussion and increase awareness of the application of ethical principles to clinical practice.

Evaluation of these basic sessions has been very positive and provides input for more advanced sessions on specific topics, related to client care needs. As a result regular sessions on basic bioethics as well as more advanced ethics education on specific topics, such as "Living at Risk" and "Mental Health Ethics" are presented. The evaluation results continue to provide data to enhance the quality of the education, and in turn positively influence clinical practice. If increased knowledge and understanding of bioethics meets the learning needs of staff and assists them with greater ethical decision making skills there will be a decrease in the moral distress experienced by the professional staff members providing care to Home Care clients.

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The Case for Dignity

The notion of dignity is contested in North American bioethics. Some scholars have called dignity "useless," claiming that it is vague, or contradictory, or inadequately distinguished from concepts like autonomy. Indeed, dignity has been described as objective and as subjective, as public and as private, as individual and as collective, as internal and intrinsic and as external and extrinsic, as hierarchical and as democratic, as unconditional and static and as contingent and dynamic, and as descriptive and prescriptive. Despite this vexing conceptual disorder, other disciplines have embraced dignity, and dignity related scholarship and activism is thriving in European bioethics, in law, in health and human rights, in clinical care, and in movements for global health and social justice. This paper will review the literature in these arenas to clarify two related, but distinct meanings of dignity—human dignity and social dignity--and to illustrate the range of ways in which these concepts are currently understood and applied. It will then draw upon interviews conducted as part of a grounded theory study of dignity to show how salient and powerful an idea dignity is in the daily lives of individuals who are marginalized by health or social status. Finally, it will suggest ways in which dignity can be made useful in both ethical analysis and practice.

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Justice for incompetent patients?

Objective: To determine preferences for resuscitation of different patients among students in ethics, law, anthropology, medicine, residents and attendings

Design/Methods: 8 scenarios of incompetent patients needing resuscitation (Resus)

- 24 wk infant, term with malformation, 2 mth with meningitis: all 3 with 50% survival. Among survivors, 25% chance of serious & 25% chance of mild disability.

-7 y multiply handicapped. New head trauma: 50% survival, 50% chance to recover.

-13 y with acute leukemia: 5% survival and 20% impairment.

-35 y with brain cancer: 5% survival, 100% serious sequelae

-50 y with multiple trauma: 50% survival, 50% serious abnormal outcomes.

-80 y with dementia and new stroke: 50% survival and 50% return to baseline

Respondents were asked if they would resuscitate these patients, and about Resus decisions if the children were their own.

Results: 842 responses, 88% response rate. Would always Resus if no time to consult family: 24 wk: 39%, term: 56%, 2 mth: 76%, 7 y: 78%, 13 y: 68%, 35y: 65%, 50y: 61%, 80y: 20%.

All groups were most likely to want Resus of their 2 mth and 7 y (range 82-100%). Most groups wanted Resus for their preterm less than all the other children (37-78%).

Participants were asked in what order they would resuscitate the patients if all needed intervention at the same time.

Median order of resusc: 1st: 2mth, 2nd: 7 y, 3rd: term baby, 4th: 13y, 5th: 50y, 6th: preterm, 7th: 35y, 8th: 80y old. The only groups resuscitating the 24 wk among the 1st four patients were peds ER staff, peds residents and neonatologists

Conclusions: The reasons underlying choices for Resus are not closely related to the potential life years gained. Impairment (or potential) does not seem to influence these choices. Despite the highest quality adjusted life years, the 24 wk is often resuscitated after others which much worse likely outcomes.

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Clinical Ethics in Nigeria : A Critical Appraisal

Clinical ethics is a major response to technological and scientific revolutions in health care delivery. This is more important in developing countries where ignorance, poverty and disease interplay especially in Nigeria.

The relevance of clinical ethics in resolving challenges in clinical practice can not be over emphasized in resolving complex ethical issues. In Nigeria, there is a preponderance of cases of ethical dilemma for which the application of basic ethical theories and principles were not applied either due to the ignorance of the health workers concerned or total disregard for ethical guidelines. A specific case of transfusion of HIV contaminated blood to a baby in one of the foremost teaching hospitals in Nigeria showcases the relevance of a clinical ethics consciousness in health care delivery in Nigeria.

Although several factors account for the current non integration of clinical ethics into health care delivery in Nigeria little or no information exist in this regard. Therefore, this paper critically examines the context of the case presented above and also makes recommendations for future direction.

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Ethics in Pandemic Planning – Getting to the Nitty Gritty

The amount of ethics-related activity related to the planning for an influenza pandemic is perhaps unprecedented relative to other areas of infectious disease. The issues are recognized as broad, ranging from human resource management to the allocation of scarce resources such as anti-virals and vaccines.

Most ethics analyses of such issues, while seeking to provide meaningful direction for practical decision making, has remained at the level of theory, specifying principles, articulating tensions and suggesting how certain principles or normative guides apply to such issues. There are at least two worries with this approach. First, it prescribes normative guides – an approach that runs the risk of being perceived as too directive by those to live according policy decisions, as well as those in charge of developing policy. Second, the approach does not offer practical tools for decision makers to actually develop policy decisions for the issues in question based on the principles offered.

This paper outlines a practical process and framework for system level decision making based on the author's work in the articulation of four ethics dimensions of system level decision making. These tools have been used in policy making by the Fraser Health Authority in BC and Alberta Health and Wellness' Pandemic Planning Ethics Subcommittee.

The author will describe the decision tools and their application to various questions within the pandemic planning process.

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The wish to hasten death among ALS patients in a palliative care program

Background. Amyotrophic lateral sclerosis (ALS) represents a major challenge to palliative care, particularly as the characteristics of the disease may provoke patients' wishes to hasten death.

Aim. This study investigates the prevalence and determinants of the wish to hasten death in ALS patients and the opinion of their caregivers.

Methods. The prospective, semi-quantitative questionnaire study includes patients and their primary caregivers, enrolled in an outpatient ALS palliative care program in Munich, Germany. The second questionnaire is administered one year after the first or after a substantial clinical decline.

Results. The cross-sectional results of the first questionnaire are presented, comprising a sample of 30 patient-caregiver-pairs. 31% of patients expressed the desire to hasten death. Suicidal ideation was admitted by 50%, while 24% had planned and 6% actually tried suicide. 44% of patients could imagine asking their doctor for physician-assisted suicide or euthanasia. The desire to hasten death correlated significantly with loneliness and both the depression and anxiety subscales of the Hospital Anxiety and Depression Scale, but not with religiosity as measured by the Idler Index of Religiosity. Only 11% of primary caregivers said their relatives communicated with them about their desire for hastened death. 25% of caregivers could imagine assisting their relatives in suicide, and 20% could think of performing euthanasia.

Conclusions. The wish to hasten death is common among German ALS patients in a palliative care setting. Its correlations with loneliness, anxiety and depression pose significant challenges to palliative care. Physicians and caregivers should address this issue more openly.

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Encadrement juridique et éthique de la recherche biomédicale en Afrique Noire

On compte environ 25 millions d'africains sur les 38,6 millions de personnes dans le monde vivant avec le VIH à la fin de l'année 2005 (UNAIDS, 2006). Avec la progression fulgurante de la maladie, les pays africains ont un besoin crucial de recherche biomédicale tant sur cette maladie que sur d'autres telles la malaria et la tuberculose qui déciment leurs populations. C'est paradoxalement cet impératif besoin de recherche qui rend vulnérables les populations de ces pays en termes d'exploitation. Une question se pose dès lors avec acuité : Comment s'assurer que les recherches biomédicales internationales sur le VIH réalisées dans les pays en voie de développement se font dans un cadre éthique adéquat respectant les intérêts des populations?

Sur le plan méthodologique, nous avons privilégié l'analyse de contenu des textes internationaux et nationaux (Déclaration d'Helsinki (2002), les lignes directrices du CIOMS (2002), les Bonnes Pratiques Cliniques (1995), la Déclaration Universelle sur la Bioéthique (2005) de l'UNESCO, etc. En l'absence de normes nationales régulant la recherche dans les pays africains, ces dispositions internationales revêtent une importance déterminante et elles bénéficient d'une valeur morale largement acceptée. Cependant, il n'est pas certain que les projets de recherche en cours dans les pays d'Afrique bénéficient d'une évaluation adéquate. Il existe trop peu de CERs fonctionnels dans les pays africains. Dans les pays où il existe des CERs, ces derniers ne disposent pas de moyens financiers et de compétences nécessaires. De plus, l'évaluation actuellement faite de ces projets est très largement inspirée du 'principisme' américain peu adapté aux réalités contextuelles africaines. Les spécificités culturelles, sociales, économiques et politiques interdisent le transfert pur et simple des principes et procédures des pays développés en Afrique.

Les problèmes posés par l'application des principes véhiculés dans les textes normatifs amènent à repenser un cadre éthique pragmatique axé sur les valeurs et normes culturelles des pays d'Afrique Noire.

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The Ethics of Bioethics: Some Elements of Code Development

Though the field of bioethics characteristically focuses on normative problems faced by professionals in health care and the biological sciences, growing attention is being given to a second set of quandaries that we in bioethics face in our own professional work. We are sometimes required to (1) recognize and manage our own conflicts of interest, (2) negotiate tensions between our obligations of confidentiality and our duties to report, (3) appreciate potentially conflicting obligations before they erupt into impossible dilemmas, (4) deal effectively with improper pressures, and (5) respond impeccably to observed wrongdoings. While many of us have struggled with these issues at the level of conscience -- and a few of us have written about them -- there are currently no easily accessible, comprehensive, authoritative standards for managing ethical problems emerging in the context of clinical consultation.

With attention to some earlier and present efforts to map the ethical dimension of our professional practices, the author sets out (1) a generic description of a code of ethics (preamble, ideals and principles), (2) some organizational requirements for an ongoing code development process, and (3) one procedure for developing consensus on the provisions of a candidate code: a procedure based on values that are implicit in our shared professional work.

Drawing upon recent empirical research undertaken for ASBH, the author will review (1) salient ethical problems reported by ASBH members and (2) arguments for and against undertaking a code development process for health care ethics consultants.

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Whose Decision Making Authority *Should* be Privileged Postmortem When Affirmative Wishes to Donate are Known?

In this paper presentation, I examine an under-explored issue in the challenging arena of organ donation: whose decision making authority *should* be given postmortem priority in the context of known, explicit consent to donate? Current organ donation practices in western countries recognize and affirm the family as the legitimate decision maker in these circumstances. Is this the right time to consider whether a normative gap exists between 'what is' and 'what should be' in this organ donation practice? This complex question arises within the context of an existing, strong social mandate to increase the number of human organs available for transplantation.

The primary arguments for and against privileging each of two possible decision makers - the family and the potential donor (through previously expressed wishes) - will be offered in summary form. Informing this academic and pragmatic debate are considerations of individual vs. relational autonomy; a consequentialist framing of beneficence; 'do no (or as little as possible) harm' to the family/others; the relevance of distinctions between living persons and dead bodies; and various conceptions of distributive, social, and formal justice. From these considerations, tensions and competing obligations emerge that will require a respectful and collaborative approach to decision making among the various stakeholders.

Ultimately, I argue that the decision making authority of potential donors should be privileged postmortem when their wishes to donate are known. How we as a society choose to deal with this challenging organ donation issue is likely to have significant effects on the health and well being of some of our most vulnerable citizens, i.e., those in end-organ failure. It matters.

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Improving Transparency: The ODBP and the Transparent Drug Systems for Patients Act (2006)

The Ontario Drug Benefit Program (ODBP) is a provincial program that covers the cost of approved prescription drugs for seniors and other vulnerable groups in Ontario. The Transparent Drug Systems for Patients Act (TDSPA) makes a number of important changes to the ODBP, and this new legislation is now in effect (October 2006). In this paper I provide a brief overview of the ODBP and how listing decisions have been historically made, and I introduce the changes made by the TDSPA. I offer an ethical assessment of the current system by applying the four conditions of "Accountability for Reasonableness" (Daniels and Sabin, 2002), and I conclude with recommendations for further improvement.

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**To Treat or not to Treat
 Medical Aid for Children and Adults in Developing Countries faces Allocation Problems**

Members of our medical team regularly volunteer to provide treatment in developing countries. During these two-week services the nurses and physicians are confronted with various challenging aspects of distributive justice.

The problems are twofold: first, while the group is acting on location, hundreds of patients ask for help. Since time and resources are limited, many of them have to be rejected. Time is a pressing factor when concerning these questions. Under time pressure, however, selection mistakes are made and unfair decisions appear to be unavoidable.

Second, next to those patients who receive treatment immediately, there are others who, due to the limited medical facilities in their home countries, cannot be taken care of on the spot. However, transferring them to Germany either for an operation or for another procedure can give them a realistic chance to significantly improve their health.

However, sometimes these procedures do not lead to a positive outcome. In the past we dealt with cases that turned critical and did not allow the patient to return home in an adequate time span.

The pre-selection of patients by field workers abroad was often biased by subjective emotions. Therefore our hospital's HEC has developed a policy to regulate access to treatment within our institution for patients from developing countries. The goal was to find a just way to allocate our limited resources and thus to avoid harm to those who were intended to be helped by elective operations.

An introduction into the policy will be given first. After that, some examples will be presented to illustrate its practical use.

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Security or Survival? Prenatal Diagnosis and Justice for Affected Communities

Prenatal diagnosis (PND) and Preimplantation genetic diagnosis (PGD) are used to prevent (and/or treat) heritable biological endowments typically described as genetic diseases or disabilities. Some see in these new technologies tools for justice allowing us to rectify Nature's lottery system that undeservedly leaves certain populations and their prospective progeny genetically disadvantaged. In contrast, some disability and patient advocacy groups have criticized these new capacities for control as a threat to the persons whose identity is fundamentally informed by the conditions being screened for. The rejoinder of some bioethicists who defend *PND* and *PGD* from the standpoint of liberal justice, is that these minorities are right to protest measures which infringe on their security as existing vulnerable populations but that their objections are morally insupportable insofar as they are motivated to ensure the survival of like persons and like communities into the future.

For certain strains of liberal political theory, justice requires special protections in the form of group rights to preserve the conditions for identity for members of minority groups or cultures. Diseases and disabilities identify not only states of affairs of the body but also cultural norms and values. As such, they act as markers for both personal identity and community. The following presentation compares and contrasts if, or to what extent group rights claims against PND and PGD for Down's syndrome and deafness are morally defensible when aimed at ensuring the continuance and preservation of the respective communities associated with these conditions now and into the future.

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Health for Some: An Examination of Global Health Discourses

Globalization has created a demanding new context for health policy, one in which both threats to health and necessary policy responses may involve not only multiple national governments and an expanding range of non-state actors. Emerging discourses on 'global health' – itself a concept and a field of recent origin – can be grouped into five categories, which are not mutually exclusive:

- Health as (national) security (exemplary document: UN Secretary-General's High-level Panel, *A More Secure World: Our Shared Responsibility*, 2004)
- Health as development (exemplary document: Commission on Macroeconomics and Health, *Macroeconomics and Health: Investing in Health for Economic Development*, 2001)
- Health as commodity (exemplary document: WTO *Agreement on Trade-Related Aspects of Intellectual Property (TRIPS)*, 1995)
- Health as public good (exemplary document: Labonte & Spiegel, "Setting global health research priorities, *BMJ* 326:722-723, 2003)
- Health as human right (exemplary document: H. Nygren-Krug, *25 Questions and Answers about Health and Human Rights*, 2002)

Some of these discourses are more problematic for health equity than others. However, each distinct understanding of global health contributes to identifying the ethical challenges created by globalization and devising concrete health equity agendas for public policy.

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The Ethics of Imperfect Cures

The demographic shift experienced in North America is an opportune time to question not only the distribution of health services but also their delivery. As Daniels states, "societal aging dramatically changes the profiles of needs in a country" (2006); this implies for many bioethicists an imperative to focus on a possible scarcity of health care resources. However, the problem of societal aging needs to be recast as two distinct but related problems. The first one, elaborated upon by Daniels in many of his writings, deals with the issues of intergenerational justice. The second one, which concerns this paper, is a consequence of the increasing success of medicine. Medical advances help individuals live longer with chronic ailments as well as survive traumatic events. This class of patients encompasses elderly individuals as well as younger ones, such as children with congenital birth defects, and victims of accidents or warfare. For such patients, cure may imply the need for on-going custodial care.

The consequences of imperfect cures require ethical examination and I put forward the reasons for this in the first part of the paper. In the second, taking Fins' proposal for a palliative neuroethics (2005) augmented by Sherwin's concept of relational autonomy (1998), I make the case that the paradigm of health care services centered on acute interventions needs to be recast. I argue that the implicit independence of acute care services is questionable as health care services are not a series of isolated events evolving separately in time, but are interconnected.

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National Ethical Guidelines for Biomedical Research in Iran

Rapid advances in biomedical sciences have been associated with increasing discussions about ethical aspects of the new knowledge in different societies. These advancements could lead to irreversible disasters if not limited by ethical guidelines. The growing trends in biomedical technologies advances in genetics, stem cell research, and organ transplantation are some of the medical issues that have raised important ethical and societal issues.

In the last decade, there has been special attention toward biotechnology development and bioethics empowerment in Iran. Compiling the Specific National Ethical Guidelines for Biomedical Research has been an important effort in recent years. The guidelines consist of: Ethical Guidelines for Clinical Trials, Ethical Guidelines for Research on Vulnerable Groups, Ethical Guidelines for Genetic Research, Ethical Guidelines for Gamete and Embryo research, Ethical Guidelines for Transplantation Research, and Ethical Guidelines for Research on Animals.

In this paper we aimed to review the latest bioethical activities in Iran. Likewise, we will also intend to mention the "National Ethical Guidelines for Biomedical Research".

Keywords: Bioethics, ethical guideline, clinical trial, Genetics, transplantation, vulnerable groups, embryo donation, Islam, Iran

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On the Banality of Ethics

In 1961, the philosopher Hannah Arendt visited Jerusalem to cover the trial of the Nazi SS Officer Adolph Eichmann who was responsible for much of the practical planning of the holocaust. Arendt's remarkable conclusions on the trial appeared in her book entitled, *Eichmann in Jerusalem: The Banality of Evil*. In her commentary, Arendt makes a remarkable point in dismissing both Eichmann's claim of innocence and as well, the explanation of Eichmann's actions as pathologically motivated or spurred through pure hatred. What she introduces is the notion that a more or less unremarkable, ordinary person can act in the most grotesque fashion under the appropriate influences and conditions.

In 1963, American psychologist Stanley Milgram provided what we might consider 'empirical evidence' in support of Arendt's banality thesis. Motivated himself by the Nuremberg trials, Milgram devised a cunning experiment to determine to what extent an authority figure could motivate an experimental subject to perform acts contrary to his or her own conscience. In the now infamous experiments, Milgram demonstrated the extent to which blind obedience to authority can facilitate the cruel and atrocious behaviour of human beings who by all accounts are 'perfectly ordinary'.

I use Arendt's 'banality thesis' and the experimental results from Milgram and others to suggest that the culture of healthcare in which we practice is as fertile ground as any to witness outcomes similar to those disturbing studies. I continue by demonstrating that an acute awareness of this fact has a direct impact on clinical ethics pedagogy, and more importantly, on the way we perceive the role of the ethics in the provision of care. I conclude with several recommendations derived from the recognition of the banality of ethics.

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Postgraduate Bioethics Education: Answering the call to action

In 1995, the Royal College of Physicians and Surgeons mandated that all residency programmes must teach bioethics within their specialty specific curriculum as a condition for accreditation. This mandate is continued within the Professionalism role of CanMeds. The Postgraduate Bioethics Education (PGBE) initiative at the University of Toronto, based on a "hub and spokes" model in which the Joint Centre for Bioethics and the PGBE Director serve as the "hub" to provide leadership and coordination in postgraduate bioethics teaching in each residency program through each program's Bioethics Coordinator (the "spokes"), is a unique model for developing compliance with the RCPSC mandate and providing bioethics education to all residents. The goals of the initiative are to ensure core bioethics knowledge, skills and competencies and build bioethics teaching capacity within each residency program. It also serves to encourage residents towards life long learning and teaching in bioethics and to encourage research in bioethics. This is accomplished through faculty development seminars (Teaching the Teachers), an annual Research Ethics Day and Clinical Ethics Day for residents, co-teaching within residency programmes by bioethics trained physicians, a listserv connecting the Coordinators and other means. A research focus is addressing the mismatch between formal and informal curricula in particular with regards to the impact this mismatch has on evaluation of resident performance in ethically challenging situations. This strategy has enhanced the integration, viability and sustainability of bioethics education within the residencies at our University and created a potential national and international model.

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Geographies of Dying in Intensive Care Units

Medical geography has undergone a dramatic shift in the last decade. The nearly exclusive focus on mapping the distribution of diseases and the access to care in populations has taken a 'cultural turn.' In the latter approach, space and place are not neutral but instead play a central role as the context for human action in health care. This paper reports a major finding of a study of intensive care nurses' inclusion of families in end of life issues. In this focus group study, their talk was laced with geographical concepts revealing knowledge of three ways in which space and place are central to trajectories of dying. First, once the decision to move from aggressive care to comfort care had been made, nurses experienced a moral imperative to transform ICU space to sacred space. The authors argue that this reflects the ICU as a cultural place of liminality, an anthropological concept referring to a state in which a person is between defined social statuses. These human/social transitions are typically marked by rituals. But their attempts to provide "a really good place" were not without problems. Secondly, patients' bodies were 'mapped' in keeping with the division of medical specialties, thereby diffusing responsibility for the embodied patient. Thirdly, the wishes of the patient not to be resuscitated would be rendered inoperative if the patient 'needed' certain procedures, for example, a cardiac catheterization. In this situation, space and not the patient governed the trajectory. These three findings add new insights into what is known about the complex trajectories of dying and the morality embedded in them.

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Title: Linking the Political to Ethical Clinical Practice: Impacts on Knowledge and Identities for Nurses Who Advocate for Lesbian Health

In a Canadian context, professional, legal and ethical mandates encourage nurses to participate in political processes to enhance the health and well-being of vulnerable groups (Canadian Nurses Association, (CNA), 1992). Yet, despite increasing attention to social justice and diversity, systemic barriers continue to hinder access to relevant and safe health care for diversely situated lesbian, gay, bisexual and transgender (LGBT) people. Heterosexism and biphobia contribute to the invisibility of LGBT issues with well-documented negative health impacts.

How do nurses, both those who are same-sex identified and those working as political allies in relation to lesbian health, conceptualize their activist practice in an ethical context and what are the impacts of this work on the nurses themselves? This paper is based on the findings of a comparative life history study of ten female nurses in Ontario who are known for their lesbian health activism in their communities. Ten well-educated nurses with high social privilege representing diverse sites of clinical practice, geographic regions and sexual orientations participated. A critical feminist analysis of their narratives shows that addressing activism in a context of nursing ethics offers a legitimate space for bringing issues such as lesbian health to voice within nursing. These nurses acquire embodied political knowledges consistent with sociopolitical knowing (White, 1995), with its focus on ethics and power dynamics. As activists, their political identities shift with the context and challenge their notion of a coherent nursing identity. There are implications for understanding the intersections of ethics, political practice, knowledges and identities in professional practice.

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Evaluating the Success of Priority Setting**Purpose**

The overall aim of this project is to answer: 'How can we measure the success of priority setting (ps)'. Specifically, we will describe major stakeholder's views about successful ps; present and explain the derived parameters for success of ps; and present the resulting evaluation tool. By measuring the success of ps, we can take steps toward improving it.

Problem

There is little agreement about the goals of successful ps. In order to know what successful ps is, we need to ask those involved in, and effected by it. To our knowledge, there exists no means for evaluating ps, to know whether or not ps was successful. Success is difficult to define as different disciplines have competing interests - - e.g. efficiency, justice, fairness, equity.

innovation

Currently there is very little information or guidance for decision makers who want to engage in successful and improved ps; this research fills this gap by providing parameters of success in ps. The parameters are the basis for an evaluation tool. The parameters and the tool relate to both the procedural and substantive dimensions of ps.

lessons

Healthcare organizations in Canada need guidance in order to figure out the best way to set priorities. The parameters identified in this research provide this guidance as well as insight into the complexity of ps. By presenting the parameters of success in ps, and the accompanying evaluation tool, organizations can take steps toward improving the success of ps.

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Title: Citizen Science for Safer Health Care: A Five Year Program of Research

Health care organizations are frequently urged to build ethical work cultures and decision-makers often ask for evidence to improve care. However, places where researchers and practice communities can come together to translate ethics and evidence into better care are few and far between. The purpose of this presentation is to outline a five year program of clinically based research where ethics, science, and clinical practice are studied together in order to build the kinds of organizational relations, dialogue, and actions that support the provision of safe, competent, ethical care. Using principles of good ecological restoration to guide our work, the *Safer Systems* research program has evolved over five years from a "mom and pop shop" of one faculty researcher working with one local hospital to partnerships with health care regions, leaders, practitioners, students, fellow researchers, ethicists, several funding agencies and universities, the Canadian Patient Safety Institute, and patient representatives. In a strong sense, the research program provides a safe place for us to collectively question what we do and imagine our way into better approaches to learning about, giving, and receiving care. By collaborating on research projects, our *Ethics-in-Practice Series*, a summer research student program, and other communal work, we can use citizen science to challenge arbitrary boundaries between ethics, research, and practice that do not serve the everyday realities of maintaining good clinical care. Our ultimate goal is to build a health systems commons where sound research, good practice, and ethical health care management find a shared, sustainable home.

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Health Technology Assessment in Argentina: Social and Ethical Aspects

Health technology assessment can help improve decision making about the application of specific health care services and the management of health care systems more generally. While health technology assessment is common in developed nations, is the exception in developing countries. Nevertheless, in both contexts, little space is made for socio-ethical questions or analyses; technology evaluation is primarily epidemiological and economic in nature. This situation is particularly problematic in countries such as Argentina, where there is limited public access to needed health care services; an important poverty and many other concerns about social justice. Currently, some public and private agencies are starting to work lightly on the subject. The introduction of new biotechnologies in any health care system is a complex process that is closely tied to economic, political and cultural factors, and thus poses a host of challenging social and ethical issues. Taking the example of prenatal genetic tests, I examine some critical issues for health technology assessment in Argentina (e.g.: scarcity of resource, and big inequities in the access to health services,), a country where genetic services are provided primarily by private service providers and where abortion is a criminal offence. I suggest that bioethics, which is a rapidly growing field of study in Argentina, can have an important role in stimulating ethical reflection amongst policy makers on the moral values and principles that should be integrated into health technology assessment in order to design public policies adjusted to the particular socio-cultural context of Argentina.

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The ethics of sham surgery arms in randomized clinical trials

The randomized, double blinded clinical trial (RCT) has long been considered the gold standard when studying the efficacy of a new medical intervention. Where no accepted standard of care treatment exists, a placebo control is often used to minimize bias. A common critique of novel surgical procedures is that they are held to a different standard in contrast to novel pharmaceutical agents. Indeed, the vast majority of commonly used surgical procedures have not been studied through an RCT. To address this concern, some have suggested that novel surgical procedures must be studied through an RCT and that where no accepted standard of care exists, a sham surgical arm be utilized in order to minimize the potential for bias through the placebo effect.

Over the last five years, a number of trials of novel neurosurgical treatments of Parkinson's disease have utilized a sham surgery arm. The designers of these trials have justified the use of a sham arm on the basis of a significant placebo effect for any intervention in Parkinson's disease.

We will review the history of surgical innovation, with an emphasis on novel neurosurgical procedures for Parkinson's disease and the ethics of the use of placebos in surgical trials. We argue that the use of sham arms in surgical trials is never ethically justified because 1) it is not methodologically required 2) the placebo effect can be controlled for 3) the risks of a sham procedure are not minimal 4) the use of deception by the surgeon is unacceptable.

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Strengthening National Capacity for What? The Means, Ends & Ethics of Emerging International Public Health Law

In response to SARS, the development of a globally integrated network of national public health surveillance systems has emerged as a multi-level policy priority, and has been mandated in the recently approved revised International Health Regulations (IHR 2005) as the keystone of global pandemic preparedness. Improvement of communicable disease surveillance and response capacities (CSR), however, will be intensive, expensive, and extensive. Substantial ongoing investments will be required in nearly all countries in order to comply with the IHR, more so in developing countries where public health systems are presently under-developed and overburdened by existing pandemics, most notably of HIV/AIDS, malaria and tuberculosis. Given the severity of these actual human pandemics, many countries are justified in refusing to expand surveillance activities for theoretically emerging pathogens with pandemic potential, particularly since outbreak detection without response capacity is of limited local value. In contrast, developed countries would greatly benefit from developing countries making investments in surveillance, since early warning of outbreaks permits better prevention, preparation, and harm-limitation. Although the IHR were specifically designed to reconcile these tensions, the framework it proposes is revealed to be strategically insufficient, morally deficient, and of limited practical feasibility. Moreover, rival surveillance networks grounded in national security terms threaten to displace the IHR's core advance – the articulation of a collective human security approach for all CSR activities. A policy stalemate has resulted, one that raises fundamental ethical and governance challenges. Drawing from recent scholarship in international relations and critical public health ethics, and informed by qualitative research undertaken by the author, three concrete policy recommendations are proposed as initial steps towards remedying the current impasse with regards to the strengthening of global public health capacity.

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Responding to Trust: Perspective of Surgeons on Informed Consent

"If we've gone through this together, it's harder to let go...if they get into trouble. I tend to push very hard to try to get them through." Thoracic surgeon

The bond forged by patient trust powerfully influences the practice of surgery. In an interesting inversion of the doctrine of informed consent, surgeons assess the trustworthiness and commitment of patients, then give their own consent to take on the risks and burdens inherent in performing operations. Because of the irreducible asymmetry of knowledge, the magnitude of surgical violence, and the heightened vulnerability of patients under anesthesia, surgeons manage a uniquely unbalanced, burdensome version of the caregiver-patient relationship. They implicitly consent to a binding, benign, paternalistic role that is mutually accepted, though viewed with suspicion by ethicists.

We conducted open-ended qualitative interviews with 46 surgeons (15 in one-on-one interviews; 31 in focus groups), and analyzed the data using techniques adapted from grounded theory methods. All interviews were audio-recorded. These surgeons believed:

1. The patients they inform are often emotionally incapacitated by fear.
2. Expectations and fear should be managed by the surgeon.
3. Confidence and courage should be instilled.
4. Patients' courage and determination to survive are critical decision factors.
5. Surgical consent is a mutual decision to trust.

The bond of mutual trust drives decisions to push the boundaries of risk and cost, sometimes to heroic and disturbing levels that induce moral anguish among critical care personnel. Uncoupling critical care from perioperative management helps to relieve the burden of surgical responsibility.

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"Ethics on the Move": Reflections on Three years of Capital Health Ethics Support

The past three years has been a time of tremendous growth and development for Capital Health Ethics Support (CHES), an innovative ethics model that was launched by the Capital District Health Authority in Halifax, Nova Scotia in 2003. The purpose of this workshop is to share our experiences as part of the collaboration of ethics professionals, volunteers and staff, who have been and continue to provide ethics support for this large and diverse health district. Capital Health provides services to forty percent of Nova Scotia's population, employs ten thousand people, and has an annual budget of \$600 million. Its health care facilities range from small, rural outpatient clinics to a large, academically integrated, tertiary care hospital complex.

The CHES model, with its commitment to systematically enhancing social justice, is instantiated in four distinct components: 1) the Ethics Committee (whose primary function is addressing organizational ethics issues); 2) clinical ethics consultation; 3) policy development and review; and, 4) ethics education. Over the past three years, hundreds of staff members have benefited from ethics education sessions; clinical ethics consultations have addressed a broad range of challenges; dozens of organizational policies have received ethics support for their development and review; and, a variety of organizational ethics issues have been addressed by employing an inclusive organizational ethics consultation process. Using a variety of interactive approaches, this dynamic workshop is designed to share the many experiences, successes and challenges that have taken CHES from the "bedside to the boardroom".

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Why 22 Weeks? Ethical Questions Re: the UK's New Guidelines on Resuscitation and Intensive Care of Premature Newborns

When do we draw the line between giving some premature babies a chance to live and not treating others? The Nuffield Council on Bioethics recommends an approach based on gestational age, saying that babies born earlier than 22 weeks should not be resuscitated. Babies born between 22-23 weeks should not receive intensive care unless parents request it and doctors agree. For babies between 23 and 24 weeks – 11% of which survive, two-thirds with disabilities – it recommends parents should have the final say. At 24-25 weeks, intensive care should be administered unless parents and doctors agree there is no hope of survival. At 25 weeks and above, care should be given as standard.

The paper will review:

- Medical evidence used for and against the cut-off of 22 weeks in the UK
- The differences between this approach and that of Holland
- The current treatment of premature babies in Canada
- The views of some disabled rights campaigners
- The views of groups who raise concerns that improvements in medical technology will increase the numbers of children being born with disabilities, but that society will not necessarily have the resources and care to support them beyond the neonatal unit
- The views of the Catholic Church which teaches that life does not need to be preserved at all costs

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Rounding as a Clinical Ethics Consultation Service

The Center for Ethics at Washington Hospital Center has been providing rounds in several of our Intensive Care Units (ICU) for many years. As pioneers in the area of clinical ethics rounding, we have seen its effectiveness in providing upstream interventions that prevent conflict and truly dilemmatic cases which invigorate ethics committee discussions. Since our presentation at the Second International Conference on Clinical Consultation in Basel Switzerland in 2004 the request for rounding has increased exponentially. We have responded by increasing our regularly scheduled weekly walking rounds from 2 to 8 units; 5 ICUs, 1 IMC (intermediate care), 1 Trauma service, and 1 ED (emergency department). In addition, we are involved in more traditional sitting rounds, such as discharge and high risk OB rounds, as well as Grand Rounds for several departments. With our computerized consultation database we have been able to track consultations from the units that we currently round in and have noticed a decrease in formal consultations called from these areas of the hospital. We believe that rounding causes a reduction in moral distress, decreases conflict, and increases effective communication with families thereby resulting in optimum patient care.

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Implementing Clinical Moral Deliberation Processes

During this paper presentation experiences with facilitating, training and research of moral deliberation processes in clinical settings will get presented. There will be a special focus on a 4-years moral deliberation implementation program for hospitals. This program is recently developed by ethicists from the moral deliberation group of the University Maastricht, the Netherlands. Within this program, caregivers and managers are trained as facilitators of various methods for moral deliberation ('train the trainers'). The overall program is based on a pragmatic-hermeneutical and dialogical view on ethics.

The program consist of, among other things, five different modules: A) offering short courses in basic knowledge about ethics; B) facilitating a structured moral deliberation about a moral case; C) observing (and report and present our findings) moral aspects of daily care processes and various meetings; D) supporting the merger of teams or the development of new policies; and E) organizing a train the trainers program for facilitating moral deliberation.

The 4-years implementation program was both monitored and supported by the method of Responsive Evaluation. This method not only provided us with rich information about the implementation process and results, the research process itself also

In the end, presenters will critically point at both successes and pitfalls of the implementation program (e.g. issues of 'appropriate goals & methods of implementation of moral expertise', 'power issues within clinical ethics', 'moral expertise', 'bottom-up versus top-down implementation', 'morale of facilitator and trainer').

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Making Ethics Matter to Clinicians: First, Do Not Harm Each Other

The World Health Organization Declaration (2002b) states that "violence is a leading worldwide public health problem" (p.2). Few would disagree that there is an ethical imperative to establish and maintain a clinical environment where clinicians can work collaboratively and respectfully. Making ethics matter that is putting ethics into practice in every day clinical life is a challenge. Many will agree that this imperative is not always honoured. Recently, abuse and harassment of health care professionals by patients and families has attracted considerable attention. In contrast, violence between health care professionals has received less attention. Research confirms that some health care employees and students have negative experiences as a result of the abuse of power by colleagues, supervisors and peers. Our presentation starts with a discussion of the ethical foundation of relationships among peers and colleagues. Secondly, by means of systemic analysis, horizontal and vertical violence is placed in context. Health care organizations are complex and have a distinct culture, often hierarchical. Given the established structures and processes, there is the opportunity for abuse of power both vertically and horizontally by clinicians. Some of the consequences are examined. Clinicians may experience moral distress leading to "burn-out" and walking away from health care employment. When the clinical environment is toxic, any hope for establishing and maintaining a moral community is extinguished. Horizontal and vertical violence among health care professionals can lead to silencing employees who want to improve the moral climate. Those who do speak and take action that is express moral courage, may be exposed to further harm and be penalized severely.

The reasons why health care organizations may foster and support violence is examined. Finally, we provide recommendations based on the ethical analysis and research about workplace violence. The proposals address the root causes and include relevant, concrete strategies to respond to and improve the ethical climate of the clinical world.
World Health Organization. (2002b). World report on violence & health: Summary, Geneva: Author

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The Genetics Outcomes Study: empirical results and an ethics framework for understanding

Outcome measures examine what is achieved for a patient/population relative to a health care service or intervention. Often, important outcomes are readily identifiable, e.g. one can measure the efficacy, side-effects, cost, reduced mortality/morbidity, population uptake etc. for an influenza vaccine program. For clinical genetics services however, there are few agreed upon outcomes. Clinical genetics comprise a burgeoning segment of the health system, yet there is much controversy regarding costs and benefits, writ large.

The overall aim of this project is to assemble potential outcome measures for clinical genetics services which appear feasible, ethically acceptable, and supported as relevant by the broad community of potential users. This effort includes four iterative processes (i) systematic review of published genetics outcomes (ii) a consensus process (modified Delphi) undertaken with distinct participant groups – patients/advocates, providers, researchers and policy experts (iii) an expert panel to evaluate potential measures (iv) ethics analyses both to describe the values component of outcomes generated by the consensus process (descriptive ethics) and to examine these critically (normative ethics).

This paper describes the modified Delphi process by which participants generated 'good' and 'bad' outcomes related to 6 distinct genetics services scenarios: adult predictive testing for Huntington Disease, prenatal screening for Down syndrome, carrier testing for Cystic Fibrosis, newborn screening for Phenylketonuria, susceptibility testing for hereditary breast cancer, diagnostic testing for a child with developmental disabilities. Analyses of the results for one scenario with respect to values and implications for ethical care using a feminist ethics lens will be presented.

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Genetic Justice after the Human Genome Project

Some early proponents defended the Human Genome Project (HGP) by saying it would transform international public health. The HGP was also supposed to advance genetic justice by demonstrating the genetic commonality of human beings. The HGP and genomics have, in fact, made substantial contributions to the theory of disease treatment. However, when it comes to people with the greatest burdens of disease the relative value of genetic medicine compared to public health measures remains a matter of debate. Moreover, genomics have also shown that – when it comes to medical treatment – individual differences may matter more than collective commonality. In other words, genetic differences influence the way in which people respond to drugs (not at all, with therapeutic effect, or in toxic fashion). These kinds of differences stand to magnify – not decrease – social differences between people who have access to individually tailored pharmacogenomic medicine and those who do not. Moreover, some theorists (e.g., H.T. Engelhardt) of healthcare justice have argued that the ‘natural lottery’ of genetic differences defines the border of social obligations. On that view, genomic research / medicine may ultimately work to underline the divide between the genetic ‘haves’ and the genetic ‘have nots’ except as charity makes up the difference. In other words, genetic research will increasingly show more and more conditions as having some root in the ‘natural lottery’ and therefore outside the realm of anyone’s duty to help. These effects show ambiguities in the value of the genomic research to international health as well as the limitations of a theory of healthcare justice that treats accidents of nature as if they were also moral guidelines.

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Social Determinants of the Health of Embryos and Implications for Children

Just as embryo “health” is increasingly subject to genetic and biomedical determinants, it is also subject to social determinants. These social determinants are in many ways analogous to the social determinants of health of children, such as poverty and resulting poor nutrition and environment. The social determinants of embryo “health” are affected by determinants of what a child’s social health should include, such as desirable cognitive and physical capacities that can lead to social advantages (e.g. advanced education and mobility). However, the social determinants of embryo “health”, also have implications for our understandings of the “health” of children already living, as well as those not yet born. Particular considerations of social determinants of embryo “health”, among scientists, clinicians, ethicists, those who write about and use the law, and wealthy potential parents who would like to design children of social advantage may be coloured by personal, research and financial interests. As more genetic and biophysical determinants of “health” become available, a woman may increasingly feel the duty to produce a “healthy” child, not only through optimizing her nutrition (pre and during pregnancy) and ceasing smoking and alcohol consumption, but by accessing preimplantation or prenatal genetic diagnosis. Determining the criteria through which we assess the social determinants of the health of embryos must include normative and factual, ethical and legal, as well as scientific perspectives. Making determinations about embryo health should be a multi-dimensional social process, which requires location in a political, economic and social context.

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UK Clinical Ethics Support: The Challenge of Patient Access

Mechanisms of clinical ethics support in the United Kingdom are prospering. Hospital Trusts, Mental Health Units and Primary Care practices are now convening committees and the discipline is gaining policy attention. The issue of patient access has, however, gone largely unrecognized. Contrary to practice in North America, it is currently unusual for a clinical ethics committee to gain patient consent before discussing a case, albeit one which has been de-identified. And unless a consultation is acute, patients are unlikely to be invited to participate in discussions. In this paper, I will consider the question of access to and participation in clinical ethics consultation by patients and family members in the UK. The semantic dimensions of the issue will be explored, and I will reflect on current practice around the world. I will then critique the arguments for and against access by patients in light of the goals of ethics consultation. It will be argued that current practice in the UK fails to respect patient autonomy and may lead to unbalanced consultations. That said, it is also important to reflect on the context of UK health provision, and question whether the political structures inherent in the National Health Service will support this type of dialogue with patients. At the very least, committees should not consider soliciting cases from patients until they are well established within the health care Trust.

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Implementing Clinical Ethics in German Hospitals: Content, Didactic Methods and Evaluation of a Nationwide Training Program

Clinical Ethics Committees (CEC) and ethics consultation have been developing in Germany during the past decade. Many individuals from different professional backgrounds are engaged in this field on a voluntary basis. The necessity for adequate educational and teaching resources soon became obvious among this group of people. Special qualifications predetermine the success of ethics consultation both on the level of individual case deliberations and on the institutional level. A task force in the German Academy of Medical Ethics (AEM) developed and published a curriculum for teaching programs on "ethics consultation in the hospital". The curriculum will be described briefly in the presentation. In accordance with this curriculum in 2003 an ethics education program was established in Hannover (Qualifizierungsprogramm "Ethikberatung im Krankenhaus", Hannover) as a cooperation between AEM, Center for Health Care Ethics (ZfG), Ruhr-University Bochum and Hannover Medical University.

The program offers a 5-day basic module and several advanced modules. The basic module covers topics such as ethics in the hospital, structure and models of ethics consultation, implementation of Ethics Committees, institutional ethics. So far it has taken place 6 times with 25 participants each. The advanced modules deal with specific issues of clinical ethics such as passive euthanasia and terminal care, living-wills, mediation of ethics consultation. Up to now 8 advanced modules have been carried out. Experiences from the educational program will be reflected concerning course content, didactic methods, evaluation, and characteristics of participants.

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"Poetry [like Bioethics] Resists Easy Answers" (C. Milosz)

From Beowulf to Poetry Slams, from Aristotle to the Dalai Lama, there have been divergent and strongly held opinions about poetry. Poetry has been praised for its usefulness, criticized for its dangers, enjoyed for its own sake and has been pursued for its relevance to life and society. Poetry attaches emotion to ideas and serves to illuminate.

In this workshop:

- We will show how poetry illuminates ethical principles, ethical frameworks and ethical dilemmas.
- We will demonstrate how one class at the University of Toronto (MHSc - bioethics) added another dimension to their educational process. They used poetry throughout their program to elicit emotions, to discover how emotions can inform what one values and to illuminate some ethical concepts (sometimes light heartedly and sometimes with heart-felt conviction).
- We will show how poetry has been helpful in illuminating ethical practice for medical students at the University of Western Ontario over a number of years.
- Participants will then be invited to share either their own writings or other poems that have illuminated ethical issues for them.

Finally, an emotional, real-life story written by one of the presenters will be presented in a 'reader's theatre.' By the end of the workshop, and building on that story, the audience's collective, creative muse will be exercised in a fun and entertaining Victorian Parlour game. Thus participants will; hear poetry read aloud, share poetry with each other and create poetry.

"The purpose of poetry is to remind us how difficult it is to remain just one person, for our house is always open, there are no keys in the doors," (Seamus Heaney)

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Is pharmacogenomics the science for global justice?

Among the new technologies that are emerging from advances in molecular biology, pharmacogenomics is one of the most promising for medical applications. It has been proposed as a method for better personalizing medical practice, and substantially lowering the cost of drug development to increase drug accessibility around the world. But given the significant social, economic and health inequities and the inability of national and international programs to make necessary medications available, it will be interesting to examine the real potential for pharmacogenomics to improve drug accessibility in the developing world. Most new drugs are developed for and marketed in the wealthy countries of the North, and are designed to treat those diseases prevalent in wealthy countries; little effort is made to address the needs of developing countries of the South (e.g., vaccines, treatments for infectious diseases). In order to improve access to needed medications, developing countries such as Brazil and Argentina have supported local pharmaceutical companies and the production of generic drugs. But these countries lack the necessary biomedical and governance infrastructures required for advanced drug development, so what is the possibility that local companies will be able to conduct pharmacogenomics studies and develop locally relevant medications? In brief, can pharmacogenomics make good on the promise of reducing health inequities that emanate from the current drug development process and enable the provision of affordable medicines in Latin America? I examine these issues by reflecting on the existing state of pharmacogenomic science, innovative models of equitable drug development and delivery, and the tension between concerns about local and global justice in health care distribution.

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Clinical Ethics and the Faith Factor

Contemporary medical ethics began in the 1960's with theologians asking questions of clinicians. Unfortunately, in more recent times, the religious voice has been marginalized or even disparaged. The questions are now more commonly addressed by philosophers, attorneys, or experts in health policy.

In spite of this significant change, many patients, many families, and many clinicians still look to their own faith traditions for guidance in addressing the "should we...?" questions in clinical ethics. But there are so many faith traditions. How is the clinical ethicist supposed to understand and apply the faith factor?

The good news: The three faith traditions most commonly encountered in North America, the monotheistic traditions of Judaism, Christianity, and Islam, share many basic beliefs that can give guidance in such matters. Such tenets as the sanctity of human life, the sovereignty of God, the dominion of humankind, the stewardship of the individual believer, and the ministry of healthcare all impinge on bedside decisions.

The bad news: Individuals or groups within these traditions may place different priorities on these tenets, and they may have different understandings of such matters as miracles, prophetic messages from God, and the role of individual faith in the outcome of specific cases.

In this presentation, I plan to explore these similarities and differences, hoping to expand the horizons of clinical ethicists to assist them in assessing matters of faith as they pertain to individual clinical decisions.

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The Perceived Role of Islam in Western Muslim Medical Practice**Background:**

Islam and Muslims are underrepresented in the medical literature and the influence of physician's cultural beliefs and religious values upon the clinical encounter has been understudied. This study sought to generate hypotheses on the influence of Islam upon the practice patterns of immigrant Muslim physicians in the United States. Our specific aim was to identify ethical challenges and value conflicts faced by these practitioners.

Methods:

Using a qualitative semi-structured interview design, a total of 10 physicians were interviewed, 7 male and 3 female, from a variety of ethnic backgrounds. Most physicians were trained in Internal Medicine subspecialties (50%), had hospital-based practices (50%), no significant biomedical ethics training (70%) and none had formal religious degrees or training.

Results:

There were a wide variety of views on how Islam affects physicians' practice of medicine. Several themes emerged from our interviews such as a trend of viewing Islam as enhancing virtuous professional behavior; the perception of Islam as influencing the scope of medical practice through setting boundaries on career choices, defining acceptable medical procedures and shaping social interactions with physician peers, and a perceived need for expertise in Islamic medical ethics grounded in Islamic studies and law. Further study into the interplay between Islam and Muslim medical practice and the manner and degree to which Islamic values and law inform ethical decision-making is needed.

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Case Studies and Consultation in Public Health Ethics: Why Not?

Case reports and case studies are two of the oldest and most important tools in the medical literature for soliciting advice and communicating knowledge and experience. Clinical ethicists have followed suit and produced a robust literature of case studies in medical ethics which provide an invaluable stimulus to the practical and theoretical discourse in ethics. Significant breaches of confidentiality, as well as other ethical faux pas, have occurred in medical and ethical case reports, highlighting the ethical issues in the cases themselves as well as those inherent in their reporting. Recent events have led to a considerable public interest in public health and a blossoming of the public health ethics literature in the past decade. However, apart from a handful of high-profile gross violations of the public trust in public-health-related cases, researchers and public health practitioners have failed to describe their dilemmas and attempted resolutions in the literature. Reasons for this include: the failure of public health practitioners to identify issues as 'ethical dilemmas', the failure of ethics frameworks to gain popularity among public health practitioners, and the near insurmountable ethical and legal issues involved in describing public health ethics cases in the public domain. Despite these obstacles, reporting, discussing, analyzing, and consulting on public health ethics cases is in the public interest and is vital for the development of the field.

In this paper, the authors describe a case with multiple public health and clinical dimensions in a city and health care system still reeling from SARS. They describe and analyze the ethical, legal, and political pitfalls involved in writing up this case. They then propose a framework and guidelines for addressing the challenges involved in the nascent field of public health ethics case consultation and case reporting.

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Clinical Ethics and Public Health Ethics: Where Does One End and the Other Begin? A Case Discussion

One area of clinical practice that exemplifies the intersection of clinical and public health ethics is around the potential loss of driving privileges for patients.

While decisions regarding driving safety are the purview of the physician, s/he often will utilize information provided by other clinicians or from driving evaluations to make a decision regarding a very instrumental activity of daily living for patients. Physician's must balance the rights and privileges of individual patients with their responsibility to the community and the public health, often leading to aspects of their own distress regarding the implications of this type of decision for their patients.

Ethical issues of autonomy, beneficence and nonmaleficence, as well as public health concerns are readily apparent in these cases. There are implications for the physician's relationship with the patient and also relationships the patient has with other members of his/her care team (e.g. PT, OT, psychologist).

A family practice physician, social worker, and bioethicist will address the various ethics issues that surround a case where the possibility of removal of driving privileges existed for a young patient with progressive multiple sclerosis. The physician presenter is extensively involved in the area of public health and will highlight issues related to the physician-patient relationship and public health ethics around driving decisions. The social worker will discuss the challenges that face teams who are involved in the evaluations related to these cases and the issues of shared decision making and team ethics. The bioethicist will discuss the use of a case analysis format for looking at this case.

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Les chercheurs sont-ils des sujets éthiques vulnérables?

La recherche universitaire est un terrain où se rencontre plusieurs acteurs issus des sphères économiques, politiques et sociales. Cette interaction se traduit par des influences mutuelles qui prennent parfois l'allure de pressions. À la lumière d'une récente controverse scientifique (cf. Dr Hwang), une problématique émergente retient notre attention : les chercheurs seraient-ils des sujets vulnérables?

Pour y répondre, l'auteur utilise trois corpus encore jamais articulés ensemble en éthique de la recherche et propose une approche socio-éthique facilitant l'étude des vulnérabilités des acteurs de la recherche. Inspirée de la pensée complexe (cf. Edgar Morin), l'approche socio-éthique développée met de l'avant une éthique de la reliance (Morin, 2004) dans le cadre de la socio-logique des sciences (cf. Bruno Latour). Dès lors, nous interprétons la vulnérabilité à l'aide du modèle analytique des vulnérabilités développé par Kenneth Kipnis. Ce faisant, la reliance des sujets éthiques avec des Alter (communautés ou sujets éthiques) tient de lieu où un certain rapport de force s'exerce entre les parties. Ainsi donc, l'approche met de l'avant la responsabilité, la solidarité et l'inclusion du sujet éthique dans l'éthique de la recherche. De plus, elle pave la voie à la démocratisation de l'éthique de la recherche et la possible inclusion du modèle des communautés de pratique (cf. Etienne Wenger).

De plus, l'emploi de méthodologies novatrices inspirées des théories des réseaux d'acteurs a permis d'affiner cette approche théorique. Bref, l'approche développée inclut les multiples acteurs de la recherche et les amène à constater que « l'éthique importe! ».

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Thinking on the Street: Ethics and Harm Reduction

Those who use illicit drugs face inequities in health and access to health care. In particular, those who use injection drugs experience a high incidence of health concerns including epidemic rates of HIV/AIDS. Illicit drug use is a primary source of stigma and discrimination that negatively impacts health and access to health care for those who are street involved. In the current milieu, moral judgments associated with drug use can impact and restrict resource allocation at all levels in the health care system. These are serious and often unattended to concerns in bioethics.

Harm reduction is both a philosophy and set of strategies that promotes adoption of a nonjudgmental response to drug use without requiring a reduction in use. As an approach to dealing with prevention of HIV/AIDS, HCV and other drug related harms, specific harm reduction strategies such as needle exchanges and supervised injection sites have been shown to be safe, effective, and cost efficient in both a local and global context. However, the ethical tensions associated with expansion of harm reduction initiatives have gone largely unexamined in the Canadian legal and social context. The purpose of this paper is to provide an analysis of the value conflicts and underlying moral framework of harm reduction. Drawing on a framework of social justice, implications for ethical policy and practice aimed at reducing inequities in health and access to health care for those who are street involved will be highlighted.

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Clinical and Psychological Issues in Survivors of Torture

Hundreds of new Canadians are survivors of war or have undergone interrogation by police or security forces in their homeland as well as countries of first or second asylum. More often than not this interrogation has included the scourge of torture and other unusual forms of treatment as defined by the UN Convention against Torture and Other National and International Instruments. This traumatic experience has a number of physical and psychological sequelae that can persist in the survivor's life years after it happened.

The presenters take a deontological ethical position against the use of torture and other forms of unusual treatment for any reason, under any guise or condition whatsoever. They will focus on Post Traumatic Stress Disorder (PTSD) and preliminary research suggesting that some survivors of torture have difficulty coping successfully with conflict in family life. Spousal or partner abuse will be discussed. An analytical discussion will be followed focusing on the danger of survivors turning into perpetrators with respect to community and family life.

Clinical or forensic referrals by lawyers in refugee claims can involve the 'awful secret' of torture about which the claimant does not find it easy to speak in public, and which the clinician must discover through sensitive and confidential interviews.

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Globalizing Human Experimentation: a Reexamination of the Moral Issues.

One major development that has contributed significantly to the advancement of scientific medicine is the increasing use of the bodies of men and women by researchers in the quest to unravel the mysteries of human health. The history of biomedical research is, however, punctuated with cases of morally questionable human experimentation from Nuremberg to Tuskegee to the more recent AZT trials in Uganda and other parts of the world.

As a result of the moral outrage that trailed the earlier horrific human experimentation, a plethora of regulatory instruments have been developed. But in spite of these regulatory guidelines, or partly because of them, there has been a tendency for researchers in the North to transfer their research activities to the impoverished societies in the South.

Against this background, this paper critically examines some of the ethical issues that have been thrown up by internationally sponsored medical research in developing countries. Employing the 1996 Pfizer drug trial in northern Nigeria as its major case study, the paper demonstrates how the issues of informed consent, beneficence etc, can become complicated in the context of rampaging disease, widespread poverty and ineffective governmental structures.

The paper argues that due to the peculiar constraints of developing nations, research on human subjects may not necessarily be carried out in an ethical manner. Instead, researchers may exploit the loopholes in research guidelines as well as the institutional deficiencies which characterize health administration in most developing nations.

Closing, the paper advocates the strengthening of multilateral arrangements for monitoring human experimentation across the globe.

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The Charter of Principle of the North Italy Transplant: a New Model of Medicine

The North Italy Transplant program (NITp), established in 1972, was the first Italian transplant organization. At present it serves an area of eighteen million inhabitants in accordance with an official contract between the Regional Health Authorities and the Reference Center where the functions of the NITp are centralized.

Due to the complexity of the process of organ donation/transplantation, the *NITp has decided to explain to the transplant community the technical and ethical principles considered in each phase of the process*. For the first time, the individual principles governing this process have been made explicit and defined as integral parts of a coherent system of decision-making. The cardinal point of the charter is the recognition that *only a full integration of ethical principles and technical considerations can result in fully equitable and transparent clinical decisions*.

Groups involved in this area of medicine represent a community comprising health care providers, institutions, patients on waiting lists and their families as well as the entire Italian population as potential organ donors or organ recipients. Every person within this community is a 'stakeholder' since they have a commitment to the best use of the valuable resource of organs and a vested interest in the outcome following transplantation. The Charter is based on two fundamental criteria: *the close involvement of all stakeholders and the transparency of the choices made with respect to use of organs and transplantation management*.

The Charter is divided in four topics: *organ retrieval, organ quality, organ allocation, post-transplantation*.

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Medical professionalism in Japan and Britain: a cross-cultural dialogue

This paper is the outcome of work following presentations at the 2006 World Congress of Bioethics in Beijing. In discussion it became apparent that debates surrounding medical professionalism in Japan and in the U.K are grounded in mutually illuminating similarities and differences. Responsible for introducing bioethics teaching at Keio University Medical School, Professor Plotnikoff recognises that traditional Japanese cultural values, and the religious traditions that underpin them, centre upon distinctive social goals. Respect for these requires a different approach to medical ethics than that found in the autonomy-based universal 'principlism' widely disseminated in the West. Ms. Shale's research challenges medical ethical orthodoxy, arguing that conceptions of medical professionalism dominant in Western thought rest upon a projective ideal of autonomous professional practice inconsistent with collaborative care in complex organizations. She argues that, paradoxically, doctors must sometimes prioritise obligations towards healthcare organizations if healthcare is to be fully ethical and properly 'patient centred'. A 'fit for purpose' medical professional ethic is essential to maintaining the integrity of health care institutions, and in both Japan and Britain healthcare professionals, organizations and educators are reconsidering the meaning of medical professionalism. The project brought together medical educators, practitioners, students and ethicists in Japan and Britain to explore culturally divergent understandings of medical professionalism. The paper presents the implications of this dialogue for the development of bioethics in Japan, and for revising conceptions of medical professionalism in Britain.

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Autonomy, Infertility and Moral Luck: casting a shadow over the 'golden age' of reproductive technologies

Over the last few decades, there has been an explosion in the development of reproductive technologies. Developments in *in vitro* fertilization (IVF), for example, have allowed us to create, freeze, screen, transfer and study human embryos in ways never before possible. Arguably, the goal of increasing reproductive choices via technologies such as IVF is to *enhance* women's reproductive autonomy, thereby increasing their overall autonomy, a capacity thought to be intimately linked to well-being. However, here we use the concept of 'moral luck' to elucidate the problem that the promotion of reproductive technologies may actually *thwart* women's autonomy. We then develop the ethical and political implications for the question of how the problem of infertility should be addressed in the context of health care, such that we may avoid the dangers illuminated by the concept of moral luck.

Moral luck is the phenomenon whereby an agent is assigned moral praise or blame, even if the agent in question did not have full control over what she is praised or blamed for. We will argue that many infertile women, in this 'golden age' of reproductive technology, are made victims of bad moral luck, since they are frequently held responsible – both by themselves and by others – for fertility outcomes that are largely, if not wholly, beyond their control. The concept of moral luck illuminates how trying to make positive changes for some, e.g., increasing access to reproductive technologies, can alter social circumstances in a way that is harmful, by making it appear as though they have more control over their actions or consequences than they in fact do. We will argue that the concept of moral luck sheds light on what ought to be done to improve the situation of women who are infertile, since enhancing some of the freedoms, e.g., child-bearing, which we take to be essential for human flourishing in a liberal, democratic society, can in fact fuel the damaging cycles of oppression we are trying to eliminate.

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The curious case of the recalcitrant defibrillator

While all will agree that a competent patient has the right to refuse unwanted medical intervention, what happens if this entails the surgical removal of a medical device that is necessary to the patient's survival? We confronted this issue recently when a 29 year old male patient requested that the implantable cardioverter defibrillator (ICD) he had received three years previously because of a potentially lethal cardiomyopathy, now be removed as he found it uncomfortable and a hindrance to his lifestyle. The patient has been informed that his chances of sudden cardiac death soon after removal are high, while his chances of survival beyond two more years are slim. On the one hand the patient states he understands and is willing to accept these risks, while on the other he denies that his condition is really all that serious and he expects to live a full and productive life. Psychiatric assessment deems the patient to be competent, although his insight and judgment are questionable. What weight should we give to patient autonomy in this case? Should autonomy be assessed synchronically or diachronically? That is, must we honor the patient's current "point in time autonomy" when we know this will almost certainly mean that his chances to enjoy an autonomous future will be curtailed? Is the patient's right to have the ICD removed a positive right, meaning someone is obligated to assist him in attaining that to which he is entitled, or is it merely a negative right meaning he can't be prevented from pursuing this course of action, but no one is obligated to remove the ICD? In either case, would removing the ICD be a violation of the physician's duty to "do no harm"? Should autonomy trump non-maleficence in this case? If so, where does the physician's autonomy figure in this equation?

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The Placebo Complex

A 40-year taboo on placebo-controlled surgical trials has been broken in the last decade, with the aim of raising scientific standards and despite ethical objections against surgery that offers no possibility of personal benefit. At the same time, scientific evidence challenges the very existence of the placebo effect.

Placebo-controlled trial design focuses on the research participant's state of mind as the site for correcting errors of subjectivity by means of scientific methodology. Olanow et al.'s placebo-controlled fetal cell transplantation trial for Parkinson's is an object lesson in the limitations of this approach: the trial proved the intervention inefficacious and dangerous, but 14 of 20 patients in the placebo arm received the transplantation after un-blinding.

This trial controlled for the placebo effect but perpetuated what I call "the placebo complex." The "placebo complex" includes the various agents and observers (beyond the research participant) whose wishful thinking may distort outcomes and practice; it also includes many moments throughout the clinical trial process (in addition to the research participant's report of benefit) where this distortion may take effect. It includes aspects of blinding (investigator bias and observer effects), the therapeutic misconception (promoted by the promise of receiving an experimental intervention as a benefit of participation), and lacunae in regulation for clinical practice that allow the results of a trial to be ignored in practice. Narrow focus on the placebo effect leads us to place significant burdens on research participants while we fail to impose standards on others implicated in the "placebo complex."

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Distance teaching and clinical ethics consultation – contradictio in terminis?

Introduction

In Europe there is still an ongoing debate over whether and what kind of clinical ethics consultation should or could be established. But most experts agree that ethical competence in reflecting, discussing and deciding about sensitive issues in clinical routine should be developed.

Method

The paper describes a curriculum focusing on the major practice-oriented modules, one being self-study with written material and the other being preparatory training workshops in ethics consultation. Teaching objectives and content issues are summarized. The value and effects of the modules will be evaluated from two perspectives:

- a qualitative analysis of the essays (take-home assignments) written by about 100 participants on their clinical ethics work, which is either a case analysis, or an institutional project,
- the teachers' perspectives on the preparatory training workshops with 40 participants, based on observations, experiences and interaction

Results

The first German-speaking distance teaching program in clinical ethics consultation responds to a lively need, as demonstrated in high numbers of applications. Data from the first courses show that despite the clinical experiences of many participants, transfer of knowledge and skills into clinical ethics consultation within their own institutional contexts remain to be a major challenge. Whereas this may be a primary goal for the teachers, it may not have such priority for the participants.

Discussion and conclusion

The results will be discussed in the light of recent developments of clinical ethics in Europe. Suggestions will be formulated for developing clinical ethics teaching and responding to the needs of participants.

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**Excessive Expense of Treatment and Disproportionate Burden:
To What Extent is the Relationship an Ethical Basis to forego Life-sustaining Treatment?**

In 2005, *Health Affairs* published an article titled "Illness and Injury as Contributors to Bankruptcy." In this article the authors examined 1771 personal bankruptcy filers in five federal courts with subsequent in-depth interviews. About half cited medical causes. Among those whose illnesses led to bankruptcy, out-of-pocket costs average \$11,854 since the start of illness; 75.7 percent had insurance at the onset of illness.

Within the Catholic moral tradition a person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, *or impose excessive expense on the family or the community*. In light of the findings from personal bankruptcy filers in 2001, the question of what constitutes "excessive expense on the family or the community" requires examination. It is the goal of this panel to (a) flesh out the meaning of "excessive expense" in light of the Catholic moral tradition that recognizes that "a refusal [of disproportionate treatment] is not the equivalent of suicide; on the contrary, it should be considered...a desire not to impose excessive expense on the family or the community;" (b) parsing whose perspective should count in such determinations, e.g., society, the patient, the hospital, the local community; and (c) to understand the organizational implications for Catholic Healthcare in end-of-life decision-making when determining "excessive expense on the community."

This analysis will provide a substantive foundation upon which clinicians can invite their patients to explore excessive expense as a legitimate ethical basis to forego life-sustaining treatment.

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Role of Media in Promoting Ethics in Health Research

Gone are the days when the development of science and technology remained largely unquestioned. After the rapid economic growth that followed World War II, belief in technological progress was tempered by the awareness of certain ironies. It all started with concerns over environmental issues and the risks of nuclear power in the early 1970s, which eventually led to increased public interest and participation in policy decisions relating to science and technology.

A research study in India suggests that public health, medicine and medical technology occupy 65% of the total space devoted to science news in the print media. Issues such as GM food, use of BST on cattle and medical interventions such as use of fetal eggs to alleviate fertility or human cloning are the issues which find frequent mention in Indian dailies. Media can play important roles in making the general public aware about the misuses and malpractices prevalent in the field of health research. It can also make efforts in the direction of inculcating a sense of social and ethical commitment and self-regulation among those involved in the business of research.

In India, efforts to formulate ethical guidelines for research in health and social sciences began in 1998 which led to adoption of the draft of guidelines after much revision and discussion. However by themselves the ethical principles and guidelines cannot resolve all ethical problems. Efforts therefore have to be made in all directions, and bringing bioethics on the agenda of the media might prove to be a useful one.

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Walking the Line: Ethical and Educational Concerns for Therapist Self-Disclosure

Self-disclosure is a relevant consideration for all therapists, regardless of theoretical orientation. This paper presents a critical analysis of existing ethical codes of conduct and graduate student training in self-disclosure. First, we examine the potential benefits and harm that can result from self-disclosure of therapist reactions to interpersonal dynamics within the therapeutic relationship, affective responses to the client, and past experiences of the therapist. In their ethical decision-making, therapists need to consider whether self-disclosure will promote patient autonomy and beneficence or whether it serves more of the therapists' needs than the clients. Next, we analyze four ethical codes of conduct for psychologists, social workers and marriage/family therapists. In order to sufficiently guide a therapist through appropriate self-disclosure, it was determined that these codes need to better promote a balanced use of objectivity and subjectivity, highlight self-care activities, provide stronger emphasis on the importance of context and individual differences, and define vague but key words. Suggestions to improve student training in the ethics of self-disclosure are also made. It is recommended that students should engage in role-playing scenarios and in-class exercises that encourage ethical discussions with colleagues. Teaching the importance of self-care activities, engaging in ethical decision-making processes in the classroom, or simply creating more self-disclosure dilemmas for study, would also be useful. We hope to encourage open discussion about self-disclosure of therapist reactions and contribute to more research and discussion about the best ethical method of handling these reactions, for both the client and therapist.

Workshop Chair: Paddy Rodney, RN, PhD**Taskforce Co Chairs: Paula Chidwick, PhD and Eoin Connolly, MA****Taskforce Members: Andrea Frolic, Laurie Hardingham, and George Webster****CBS 2007 Workshop: CBS Working Conditions for Bioethicists Taskforce****Background**

Increasingly hospitals, long-term care facilities and private clinics, as well as health insurance, biotech and pharmaceutical companies, are hiring bioethicists to provide ethics education, policy analysis and case consultation. Asking contentious ethical questions, and articulating "buried" issues are commonplace to the role of the bioethicist. Thus, bioethicists are particularly vulnerable regarding conflicts with their employers. How can bioethicists foster a mutually respectful relationship with their employers and best safeguard their integrity as professionals? The CBS Working Conditions for Bioethicists Taskforce was created by the executive of the CBS to address some of the practical issues along the continuum of a bioethicist's career. The Taskforce consists of the following members: Jennifer Bell, Paula Chidwick, Eoin Connolly, Michael Coughlin, Andrea Frolic, Laurie Hardingham, Christine Harrison, Chris MacDonald, Pat Murphy, Dawn Oosterhoff, Paddy Rodney, Randi Zlotnik Shaul and George Webster.

At the October 22, 2005 CBS Annual Meeting in Halifax the Taskforce met to present on their activities and findings. Members of the committee presented their work to date on four projects (*A Pilot Qualitative Study of Conflicts of Interest and Conflicting Interests Among Bioethicists in Canada* by Andrea Frolic, Ph.D and Paula Chidwick Ph.D; *Model Contract* by Dawn Oosterhoff, RN, SJD and Eoin Connolly, MA; *Peer Support* by Laurie Hardingham, RN, MA and George Webster, PhD; and *Dispute Resolution Models* by Chris MacDonald, PhD). The goal of the 2005 session was to inform CBS members of the work of Taskforce and solicit feedback on its various projects. Since then, the Taskforce continues to meet and is developing each project.

This Workshop

During this Workshop at the CBS 2007 meeting, Taskforce members and other CBS members will have the opportunity to continue dialogue about the work of the Taskforce, particularly in relation to the current CBS Visioning process. Taskforce members will provide a synopsis of their work to date, and there will be a semi-structured dialogue session for feedback and future planning. Workshop participants will thus have the opportunity to learn about important substantive areas related to the practice of bioethics, and they will contribute to a crucial area of planning for the future of the CBS.

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Is renal transplantation a right or a privilege?

Transplantation is one of the medical outstanding successes of the last century. At its beginnings, transplantation was an experimental therapy and considered as innovative medicine. Nowadays, renal transplantation is almost the gold standard treatment for end-stage renal disease (ESRD) patients since it increases patients' survival and quality of life. Moreover, the medical progress in organ procurement and the development of potent immunosuppressive drugs in the last years have made possible renal transplantation for patients who would have been considered unsuitable candidate before. This democratization of renal transplantation goes hand in hand with a mechanistic view of life where organs are viewed like spare parts. Consequently, ESRD patients may think that they have a right to renal transplantation. This "right to be transplanted" creates tensions on professionals working in the field of transplantation.

On the opposing hand, transplantation may also be conceptualized as a privilege. Indeed, the shortage of organs, the fact that renal transplantation is not miraculous or a panacea, the absence of ESRD patients in the decision process leading to organ procurement and transplantation, as well as the medical pressure to succeed may explain why transplantation could be seen as a privilege.

In the Québec world of transplantation, these two views are simultaneously used, closely interlinked and continuously opposed. With references to recent problematic that supervened in the field of renal transplantation, we will present the meanings and implications of these two opposing views: transplantation as a right vs. transplantation as a privilege.

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**The dangers of industry-sponsored medical research:
 Perspective of industry sponsors and academic researchers**

Industry-sponsored research is both necessary and ubiquitous at Academic medical institutions. Yet there are well-known concerns that because of its economic power and fiduciary duty to pursue profits, industry may exert undue influence and corrupt the integrity of academic research. These attitudes are often fostered by the media in reports about research misconduct and the exploitation of illness for profit. For these reasons there has been discussion about the need for formal regulation of the interaction of industry and academia when carrying out medical research.

This paper derives much of its argument from discussions with academic researchers and industry sponsors. While there are real threats posed by the increasing influence of industry on academic research this paper argues that this view of Big Pharma/ industry and its influence on research is over-simplified. Discussions with key stakeholders reveals a much more nuanced state of affairs. Although it does function as an amoral and purely self-interested party in most medical research, industry does so under considerable constraints. And while there may be concerns about the integrity of some industry sponsored research, there is also evidence to suggest that industry-sponsored research is more rigorously constructed and audited than research carried out under the auspices of the CIHR.

I argue that before hastily implementing regulations to govern the interaction of industry and universities, a better understanding of the views of both academic researchers and industry sponsors is strongly advisable.

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Living Anonymous Directed Organ Donation

Anonymous directed organ donations are those in which a donor specifies a recipient or recipient group to whom his or her organ is to be allocated. Three main arguments against allowing partiality in anonymous donations are: 1) by benefiting random recipients, directed donations violate the principles of equity and justice that form the ethical basis of established organ allocation criteria; 2) directed donations may unfairly discriminate based on sociological factors such as race, class or gender, and; 3) most directed donations involve solicitation for organs in the media, which not only creates unequal access to organs, but such donations are suspected to be contingent, explicitly or implicitly, on material gain.

These well-intentioned arguments do not justify an outright prohibition against anonymous directed donation. Three main arguments for allowing partiality in donations are: 1) directed donations benefit the recipient and each potential recipient beneath him or her on the waiting list by advancing on the list; 2) if partiality in living donation between relatives, partners or friends is morally acceptable, and yet constitutes unequal access to organs, it is unfair to impose the provision of impartiality on anonymous donations, and; 3) the concern of *quid pro quo* in anonymous directed donations applies also to standard living donations, and as with the latter, transplant centres may attempt to identify such motives but cannot prevent the future exchange of goods or reward.

Our presentation elaborates on the above *for* and *against* arguments on anonymous directed donation, while ultimately siding in favour.

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End-of-Life Decision Making in the Context of Mental Illness

Ethics textbooks and courses commonly devote chapters and class hours to the important topic of the ending of a person's life. Familiar clinical and public language includes the goal of "a good death" or "death with dignity." Associated topics also garnering considerable discussion by both the clinical and ethics communities include euthanasia, physician-assisted suicide, advance directives, and organ donation after cardiac death.

Infrequent, however, is the examination of end-of-life issues when the person has a serious mental illness (other than progressive Alzheimer's Disease) or an addiction. A bioethicist and a geriatric psychiatrist will discuss the competing clinical, ethical, and legal factors they faced when, while helping a patient living with a significant delusional disorder, it became suddenly apparent that the patient might have a terminal illness, likely in an advanced stage. Foundational concepts such as informed consent, capacity, meaning, treatment burden, suffering, and hope will be discussed.

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Surviving the Health Canada Inspection- What does that have to do with research ethics?

Since 2004, Health Canada inspections of selected Canadian Research Ethics Boards (REB) and clinical trial sites have been carried out under the authority of the Food and Drugs Act (FDA) to verify compliance with Division 5 of the Food and Drug Regulations. The selected institution, including the REB, and the clinical trial sites are approached by the Health Canada Inspectorate bureau and given a list of tasks in order to prepare for the inspection. The inspection itself proceeds by means of a series of visits from the Inspector on the assigned dates, and includes a scrutiny of the documents and a discussion with each clinical trial study team/ or REB, with each inspection lasting one week.

Our joint university/hospital REB was inspected in 2006. In addition to the REB, four clinical trial sites from the HHSC were also inspected. As the Vice-Chair of the REB, I was closely associated with all steps of the inspection and I found the process to be very illuminating. The inspector was extremely thorough and comprehensive. The focus was mainly on the standards of operations (SOPs) whether for the REB or the clinical trial site, and attention to detail was meticulous. Notwithstanding that the inspector's observations were very fair with ample opportunity for feedback, my impression was that the process was too focused on procedures rather than on outcomes and while both are often intertwined, I felt that pertinent points in reference to the ethical conduct of the study were overlooked. This paper attempts to discuss some of those impressions, including questions that were raised and others that were missed.

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Pay-For-Performance: The United States Can Learn From Britain and New Zealand

Pay-for-performance (P4P), a system of paying clinicians based on the health outcomes of their patients, is drawing an extraordinary amount of attention for its potential impact on the way medicine is practiced in the United States. But there has been little focus on how P4P programs function in other parts of the world. What are the differences between P4P programs in the United States and overseas? What ethical challenges might these differences raise? And what might we learn from such comparisons?

I recently met with practicing physicians from Britain and New-Zealand to find out. The most salient difference was that American P4P programs typically lack the safeguards necessary to protect patients with low socioeconomic status from being systematically marginalized by providers. Such safeguards have been necessary because the strong correlation between poverty and adverse health outcomes might lead to discrimination against the poor by health care providers attempting to maximize their performance-based reimbursements. In this session, I examine two safeguards common to Britain and New Zealand's P4P systems; population based risk stratification and exceptions for patient factors. I will then explore how such safeguards would likely function in the United States and argue for their timely adoption.

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On the Role of Emotions During Ethical Consultations

Ethical consultations are *rational* processes. A look at the various types of ethical consultation will reveal that feelings hardly play any role at all. At best, the starting point for ethical controversy is acknowledged as being an "instinctive unease". Ethical discourse then has the task of cutting through the emotions (unease) and arriving at the argument. Clinical experience has shown, however, that emotions have an enormous influence on ethical discourse. In their dealings with disease and death, physicians and nurses develop protective mechanisms, as do paramedics, the police and members of the fire brigade. Can any consequences be deduced from this for ethical consultations? Is it necessary for all feelings to be passed over in order to arrive at a "rational" decision? May emotions be addressed at all? How are feelings shown during ethical consultations to be handled? What about accusations of guilt? What does this mean for the basic conditions governing ethical consultations?

Should the chairperson of an ethical consultation address persons under emotional strain directly? *Must* he or she address their feelings (in order to liberate them from their emotional ties)? What feelings are to be permitted by the chairperson of an ethical consultation (and in silent admission by the group)? Crying, grief... anger, fury, annoyance....? Or is a consultation "devoid of emotion" the ultimate yardstick? This paper aims to demonstrate how ethical consultations can benefit from the structured inclusion of emotions.

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Health Care Ethics and Clinical Ethics in Ireland

There are significant differences between the state of health care ethics in North America and Europe. In my paper, I will discuss characteristics of health care ethics and clinical ethics in Ireland. In my description I will draw on preliminary results of an ongoing study by the Centre of Bioethical Research and Analysis at the National University of Ireland on the implementation of health care ethics support for practitioners in Ireland. As I will argue, health care ethics in Ireland needs to be understood in relation to its particular social context. Ireland is a small Catholic country in which the church has traditionally shaped decision-making in all domains of public life. The leadership of many health care organisations has traditionally been Catholic, and its influence has been especially marked regarding ethical decision-making. There is a comparatively short academic tradition of health care ethics in Ireland outside of the Catholic church. Most of the academic positions in the field have been created during the last decade when a range of health care professions moved their professional training to universities, but the involvement of these academics in health care practice is still limited. In recent years, a number of cases of questionable ethical decision-making in Irish health care institutions have come to public attention and have raised public and professional awareness of ethical issues. There is increasing awareness for the need for improved implementation of ethics support in health care contexts, but no consensus on desirable and appropriate models for such support has been achieved to date.

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Evidence and Ethics in Studying Globalization and Health

The vogue for evidence-based clinical practice has now spread to the study of public health policy and interventions to address the social determinants of health. Insufficient attention has been paid to the interconnected ethical and political dimensions of this trend. Explicit consideration of these dimensions is needed with respect to issues including:

1. Choice of the scale of intervention to be studied: how does preference for randomization create a scale constraint on the universe of demonstrably effective interventions?
2. Bias in selection of interventions for study: for example, when a targeted program (e.g. for the poorest households) is evaluated against a base case, what if anything can legitimately be said about the relative efficacy and cost-effectiveness of targeted vs. universal programs?
3. Choice of a standard of proof: how much evidence is considered sufficient to demonstrate an intervention's effectiveness? Relatedly
4. When must an intervention's effectiveness be considered sufficiently well demonstrated that it must be offered to all potential beneficiaries (analogous to the situation in clinical trials), and
5. What *kinds* of evidence are considered sufficient? Does preference for quantitative results and formal tests of statistical significance omit qualitative, narrative and historical methodologies that are important for understanding real-world policy and program choices?

Incorporating epistemological perspectives drawn from the clinical world into the study of social determinants of health may delegitimize critical observations about globalization and health that arise from a broader social scientific perspective, even while they are indispensable for the design of meaningful policy interventions and effective resistance strategies. The paper draws in part on the author's experience with these issues as they have arisen in the work of the WHO's Commission on Social Determinants of Health (http://www.who.int/social_determinants/en), for which he served as coordinator of one of the Knowledge Network "Hubs."

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Ethics in conditions of disaster and deprivation: learning from health workers' narratives

Background: A growing interest in global health has drawn increasing attention to ethical issues arising from humanitarian aid. Mostly this attention takes two forms, a) critical valuations of the benefits and potential harms of humanitarian aid, usually addressing macro-level questions such as lack of access to those most in need and the potential for humanitarian aid organizations to be exploited by local authorities, or b) personal stories of experiences of providing care or aid under conditions of disaster or deprivation, including occasional accounts by health care professionals or students of health care professions on electives. Personal accounts of involvement in aid efforts often highlight the enriching quality of the experience, yet include cautions about the frustrations, dangers and emotional toll.

There is little systematic understanding of ethical challenges experienced by the multitude of volunteers who provide health care under extremely difficult circumstances, or of the consequences of these challenges. This may lead to crisis and moral distress. "Moral distress is caused by situations in which the ethically appropriate course of action is [uncertain or where one perceives an appropriate course but this course cannot be taken]" (Elper E 2005). These challenges can make reintegration difficult, may deter some from doing aid work, and others from returning to provide immeasurably valuable care. For those who do return, there is concern that the constant experience of ethical challenges will lead to disillusionment and burnout.

Objectives: We have begun a qualitative study involving a systematic collection and analysis of the ethical issues health workers report during humanitarian aid work and other experiences of providing care under extreme conditions. Our intended outcome is to create a framework for ethical analysis of health workers' humanitarian aid experiences that can be used to prepare potential workers, assist them with ethical challenges in the field, and debrief them. We will explore how these findings could help prepare health professionals and students who choose international health and development electives. In addition, the findings will provide valuable insights for policy makers at a variety of levels who support humanitarian aid work. This presentation will describe the current ethical approaches to the issues and some findings from the initial qualitative interviews with aid workers.

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Re-reading Dax's case

The case of Donald (Dax) Cowart remains every bit as challenging now as it was when it first appeared. Although it lends and has lent itself to a variety of interpretations, it continues to resist being reduced to a definitive, authoritative reading. Now that our understanding of the world of chronic illness and disability (and of rehabilitative medicine) is better than it was when Dax's case first appeared, it may be worthwhile to re-read Dax's case. The working hypothesis of this paper is that misunderstanding of cases such as Dax's case and our misunderstanding of what is loosely referred to as 'post-modern' ethics mirror one another. That is to say, the more time one spends with and thinks about catastrophically injured patients, the more one can and will understand what post-modern thinkers are talking about. By the same token, the more time one spends reading the post-moderns, the more one can and will understand what is going on with patients such as Donald Cowart. By first referring to the already existing literature on Dax's case, which tries to situate his case within the framework of myth, modern philosophy, and modern theology, this paper will offer an interpretation of Dax's case that will demonstrate both that the post-modern has as much to do with re-construction as de-construction, and how reading Dax's case from this perspective can enhance our understanding of the case and of what the so-called post-modern is and is not about.

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Autonomy, public health and prenatal genetic testing: too many to tango?

The number of prenatal genetic tests offered to pregnant women across Canada is expanding rapidly and being offered earlier in gestation. While proponents attribute various benefits to testing, the emphasis on the value of autonomy is overwhelming and is revealed by even the most cursory glance at prenatal genetic testing pamphlets and the websites of obstetrics and genetics departments. Much less publicly discussed, however, is the value of public health which plays an important role in motivating screening programs. Yet for most of the conditions detected there are no treatments or cures available to improve the health of the developing fetus. Instead, implicit in evaluations of screening programs is an assumption that benefits arise when fetuses with genetic anomalies are aborted. For instance, a recent report from the Public Health Agency of Canada lists maternal serum screening – and its ability to detect cases of Down Syndrome and neural tube defects – as one of ten effective interventions to improve maternal, infant and child health; it is considered effective because increased use of prenatal diagnosis and selective termination has resulted in a decrease in infant mortality.¹

In this paper, I analyze the various meanings of public health and its role in prenatal genetic testing within a clinical context that is focused on autonomy. I argue that how the values of public health and autonomy are interpreted and understood, and how the tension between their conflicting goals is resolved, will have a significant impact on the future course of prenatal genetic testing.

Public Health Agency of Canada, 'Making Every Mother and Child Count,' Report on Maternal and Child Health in Canada, 2005, pp. 5-9.

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Just regionalisation: Rehabilitating care for people with disabilities and chronic illnesses

Regionalised models of health care delivery have important implications for people with disabilities and chronic illnesses yet the ethical issues surrounding disability and regionalisation have not yet been explored. Although there is ethics-related research into disability and chronic illness, studies of regionalisation experiences, and research directed at improving health systems for these patient populations, to our knowledge these streams of research have not been brought together. Using the Canadian province of Ontario as a case study, we address this gap by examining the ethics of regionalisation related to people with disabilities and chronic illnesses.

Ontario is in the process of implementing fourteen Local Health Integration Networks (LHINs). The implementation of the LHINs provides a rare opportunity to address systematically the unmet diverse care needs of people with disabilities and chronic illnesses. The core of this paper provides a series of composite case vignettes illustrating integration opportunities relevant to these populations, namely: rehabilitation and services for people with disabilities; chronic illness and cancer care; senior's health; community support services; children's health; health promotion; and mental health. For each vignette, we interpret the governing principles developed by the LHINs—equitable access based on patient need, preserving patient choice, responsiveness to local population health needs, shared accountability and patient-centred care—and describe how they apply. We then offer critical success factors to guide the LHINs in upholding these principles.

While Ontario is used as a case study to contextualize our discussion, the critical success factors we provide have broad applicability for guiding and/or evaluating new and existing regionalised health care strategies.

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Doing Right in Difficult Settings: medical leaders' moral quandaries

This paper presents the preliminary findings from a study of the moral quandaries faced by medical directors leading the UK National Health Service. Most medical ethical analysis has centred on the relationship between individual clinicians and service users, but providing excellent cost-effective health care requires difficult decisions to be made by the people who lead ever more complex organizations. Medical leaders play a crucial role in building organizations that are trustworthy and responsive to medical needs. However, we currently know very little about the matters of conscience that their leadership responsibilities confront them with. The aim of this study is to address that gap, and thus increase understanding of the ethical dimensions of health care organization.

This paper identifies some of the organizational ethical issues that medical directors have presented as significant, and discusses how they approach their role as moral leaders. It also considers how some familiar ethical issues, such as informed consent, are reinterpreted when reasoning from an organizational perspective. Finally it suggests the implications of these findings for an account of the ethical dimensions of medical professionalism.

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US Medicare Part D: What NOT To Do in Canadian Pharmacare

As Canada slowly moves forward in developing a Pharmacare program for outpatient prescription coverage, it is important to observe the profound failures of the US's recently introduced prescription plan for senior citizens, Medicare Part D. Created by legislation that was tailored to pharmaceutical and insurance company interests rather than medical needs, Medicare Part D is a complicated, incomplete and extremely wasteful program that fails to extend prescription coverage to the vast majority of those who need it. In fact, with the introduction of Part D during the Nov 2005 – May 2006 registration period, many Seniors *lost* prescription and other health insurance coverage that they had previously held. The program is already a failure.

In this presentation, a very brief overview is given of the complex Medicare system that already existed in the US (parts A and B, for hospitals and clinicians), and how the new program was intended to expand coverage. Even before the sign-up period had been completed, however, the program was creating more problems than it resolved. Both case examples and preliminary overviews illustrate several fundamental problems.

Applying the principles of the Canada Health Act in a manner somewhat unique to outpatient pharmaceuticals will offer a useful guide for avoiding the worst of the mistakes made in the US. In addition, such a program must be user-friendly and mindful of the difficulties faced by those who are elderly, ill or disabled; insurance and pharmaceutical corporations must be recognized as stakeholders but not allowed to be drivers of any such program, and the vast economic benefits of a single-payer approach must be incorporated.

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Organizational Ethics, the Example of Business Development

Health Care Organizations (HCOs) currently face financial pressures that impact frontline care. While HCOs have traditionally made use of supplementary revenue from parking lots, preferred accommodations, and cafeterias, many are now becoming more entrepreneurial by seeking partnerships with franchises, creating subsidiary companies, and venturing further into private healthcare. Business development opportunities used as a strategy for HCOs to improve their financial sustainability (i.e., looking for revenue-generating opportunities to support their clinical services) are ethically important because of their potential impact on stakeholders and the patient-care mission.

Business development as it relates to ethics is not described in the literature but was raised by decision-makers as a key challenge in a larger study we conducted on organizational ethics in HCOs. We sought to explore the specific ethical issues presented by business development and how HCOs address these challenges. We conducted one-on-one interviews with CEOs, CFOs, VPs and managers responsible for business development, as well as clinical ethicists, across 13 HCOs.

Decision makers described three key ethical questions in the experience of pursuing business development: (1) is business development ethical in the context of public healthcare, (2) if so, what businesses are appropriate to deal with and (3) what business models are appropriate. The most common strategy for dealing with these questions was to evaluate the decision against the mission and vision of the HCO. Other strategies included business development committees, seeking MOHLTC advice, and selectively choosing less contentious opportunities.

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Beyond Clinical Ethics: A Qualitative Case Study of Organisational Ethics and Clinical Ethicists

Background: Demand for organisational ethics capacity seems to be growing in health organizations, particularly among managers. Although there is some evidence of clinical ethicists' increasing role in organisational ethics, very little is known about clinical ethicists' perspective on organisational ethics.

Objective: To describe clinical ethicists' perspectives on organisational ethics issues in their hospitals, their institutional role in relation to organisational ethics, and their perceived effectiveness in helping address organisational ethics issues.

Design and Setting: Qualitative case study involving semi-structured interviews with 18 clinical ethicists across 13 healthcare organisations in Toronto, Canada.

Results: From the clinical ethicists' perspective, the most pressing organisational ethics issues in their organisations are: resource allocation, staff moral distress linked to the organisation's moral climate, conflicts of interest, and clinical issues with a significant organisational dimension. Clinical ethicists were consulted in particular on issues related to staff moral distress and clinical issues with an organisational dimension. Some ethicists were increasingly consulted on resource allocation, conflicts of interest, and other corporate decisions. Many clinical ethicists felt they lacked the sufficient knowledge and understanding of organisational decision-making processes, training in organisational ethics, and access to organisational ethics tools to deal effectively with the increasing demand for organisational ethics support.

Conclusion: Growing demand for organisational ethics expertise in healthcare institutions is reshaping the role of clinical ethicists. Effectiveness in organisational ethics entails a re-evaluation of clinical ethics training to include capacity-building in organisational ethics and organisational decision-making processes as a complement to traditional clinical ethics education.

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Reflections on 'False' Hope: Letting Our Emotions Do the Work?

How often have you heard the question, "What do we do with the patient who has false hope?" or made the comment that, "It is important not to give this patient false hope"? In this paper, I demonstrate that there are (at least) four assumptions typically built into these types of comments. These assumptions are that: (1) false hopes exist; (2) false hopes can be (reliably) identified; (3) false hopes are, or create, a problem; and, (4) false hopes should be changed, eliminated and/or avoided. Indeed, the further claim is often made that patients should have realistic expectations and hold reasonable hopes accordingly. Each of these assumptions makes an important claim that deserves our attention and critical reflection. Are these assumptions defensible? What is the basis for these assumptions? Further, what is the goal of trying to change what a person hopes for? Can this goal be achieved, based on the above assumptions about what hope is? And, more broadly, does this goal fit with our understanding of competing ethical obligations in health care? Through my analysis, I will demonstrate that these assumptions do not hold – at least not in the way we typically understand them – and will present a different approach for understanding and appreciating the role of hope in health care, including, in particular, how to address hopes that are not shared.

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The Big Patient Problem: Ethical issues in the organization and delivery of care for obese (bariatric) patients

Bariatrics is a term derived from the Greek word baros (weight) and refers to the practice of health care relating to the treatment of obesity and its associated conditions. Obesity is a significant problem in Canada as well as most of the Western world. It is associated with substantial morbidity and mortality. Studies have demonstrated that critically ill bariatric patients have higher intensive care mortality, prolonged mechanical ventilation and extended "weaning" time. As well there are significant safety concerns for staff when caring for this group of patients. Health Care Professionals within Eastern Health, Newfoundland and Labrador have, for several years, wrestled with planning programs and services for bariatric patients. The need for new programs, resources to enhance current programs, patient and staff safety issues, obesity prevention, and discharge planning prompted the request for an ethics consultation on the issues of caring for bariatric patients.

Throughout the spring and summer of 2005 an ethics working group researched the issue and consulted with frontline staff, patients, families and administrators. The working group presented a series of recommendations based on the ethics analysis. These recommendations provided a foundation for further action in planning care and services for bariatric patients within Eastern Health.

This interactive session will highlight issues and challenges involved in the provision of care to bariatric patients. The session will bring forward and discuss the ethical principles and concepts relevant to the issues.

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Why Do We Do What We Do? The Goals and Objectives of Ethics Consultation

The goals and objectives of ethics consultation can be multiple, complex, and co-existing, depending on the reasons a consultation is requested, the model of consultation being employed (i.e., individual consultant, small team, ethics committee as a whole), and the professional backgrounds of the consultants (e.g., physicians, nurses, philosophers, theologians). Further, any listing of multiple goals and objectives raises the question of the possible priority of one goal or objective over others. Nevertheless, clarity about the goals and objectives of ethics consultation is essential for the practice to be effective, to avoid false expectations and misunderstandings, to measure and evaluate the quality of processes and outcomes, and to guide training and education programs aimed at developing appropriate knowledge and skills.

This paper and presentation will summarize and critique published literature that discusses the goals and objectives of ethics consultation. Included in the literature review will be, (1) a 1995 consensus statement from the Chicago Conference on Evaluation of Ethics Consultation (J.C. Fletcher, M. Seigler), (2) the 1998 American Society for Bioethics and Humanities' "Core Competencies" report, and (3) a 2007, soon-to-be-published American Journal of Bioethics target article on "Ethics Consultation in U.S. Hospitals" (E. Fox, S. Meyers, R.A. Pearlman). Based on our more than twenty-five years of combined experience doing ethics consultations, we will provide a substantive and linguistic critique of the identified goals. We will then present, prioritize, and discuss our own recommendations for more appropriate articulations of the goals and objectives of ethics consultation.

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Ethics of Palliative Sedation: Clinical and Practical Guidelines

This paper will review both the process of creation as well as the content of the Palliative Sedation Document. In addition, an information booklet for families focusing on frequently asked questions will be presented.

The multidisciplinary Palliative Care Team of Baycrest, representative of medicine, nursing, social work, pharmacy, ethics, volunteers and allied personnel, along with input from law and the Coroner's Office, collaborated in their efforts to produce the Palliative Sedation Document, which ultimately underwent administrative review, as well as endorsement from the Medical Advisory Committee of Baycrest. In addition, an information booklet for families was created addressing some of the most commonly asked questions raised in relation to use of Palliative Sedation.

The authors will present ethically acceptable criteria and guidelines for use of palliative sedation as a form of treatment for intractable pain or symptoms associated with acute or chronic morbidity in palliative care settings. In addition, they will review an algorithm for instituting therapy, clarify definitions, review indications and drugs used.

Palliative Sedation is not without ethical controversy. The authors will present the double effect theory of moral justification surrounding use of Palliative Sedation, and identify some of the moral challenges associated with it.

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Moving towards Clinical Ethics Consultation in Italy

In Italy only initial experiences exist in clinical ethics consultation (CEC) at healthcare facilities.

The *Center of Bioethics* of the *Catholic University of the Sacred Heart* is the oldest one in a School of Medicine and since his foundation in 1984 performed CECs, beside teaching and research.

In our practice, CEC is usually performed by two persons (physicians with expertise in clinical bioethics). Methodology was Jonsen-like casuistic, supported by a specific ethical theory.

Until September 2006 we collected 55 cases. No specific trend can be observed in distribution by year. The experience we report has the following features: the CEC was requested by physicians in all cases but three, initiated by patient. Main Services requiring were: Pediatrics (21 cases), Maternal-Fetal Medicine (14 cases), Neonatal ICU (6 cases). Ethical issues concerned especially the proportionality of indicated medical treatment (33 cases), the role of patient's autonomy (16 cases) and the moral meaning of consequences of a treatment (15 cases). More than a ethical issue could be involved in each case. More frequent implicated treatment were CPR (16 cases), management of ectopic (tubaric and cervical) pregnancies (9 cases), tracheostomy (6 cases), planning care (6 cases), mechanical ventilation (3 cases), palliative sedation (3 cases), inducing labor (3 cases).

In almost all cases physicians individuated the ethical issue correctly, only seldom confusing ethical and relational or legal problems.

Conclusions: in our experience CEC is initiated by physicians; they require CEC for genuine ethical problems; the main issue is understanding beneficence. Ethical theory has a key role in solving clinical ethics problems.

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When Does Bioethics Matter to U.S. Judges?

Bioethics' engagement with the U.S. legal system can be fraught with difficulties. The use of health care ethics committee recommendations, institutional review board determinations, bioethics commission reports, briefs of bioethics amicae curiae, and bioethics expert testimony in litigation presents unique challenges to bioethicists, attorneys and judges alike. In recent litigation to determine whether Merck, which manufactured the COX-2 inhibitor Vioxx was liable for the death of a heart attack victim, for example, even the words "ethics" and "morality" were barred, while in litigation over international human subjects research, the determination of a nonexistent Nigerian ethics committee was initially taken at face value. Determining when judges are receptive to bioethics resources and when judges give them weight is therefore critical in assessing how much bioethics will matter.

This presentation identifies factors that appear to influence how receptive judges are to bioethics resources, and how much weight judges give them. Those factors include: the formality or informality of the source from which the bioethics resource emanates; the extent to which the usable component of the bioethics resource reinforces or undercuts law; the distance or proximity of the legal question and the bioethics resource to religious issues; whether the potential use of the bioethics resource is legislative or adjudicative; and the judge's approach to the relationship of law and morality. The role of each of these factors is illustrated in excerpts from recent legal cases in which a judge was presented with a bioethics resource.

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Capacity Assessment as an Integral Part of Ethics Consultation

It is a commonplace that most ethics consultations revolve around end of life issues. But many ethics consults share another important issue, one that is less often remarked upon. This second topic is whether or not the patient has decision making capacity. When the consult concerns a patient whose capacity is in dispute the consultant must be able to have their own opinion. It is not enough to trust what others tell you, especially when opinion is split. In particular, it is a common mistake in hospitals to think one needs a psychiatric consult to determine capacity.

This paper challenges some widely held but unspoken beliefs. I argue that capacity assessment is not uniquely within the domain of expertise of psychiatry and that ethics consultants must be willing to tread comfortably on this turf, whether their background is medicine, nursing, social work, philosophy, or law. The topic threatens some people unnecessarily, as they fear it will lead to excluding some group from the practice of ethics consultation.

To achieve the goal of inclusion of all groups, I present a definition of capacity informed by the traditional literature (such as Appelbaum and Grisso) but also by years of experience with ethics consultation. Equally importantly, I outline how to assess capacity seamlessly into the ethics consultation process. By the end of the presentation audience members will appreciate the importance of being comfortable with their own ability to assess capacity even when their conclusions may be contrary to an earlier psychiatric evaluation.

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Recherche chez les enfants très malades ou en soins palliatifs : normes et enjeux éthiques

Introduction : Le médecin chercheur doit gérer un dilemme important : concilier le fait que le même patient soit à la fois un sujet de recherche et un patient vulnérable qui va mourir.

Objectif : Voir si les normes et pratiques de recherche établies sont pertinentes pour les praticiens chercheurs dans un contexte de soins palliatifs pédiatriques.

Méthodes : La théorisation ancrée a été utilisée comme cadre méthodologique et analytique. Les données incluaient douze entrevues semi-dirigées avec des médecins chercheurs, travaillant dans un centre pédiatrique universitaire pédiatrique et s'impliquant à la fois en recherche et avec des enfants très malades. Les autres données étaient des notes et observations de site, des formulaires de consentement et des protocoles de recherche. Les critères de scientificité vérifiés étaient : la saturation thématique, la crédibilité et la «confirmability» des données.

Résultats : Cinq thèmes principaux ressortaient de l'analyse : 1) Une attitude positive face à la recherche, 2) la légitimation de la recherche chez les enfants très malades ou en soins palliatifs, 3) les notions d'assentiment et de consentement, 4) l'inclusion des enfants à la recherche et finalement 5) les recommandations pour la recherche en soins palliatifs. 1) En général, les médecins étaient ouverts à la recherche chez des enfants très malades, même aux études contrôlées avec placebo. Le questionnement éthique était plus important lors de l'utilisation d'un placebo lors d'une recherche impliquant un enfant en soins palliatifs qui est souffrant. 2) Pour légitimer la recherche chez des enfants très malades, les chercheurs tenaient compte, des bénéfices escomptés pour l'enfant, par exemple, des bénéfices de l'inclusion à la recherche et de l'importance de l'effet placebo en recherche. 3) Tous les médecins reconnaissaient l'importance d'impliquer les enfants dans les prises de décision, à différents niveaux. Cependant, de façon majoritaire, les chercheurs considéraient d'abord l'avis des parents. 4) Les médecins chercheurs avaient de la difficulté à préciser leur notion de soins palliatifs et par le même fait, l'inclusion d'enfants en soins palliatifs à une recherche. 5) Une fois que l'enfant était défini comme étant en soins palliatifs, les chercheurs mentionnaient l'importance de maintenir la qualité de vie de l'enfant et de soulager ses symptômes s'il participe à une recherche. Le classement de l'enfant comme étant en soins palliatifs ou non influençait donc la prise en charge des effets secondaires associés à la recherche et subséquemment l'évaluation des risques.

Conclusions : Nous suggérons de définir une classe particulière de recherche clinique en pédiatrie, nécessitant un suivi spécifique par les Comités d'éthique à la recherche. Cette classe devrait être assez large pour inclure les enfants définis comme étant en soins palliatifs et d'autres enfants qui ne sont pas «classés» comme en soins palliatifs mais pourraient l'être, exemple : les enfants présentant une maladie pour laquelle il n'y a pas de traitement curatif d'efficacité scientifiquement démontrée.

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Data and Decision Making regarding the Disclosure of Financial Conflicts of Interest in Research

Substantial attention has recently focused on managing financial conflicts of interest in research. While many have suggested the need to disclose conflicts of interest to potential research participants during the informed consent process, much about this remains unclear. Specifically, who, how, when, and where to provide such disclosures are unclear as is the effect of such disclosures on potential research participants' understanding, decision-making, trust, and participation in research. As a result, there could be unintended and unforeseen negative consequences if sponsors, investigators, or Research Ethics Boards/IRBs (Institutional Review Boards) implement unstudied mechanisms of disclosing conflicts of interest into the informed consent process. Thus, our study team conducted a range of data gathering activities in the United States to inform these uncertainties. These activities include three major projects. First, we interviewed clinical investigators, IRB and COIC (Conflict of Interest Committee) chairs to determine their attitudes and practices regarding the disclosure of financial interests in research. Second, we conducted focus groups to identify potential research participants' understanding and attitudes towards financial interests and their disclosure in research. Third, we completed a web-based survey involving thousands of patients regarding their willingness to participate as well as their trust in clinical research when presented with differing financial interests. The presentation will highlight the key lessons learned from these projects and suggest how these data will be used to inform policy as well as to develop and test a robust approach to disclosing financial conflicts of interest in research.

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Expanded Newborn Screening: Informed Consent for the Public's Health

Universal newborn screening has remained among Canada's leading public health initiatives since the early 1960s. Across North America, the calculated benefits of public health newborn screening programs, both for children and the community at large, purportedly outweigh potential harms. Public health policies deemed in society's best interest often sacrifice certain individual rights to preserve the "greater public good". In the United States, newborn screening is mandatory (with parental consent not sought) in all but three states. Similarly, in Canada parental consent for newborn screening is not sought. However, in Canada, unlike the United States, the legislation necessary to render these screens mandatory does not exist. Although parents theoretically are able to refuse screening on behalf of their newborns, few parents are aware that screening occurs. These mass population screening programs have become a routine part of paediatric care in Canada, consequently blurring the boundaries between standard medical care for individuals and a government funded public health intervention. Advanced newborn screening technology, capable of diagnosing a host of genetic conditions, challenges the once unequivocal "good" brought by the first newborn screening program for phenylketonuria. As the Ontario government prepares to implement its expanded newborn screening program, public health and hospital authorities should re-visit and re-evaluate earlier decisions not to require explicit parental consent for newborn screening. This paper will demonstrate that not only is obtaining informed consent from a parent or guardian in the patient's best interest, it is arguably also in the best interest of the public's health.

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Enacting justice in health care practice in a diverse and inequitable society: Ideological fault-lines of egalitarianism and multiculturalism

Justice is one of the central values that defines the ethical standards and expectations for professional health care practice including nursing. According to the Canadian Nurses Association, nurses "must not discriminate in the provision of nursing care based on a person's race, ethnicity, culture, spiritual beliefs, social or marital status, sex, [and so on]." Enactment of the value of justice in everyday nursing practice, however, is non-linear and far from transparent. In this paper, we hold up for scrutiny a possible 'disjuncture' between the moral ideal of nursing and its actual practice by juxtaposing two competing claims in relation to the value of 'justice': the claim made by nurses that 'we treat everyone the same', and the claim made by some patients that they were being discriminated in health care due to their racialized and/or social class background. We argue that this disjuncture cannot be reduced to merely a difference in perception between nurses and patients; rather, it is a reflection of some of the hidden ways by which society 'manages' social inequities by reifying the assumption of equality and sameness between different populations. To illustrate this point, we critically analyze how the ideologies of egalitarianism and multiculturalism can obscure nurses from being morally conscious of systemic inequities and historical injustice, and impede their ability to perceive and respond to the social suffering that some populations are subject to. We conclude by discussing strategies to enhance nurses' moral perception and capabilities to make social change through practice.

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Planning for Research Endeavors during a Public Health Emergency: Learning from SARS

Background: Pandemic planning is going on at the national, provincial, municipal and institutional levels. During SARS, there was no plan to coordinate the research that took place, in hospitals and in the community, into etiology, treatment & social consequences of the disease. In particular, researchers had little guidance about how to approach ethical issues that arose in the context of a public health emergency. The Tri-Council Policy Statement (TCPS), the main national research ethics guidance in Canada, is currently silent on the issue of research in public health emergencies. To address this gap in knowledge, the Federal Interagency Panel on Research Ethics has struck a sub-committee to examine how the TCPS should be developed in order to provide effective guidance for researchers and institutions who are engaged in research during public health emergencies. Currently, there is no consensus about what aspects of research should be addressed in any amendment. Although individual research institutions have begun to develop emergency preparedness plans for pandemics, it appears that few have considered how a public health emergency might affect their Research Ethics Boards, or the ethical challenges for their investigators.

Objective: The objective of this study is to explore investigators' experiences with ethical and procedural challenges encountered while conducting research during SARS. These insights are critical in order to ensure that any policy responses, such as possible amendments to the TCPS, are appropriately grounded in the experiences of Canadian researchers.

Method: Researchers who conducted clinical research during SARS in Toronto have been recruited from a tertiary care hospital in Toronto. Data are being collected using in-depth, face to face interviews and analyzed using qualitative methodology. A purposive, sequential-referral sampling method is being used and interviews will continue until theoretical saturation is achieved.

Results: Preliminary findings suggest that investigators conducting clinical research during SARS encountered ethical challenges related to: proposal writing, difficulty with consent forms, protection of patient rights, challenges with recruiting patients and maintaining their privacy, and the formulation of new working groups.

Conclusion: Further guidance is needed to help ensure research conducted during public health emergencies is done to the highest possible ethical standards. The preliminary results from this study have identified several key ethical challenges faced by investigators who were conducting research during SARS. These findings may serve as a useful set of domains to help guide the direction of future amendments to the TCPS. They may also provide useful insights for research institutions about how their own policies might be strengthened by including more explicit guidance and/or processes for their researchers about research during public health emergencies.

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Are ethical issues being overlooked whilst encouraging reflection in academic nursing study?

In recent years verbal and written reflection have become an integral part of academic study within nursing programmes as students are encouraged to become reflective practitioners. Academic programmes require nursing students to reflect as part of a specific pathway of study and reflection has become a common form of both formative and summative assessment. However, this common use of reflection raises ethical issues not only connected with the context in which patient information is used, but also the effects of reflection on the patient, the reflector and the lecturer.

When considering the ethical issues that reflection involves, the emphasis is on confidentiality. However, confidentiality is not the only ethical concern. Whilst much has been written on the subjects of privacy, trust and confidentiality, the focus on breaching these boundaries falls within the clinical or public arena. Reflection within academic work should not just examine how patient information is used but look at the effect compulsory participation in such exercises may have on the student. Concepts which are discussed with reference to the patient e.g. privacy, trust, confidentiality and possible maleficence may also apply to the nurse.

The conclusion of my paper is that ethical issues are being overlooked, some being totally ignored e.g. confidentiality, privacy, trust whilst others are considered, by some, to be an acceptable side-effect of reflection e.g. vulnerability. It is felt that ethical issues are not being considered sufficiently - reflection hiding behind the aim of improving standards of practice, but not considering at what ethical expense.

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Quality Improvement and Clinical Impact of Ethics Consults on Patient Care

There is scant literature available about measuring the effectiveness or quality of ethics consults. A 2003 study (**JAMA**) showed consults can shorten length of stay in critical care and length of time on a ventilator. A critique of this study pointed out there was no mechanism to show the quality of the consults themselves that led to these outcomes.

In this highly-interactive workshop we will examine some of the measures that have been used, as well as describe how we have come to determine what an ethics consults should do. This will entail a discussion of our ethics consult model and our tracking system, and a presentation of the data we have gained from that tracking. We will then show how this data, collected in an IRB approved study, is used to identify quality improvement areas in the delivery of clinical care, and the work that has been able to be done based on this data to improve patient care. We will then describe the quality assurance and quality improvement mechanisms we have developed to assure that the consults themselves conform to high quality standards.

Participants will be invited to share their own experiences and work in this area, as well as comment on the work and data we have done. It is our expectation that participants will be able to describe and critique the varieties of ways in which a consult can be done and evaluated, and measure their impact on patient care.

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Characterizing the PGD Embryo: A Review of Recent Policy Decisions

Through PGD, embryos created by IVF are selected for transfer to a woman based on particular characterizations, including the presence of genetic markers or a tissue match for a sibling. Most legislation regarding assisted reproductive technologies (ART) does not regulate directly with respect to PGD, therefore governments and professional bodies have undertaken policy analyses to determine the appropriate regulatory framework for PGD. Our research examines legislation pertaining to assisted human reproduction and governmental policy papers and those of professional bodies in a number of jurisdictions (including: Canada, New Zealand, Australia, the U.K. and Germany) to determine how the "health" (its cognates or its opposites) of the PGD and post-PGD embryo is characterized.

We analyzed the precise language in these document used to produce definitions and categories in relation to the PGD and post-PGD embryo, and how the resulting types of use or non-use of PGD and post-PGD embryos are intertwined with the processes of categorization and evaluation being developed and implemented regarding PGD. Our examination leads us to contend professional bodies play an important (and unexamined) role in informing and shaping the regulation and control of the practice and application of PGD. We contend that a broader exploration is required in order that all affected by the characterization of PGD embryos contribute to these characterizations and ultimately to the regulation of PGD.

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Rationing Vaccines in a 1918-type Influenza Pandemic: An Ethical Framework for a State

Most pandemic plans are for moderate, not worst-case pandemics, and few, if any, include explicit ethical rationales. To address this void, the Minnesota Center for Health Care Ethics convened a public-private multidisciplinary work group to develop recommendations for rationing vaccines in Minnesota during a worst-case influenza pandemic. The recommendations encompass an ethical framework of principles, goals, and strategies to guide vaccine rationing decisions. The group determined that an ethically informed vaccine rationing plan should be efficient, fair, designed from a statewide public health perspective, and reduce significant differences in influenza-related mortality. The primary goal is to maximize Minnesotans' chances of surviving both the pandemic and the years immediately thereafter and to limit two major causes of death: (a) influenza and complications of influenza, and (b) disruption of basic health care, public health, and public safety infrastructures. The work group also developed a sample rationing plan, but stressed that any final plan must reflect the best available evidence during an actual pandemic. The sample plan prioritizes groups that are both at high risk of influenza-related death and likely to respond effectively to the vaccine along with healthy, young workers who support critical infrastructures. It then proposes a stepped approach to vaccinating groups of people according to their relative mortality risk and vaccine response. We will discuss the work group's recommendations, public and expert reactions, and how the recommendations might apply to rationing other scarce resources during a pandemic.

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Enhancing Health Care Providers' Core Competencies in Ethics: Education Modules on Ethics Awareness, Imagination, Assessment and Reasoning

Members of the University of Toronto Joint Centre for Bioethics (JCB) Clinical Ethics Group (CEG) are developing a broad tiered ethics capacity-strengthening program to support health care providers participating in ethics activities in JCB health care organizations. This capacity-strengthening program is designed to develop core competencies that support not only ethics consultation but also ethics education, research ethics, and organizational ethics.

This presentation focuses on the first 2 modules of this program, already developed and piloted. It will be co-presented by a CEG member who has helped develop and deliver these core modules and a health care provider who has completed and evaluated this training.

Module 1 focuses on enhancing the ability to recognize diverse ethical considerations in daily practice and to understand how ethics awareness and imagination contribute to sound judgment. Participants are involved in small and large group exercises focusing on knowledge of key bioethics terms and use of cases to stimulate ethics awareness. Imagination skills are then targeted using additional interactive exercises and case-based discussions within small groups.

Module 2 engages participants first in a didactic-interactive session introducing ethical processes, reasoning, justification and an ethics worksheet. Participants then divide into small groups to use the worksheet to guide their discussion of a rich case study, including: fact-finding, identification of relevant values and principles; exploration of options and identification of the most ethically justifiable option; and development of action plan. Following report-backs from the small groups, participants are engaged in a facilitated large group discussion and provided with a model response using the ethics worksheet.

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Maternal/Fetal Conflict at the End of Life

Case-Focused Presentation: Most publicized cases of maternal-fetal conflict involve questions of whether a woman can refuse a cesarean section deemed necessary to save the life of her fetus. This case differs in that a pregnant terminally-ill patient's right to refuse life-sustaining treatment is put into conflict with the interests of her viable third-trimester fetus.

SB was 34-year-old female who presented with a painful tongue lesion and an enlarging neck mass. Biopsies revealed poorly differentiated squamous cell carcinoma. Though SB was 16 weeks pregnant, she decided against termination. Just prior to undergoing radical surgery she completed a living will and appointed her mother as healthcare surrogate. After learning she had metastases, SB deferred cancer treatment until the third trimester, when fetal risk was lower.

After discharge, SB was readmitted several weeks later with painful recurrence of her cancer. She became increasingly ill while her tumor enlarged, bringing her to the brink of respiratory failure from extrinsic airway compression. Because of associated metabolic problems, sepsis, and pain medication, SB lost capacity. She was now 27 weeks pregnant with a viable fetus. The pulmonologist wanted to intubate SB, but her mother refused consent based on her daughter's living will. A stat ethics consult was called.

Options included a) immediate delivery without intubating SB and b) intubating SB to maximize the chance of a good fetal outcome, with a plan to honor SB's living will post-delivery. We present an analysis that will help ethics consultants/committees address this new kind of maternal fetal conflict.

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Rethinking the notion of risk in social science and humanities research

Currently, the notion of risk in all types of research has been measured using the same "yardstick". Risk in clinical research is assessed using the same conceptual measure as risk in social science and humanities research. According to the Tri Council Policy Statement, research is deemed to be either less than or more than minimal risk, although there is a proposal to update this classification to reflect a broader, more flexible approach to risk.

When assessing research for risks, Research Ethics Boards use guidelines that incorporate principles founded in relevant historical documents such as the Nuremberg Code, the Declaration of Helsinki. Each of these documents, in turn, were created out of commitment to protecting human participants in research and were reactionary, in part, to atrocities in medical research such as those uncovered from the Nazi regime and the Tuskegee Syphilis Study.

While the notion of risk has been adapted from a primarily clinical model to social science research, research in the humanities and social sciences has become highly diversified and sophisticated. It is no longer adequate to think about risk in terms that are derived primarily from clinical and medical research as this approach fails to capture important potential risks within non-clinical research. Instead, I propose that we create an entirely different "yardstick" with which to measure and think about risk in the social sciences, with an attempt to incorporate some of the unique and highly diverse potential risks inherent in social science research.

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Analysis of the Decision-Making Process in Stem Cell Transplantation – Empirical Findings and Ethical Implications

Because of the life-threatening and complex situation, decision-making on allogeneic stem cell transplantation (SCT) is a very challenging process. Despite the difficulties encountered by the professionals in the clinical setting, there is a lack of specific studies in this area. The aim of the presented study was 1) to retrospectively analyze the decision-making process of patients with malignant hematological disorders and 2) to reconsider the ethical paradigm of patient autonomy based on our empirical findings.

We conducted 18 qualitative interviews with patients suffering from different forms of malignant hematological disorders. All except one underwent SCT. The patients were asked to retrospectively explore the most important aspects and contents of their decision-making process, before undergoing SCT.

In contemporary medicine as well as in medical ethics patient autonomy is a fundamental and indispensable moral principle. Informed consent is the legal process to promote patient autonomy. Within this process the patient is being extensively informed about a pending treatment. Ideally the patient then makes a free and uncoerced decision about further treatment which is consistent with his values and life's plan.

For patients with malignant hematological disorders, SCT is often the only remaining life-saving treatment option. In such a life-threatening situation the patient's ability to meet the normative claim on autonomy seems to be restricted. Here, the health care professionals involved are required to go beyond the respect for patient autonomy and to integrate further ethical aspects in the decision-making process.

Based on the empirical findings from the conducted patient interviews, we will try to provide a moral framework for the decision-making process in SCT in order to achieve a set of structures and guidelines, so that the decision-making process will lead to an adequate, individually appropriate treatment decision for these highly vulnerable patients.

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Researching Polymorphisms in Indigenous Populations: Developing New Ethical Guidelines Encouraging Greater Scientific Responsibility in Research Design and the Dissemination of Results

This presentation outlines research undertaken for the Human Genome Research Project (NZ). The multidisciplinary, international research project is led by the Faculty of Law, University of Otago, with funds provided by the New Zealand Law Foundation.

One unifying factor of the over 300 million indigenous people around the world is that they suffer greater disease burdens than their non-indigenous counterparts. One response to these statistics has been to identify genes that might influence these greater disease burdens, with particular emphasis being placed on the role of polymorphisms. This presentation will outline how research into polymorphisms in indigenous populations can raise unique and significant ethical concerns. To illustrate the point, the presentation will map the path of a recent controversy that unfolded in New Zealand when a well respected research team used stored tissue samples to identify what was described as genetic determinants for a range of 'antisocial disorders' such as criminality, gambling, violent behaviour, and alcoholism among Māori (the indigenous population of New Zealand). The discovery was dubbed the 'warrior allele', and the researchers were widely criticised by Māori observers as hiding behind a 'vener of supposedly "objective" western science' used to perpetuate 'racist and oppressive discourses'. As a result of the controversy, genetic research on Māori has fallen under heightened scrutiny in New Zealand. A major report on the ethics of conducting genetic research on indigenous populations in general (and Māori in particular) was recently released by the Human Genome Research Project at which the presenter is based. The presentation will outline the findings of the report, and examine new ethical guidelines currently under discussion in New Zealand to oversee genetic research on Māori to prevent further controversies of this kind developing in the future.

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Sharing Responsibility for At-Risk Children & Youth: Finding Morally Credible Solutions Within Constrained Services

*This paper will present key findings arising from my doctoral research.

Determining level of risk and need for hospitalization in children and adolescents presenting to hospital with psychiatric emergencies is an important, yet challenging task for crisis workers. Decisions are often made in high-risk situations with conflicting tensions and competing notions of what is good to do. To better understand how clinicians act for the "good" of these patients, narrative stories of clinical situations were gathered through small group interviews with crisis workers from three urban hospitals. These stories were analyzed using interpretive phenomenological methods. By virtue of their close proximity to patients and families, crisis workers typically had the most intimate knowledge about patient needs, but they did not hold the authority to make the final decision about how to act. Instead, crisis workers discussed their recommendations with a physician, who made the final decision. While crisis workers were typically drawn to respond to these vulnerable patients in helpful ways, they could not always act in the ways they deemed to be most helpful. Their actions were affected by how roles and responsibilities are structured in hospital-based crisis services, and by available resources. Issues such as bed availability, scarcity of outpatient services, fears of litigation and differences of opinion about risk influenced what decisions were made. When the decisions did not match the crisis workers' notion of what was good to do, crisis workers attempted to compensate by finding "morally credible solutions" within the given circumstances and available resources.

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Ethics Programs in the Era of LHINs: Planning for Success

The introduction and integration of Ethics Programs into health care organizations, community hospitals, long term care facilities and community care providers is now an everyday occurrence. Integration is the foundation of sustainability for these programs and so their activities focus on outreach and collaboration in support of excellent patient care (i.e., safe, effective and patient-centred), and support for staff and organizational activity directed to initiation and maintenance of a thriving moral community.

With the introduction of a new regional framework for delivery of healthcare services in Ontario - Local Health Integrated Networks (LHINs) - the Ministry of Health and Long Term Care (MOHLTC) has demonstrated its interest in enabling health service integration through a focused rationalization of resources within regions; the end goal being to "ease the movement of people across the continuum of care so that they get the best care, in the most appropriate setting, when they need it." The secondary objective is not only less duplication, but decentralizing some services from their concentration in acute care centres to community-based settings so that the accountability is more broadly shared between large acute care centres and primary care community-based resources. While consonant in language with the goals of institutional Ethics Programs - integrated, patient-centred care - the LHIN initiative does present challenging opportunities for delivery of Ethics Program services throughout the province. One challenge will be to rethink clinical bioethics as an institutional resource focused on ethical issues in the provision of acute care services, to one that is a community-focused service providing support to patients, families and clinicians on ethics-related issues across the broad continuum of care.

To meet these challenges and provide a positive contribution within the LHINs context, those attempting to develop Ethics Programs must begin by developing a firm theoretical foundation re: mission, strategic priorities, objectives, and 'success factors', etc., as the platform for their work. They must give also careful attention to the different communities within their LHIN (e.g., demographic, cultural, geographic, organizational) in development of a model of service provision that is suitable to the particular needs of these groups and mindful of the emphasis on integration and continuum of care. Questions of *core competence in ethics for health care professionals, sustainable and accountable programming*, as well as *available education resources* must all be considered. Certainly, matters appropriate to ethics activity itself must also be addressed, e.g., core principles and decision-making frameworks suitable in the local LHIN environment.

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Being Kind Is Its Own Reward: Anonymous Living Organ Donation

In Canada, the demand for organs from deceased donors is greater than the supply available for transplantation. Many people die on transplant waiting lists. Organ donation from living donors is a viable, effective alternative for those needing kidneys and livers. Most systems that use living donations limit the procedure to donors and recipients with a prior familial or emotional relationship.

Anonymous living donation (ALD) is a donation of a kidney or liver lobe from a living person who has no prior relationship with the recipient. Altruism motivates the anonymous donor on the understanding that his organ is distributed according to standard allocation procedures, which reflect justice and utility.

ALD should balance the medical practitioner's duty of nonmaleficence and the autonomy of the potential donor. Some argue that ALD provides the donor with little benefit and thus, cannot justify the potential harm to the donor. This argument fails to acknowledge the moral virtue of altruism, which raises the question of whether humans can or should act altruistically. We hold that, practically speaking, altruistic acts are possible, while conceding that debates regarding psychological and ethical egoism versus altruism remain difficult to mitigate. In practice, if the donor provides free and informed consent, then ALD is morally acceptable. Fulfilling informed consent for ALD requires psychological evaluation to establish that the donor is acting voluntarily. If informed consent is valid, ALD promotes the donor's autonomy and acts as an important source of life saving kidneys and liver lobes.

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Withholding and Withdrawing Life-sustaining Care in a Rehabilitation Centre

When individuals with high lesion quadriplegia in a rehabilitation centre request to discontinue ventilation or decline all food in order to die, what response should the rehabilitation team and centre have? Rehabilitation clients with spinal cord injuries are not ill, much less terminally ill, but rather are disabled with many potential years of life ahead of them, and rehabilitation's purpose is to affirm life's possibilities. In light of this, should we understand and act on these clients' choices using the autonomy-driven acute care model of bioethics and the law, or might there be another and better way to approach them?

This is the main question we will pursue, and we will do so by considering two cases that occurred in a centre in Vancouver, where the clients made exactly the above requests. These cases raised many questions and concerns from both staff and the disability community. Does the law allow for such withholding or withdrawing of life-sustaining care? Do the clients really understand the nature and consequences of their decisions, and are they free of depression? What kind of message would honouring their requests send? We will examine these and other questions as they in fact arose, and unfold our recommendations about the management of such clients by following the stories of our two clients and the responses that their requests provoked.

Participants should emerge from this interactive workshop with a better understanding of the law, assessing decision-making capability, the special situation of rehabilitation clients, and the role of a rehabilitation centre.

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**Ethical Dilemmas and Expert Medical Evidence in the Criminal Justice System:
The Case for Sexual Assault Nurse Examiners**

Despite the traumatic impact of sexual assault, up to 90 percent of victims – mostly women – do not report the assault to police. The justice system is often faulted for inadequate sensitivity to the victims. However, the introduction of specially trained sexual assault nurse examiners (SANEs) in emergency rooms and treatment centres are a welcome change in the assessment and treatment of victims. It is argued the SANE model of care provides superior victim services along with improved prosecutorial outcomes.

This paper addresses two topics: (1) the role of SANEs within Canadian health care and the criminal justice systems; in particular SANEs as expert witnesses; and (2) the push in some arenas to conduct full forensic screenings of victims even without the victims' consent. The authors outline the case for qualifying SANEs as expert witnesses and explore a recent Ontario Superior Court case where a SANE was refused qualification as an expert witness.

Advances in forensic science and evidence gathering are playing an increasing role within the criminal justice system. This however raises critical questions about consent, autonomy and justice. We explore the medico-legal / ethical-legal implications of taking a complete medical history as the standard of care in sexual assault treatment and whether a Crown protocol for universal completion of all Sexual Assault Evidence Kit elements is ethical, regardless of the history of the assault.

Keywords:

Sexual assault nurse examiner, rape, medical evidence, forensic evidence, medico-legal findings, legal outcome, ethics.

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Innovating a Process for Innovations in Patient Care

Health Care institutions recognize that innovation is essential to ongoing improvements in quality of care. Even when innovation does not fulfill criteria of formal research, it should still meet standards grounded in principles of accountability before being introduced in the clinical setting. Introducing innovative procedures and treatments may:

1. pose additional layers of risk to patients and staff,
2. have significant organizational impact, and
3. draw resources away from other ongoing or potential initiatives.

This potential impact must be considered, prepared for, and consented to in an approved and transparent process.

A surgical innovation policy was first implemented at the Hospital for Sick Children in Toronto in 2003. In November, 2006, this original policy was redeveloped into a hospital-wide innovation policy, operationalizing a combined commitment to innovation facilitation and accountability. The authors will present and facilitate discussion on the following:

1. the importance of innovation, and how it can differ from formal research
2. how ethics and law matter in relation to clinical innovation
3. the development of an innovation policy with a Department of Surgery
4. a formal evaluation of the policy one year of use
5. expanding the scope of an innovation policy to innovative clinical procedures and treatments across a hospital
6. lessons learned from bringing a hospital-wide innovation policy through a Medical Advisory Committee approval process
7. other potential good practices that attempt to meet accountability principles while facilitating innovation.

**ABSTRACTS:
Poster
Presentations**



**RÉSUMÉS:
Présentations
par affiche**

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Resolving Conflict through Bioethics Mediation

Introduction: While consensus has been developed regarding many ethical issues, conflict has become increasingly problematic for hospitals.

Initiative: To address this problem, we redesigned the ethics consultation process at a tertiary care, children's hospital to incorporate mediation. Mediation emphasizes shared decision making which seeks to accommodate all parties' interests. Rather than a full committee, the revised process utilizes co-consultants who collectively possess formal mediation and bioethics training. After obtaining background information, the consultants facilitate a group process whose outcome is bounded by ethical and legal norms.

Results: The redesigned consultation service has been in operation for twelve months and has conducted fourteen consultations. One exemplary case involved staff concern that parents' request for a do-not-resuscitate order for their daughter with Down syndrome was discriminatory. Rather than retiring to deliberate and later conveying a recommendation to the attending physician, the consultants helped the parties construct a treatment plan that they all agreed with. This permitted a more determinative outcome than narrowly recommending that the parents' request was not immoral. All consultations have been resolved within the process and have not required further administrative intervention.

Future of the Initiative: Given this initial success, the next steps are to make the service more widely known and to conduct a formal evaluation.

Key Lessons Learned: Conflict has been more effectively addressed through the incorporation of mediation into ethics consultation. Mediation is an established technique with a variety of training programs and, therefore, other institutions can acquire these skills and implement similar programs.

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Trainee Selection for Research Bioethics Training in a Developing Country (Bangladesh)

The paper describes procedures for selection of trainees for a short non-degree Certificate Course on Research Bioethics with 10- weeks duration under a training program sponsored by the Fogarty International Center of the National Institutes of Health, USA. The Courses were conducted in Dhaka, Bangladesh during 2003-2006 by the Bangladesh Medical Research Council. The mentioned program being first of its kind and the only available training in bioethics, generated wide interest amongst multidisciplinary professionals in the country. High number of applicants against limited number of opportunities to attend the Courses warranted for development of a method for trainee selection following ethical standard. With this aim in mind a method was developed, tested and found reasonably useful for selection of appropriate trainees. The selection method consisted of 3 major steps and utilized a newly developed rating Instrument containing 8 criteria with total score 40. This Instrument occupied central position in selection of the trainees. The paper highlights major steps for trainee selection and provides comprehensive description of the whole Instrument. The Instrument was quite helpful in selection of trainees for the Certificate Courses on Research Bioethics. Using the Instrument total 120 trainees were selected for 6 Courses from 224 applicants. The Instrument played proactive role for exercising justice and was appreciated by the applicants, trainees and administrative authority. We recommend this Instrument (with due adaptation) for trainee selection specially in developing countries where ethics matters in selection of trainees.

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Experiences of genetic discrimination among presymptomatic Huntington disease mutation carriers

Despite the fact that it has been 20 years since the inception of predictive testing for Huntington disease (HD), the social implications of knowing one's disease risk for HD have not been fully investigated. Genetic discrimination has been identified as a risk associated with predictive testing. Genetic discrimination (GD) refers to the differential treatment of individuals or their family members based on actual or presumed genetic differences as opposed to physical characteristics. Although anecdotal reports of GD suggest it occurs in Australia, the United States and the United Kingdom, considerable debate still exists regarding the nature and frequency of GD. The purpose of this study was to describe individuals' perceptions and experiences of GD in insurance, employment, social and family settings. Semi-structured interviews were conducted with 37 presymptomatic individuals with a positive predictive test for HD. These data were analyzed using grounded theory methods. The findings describe how individuals managed the risk and experience of GD. Important dimensions of this experience included: interpreting the meaning of GD, determining its personal significance and employing strategies to manage the risk and experience of GD. Four types of 'strategies' were reflected in the accounts of these participants, and included *keeping low*, *preempting GD*, *confronting GD* and *disregarding GD*. These results help identify areas where more education and support is needed and may provide direction to counselors supporting their clients as they grapple with issues of GD and genetic testing.

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Cesarean Section: Jewish Ethical Requirements

Pregnant women may be faced with the decision to undergo a Cesarean section to save the life of the fetus. Conflict can ensue when a woman's desires differ from the obstetrician's recommendations. I intend to explore what Judaism requires morally of pregnant women in this situation when their lives are not threatened by having the Cesarean section and how this contrasts with legal, professional, and Catholic views.

What is required morally in this situation can vary between Orthodox, Conservative, and Reform branches of Judaism. All three branches hold that the fetus is not yet a person with rights equal to the mother. All branches agree that abortion is permissible to save the mother's life. However, some very conservative Jewish writers feel that a fetus does have a right to life when the mother's life is not endangered. The branches will differ on the role of halakhah, autonomy, and ownership of one's body. Differences can also be seen as to the role the Jewish teachings of the obligation to heal and seek medical treatment, the mitzvah to have children, and love of neighbor have in this situation.

Courts have ruled that women can refuse the surgery based on the rights of bodily integrity, due process, and liberty. Medical organizations feel women can refuse based on autonomy and right to self-determination. Catholic moral teaching holds that the fetus has rights equal to the mother, morally obligating women to undergo a Cesarean section. How these views compare to Jewish teachings will be discussed.

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Dignifying Canadian Biomedical Policy

Concern for human dignity is a core component of health policy in areas as diverse as research involving humans, assisted reproduction, stem cell research, and end of life care. At a minimum, dignity affirms the intrinsic worth of persons and should be specified as the principle that one should never treat another person merely as a means to an end. Beyond the general principle, there is little consensus on how dignity should be applied in specific contexts. Indeed, there have been repeated demands to greatly circumscribe its use in health policy if not abandon it altogether because of its apparent "uselessness" (Macklin 2003) but also because it has been used too well by social and religious conservatives.

In this presentation, I will elucidate how dignity should be applied in health policy, focusing on the need to balance substantive principles (such as non-commercialization of human tissues) with procedural guidelines that allow us to see how dignity should be interpreted in various contexts. I do so by contrasting effective applications of the principle of respect for dignity in the *Tri-Council Policy Statement* with what appear to be merely "aspirational" (i.e., vague and minimalist) references, e.g., in the *Assisted Human Reproduction Act* and the *2006 CIHR Updated Guidelines for Human Pluripotent Stem Cell Research*.

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Teaching and Assessing Professionalism and Ethics in an Undergraduate Medical Program

Recent societal demand for greater professional accountability has led to a renewed focus on professionalism in medical education. Most medical schools have responded by introducing new courses or themes in professionalism and ethics. The purpose of this paper is to describe the integrated Professionalism and Ethics Curricular Themes in the widely distributed UBC Medical Undergraduate program and to discuss the associated challenges.

We define professionalism as conduct that adheres to the behavioral standards of the profession. In our program, behavioral competencies are categorized as: 1) Ethical-Legal Competency and Accountability, 2) Reliability and Honesty, 3) Self Assessment and Initiative, 4) Communication, Respect and Compassion, 5) Collaboration and Teamwork, and 6) Health Advocacy and Social-Cultural Understanding.

Specific defined competencies are assessed as students progress from the highly structured and supervised Pre Clerkship training to the clinical contexts and increased independence of Clinical Clerkship. In the Pre Clerkship years, these competencies are taught through plenary sessions, tutorials, projects, essays, journaling and doctor's office visits. They are assessed by tutors, preceptors and peers. In the clerkship years integrated competencies are taught and regularly assessed by preceptors in clinics, clinical teaching units and in a professional development review course. This paper will review the organizational structure, curricular content, instructional and assessment methods, tutor/preceptor training, remediation processes, and web site of the Themes.

The discussion will address the challenges of providing the students with consistent instruction, assessment, and remediation for professionalism and ethics in the context of a widely distributed educational program with diverse elements.

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Development of Donation after Cardiac Death Policy, Essential Involvement of the Institutional Ethics Committee

Organ donation has become very technologically advanced and more and more important to life prolongation. Government has documented an ongoing shortage of available organs and eligible donors. Agencies for accreditation of healthcare institutions have created higher standards of organ procurement goals. Organ donation involves many ethical issues. Donation after cardiac death (DCD), has become more prevalent at many institutions and adds to the complexity of ethical issue relating to organ donation, yet offers many more families the opportunity to bring some good out of a tragedy. DCD is an option for families of patients with severe neurological injury, but who do not meet criteria for brain death. After several families at our institution requested organ donation for their family member who was not yet brain dead, our ethics committee began the exploration of a policy.

First we reviewed several articles on DCD and several policies from other institutions in our area, obtained through their ethics committee. We then established a hospital-wide committee of hospital leaders involved in organ donation, chaired by a member of our ethics committee. A policy was written and distributed. Multiple educational sessions were held by ethics committee in support of policy. Multiple ethical issues were addressed by ethics committee. Final draft was then presented to all physicians in large forum with opportunity for questions. Ultimately policy was supported hospital wide.

This process identifies how instrumental an ethics committee can be to healthcare across an entire institution and ultimately to the individual patient and family.

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The Effect of the Routinization of Medical Care on Patients Informed Consent

This is a presentation of the empirical findings of research that examines a prenatal screening test, the Quad screen, and patient's informed consent. The Quad screen serves as an example of a type of medical care or procedure that has become part of standard and routine medical care. Technological advances, and in particular genetic testing, allow many medical procedures to be performed that are minimally invasive and involve little or no medical risk to the patient. It is these very characteristics that contribute to these types of medical care becoming standard and routine practice. This leaves open the question of what happens to informed consent under these conditions.

This research uses survey methods to measure the characteristics of routinized medical care and the constructs of patient informed consent. The populations surveyed are obstetricians and patients seeking prenatal care. The sample is from 10 obstetrics clinics in a large metro area. The dependent variables in the model are the major constructs of patient informed consent as defined by Beauchamp and Faden; understanding, intentionality and freedom from controlling influence. The major constructs of informed consent have been operationalized and survey items developed to measure the quality of informed consent a patient may give for the Quad screen.

Latent variable analysis and hierarchical linear modeling is used for the analysis of the data. Results provide an empirical model of the relationship between the routinization of the Quad screen and the quality of informed consent a patient may give for the screen.

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Approche éthique des stratégies décisionnelles dans une situation d'incertitude et d'urgence d'accident vasculaire cérébral grave

L'occlusion du tronc basilaire est une pathologie rare dont le pronostic difficile à déterminer est souvent catastrophique conduisant au redoutable *locked-in syndrome*. En l'absence de recommandations consensuelles et au regard de la gravité potentielle, il est habituel de proposer un traitement invasif endovasculaire soit selon une procédure écrite locale soit en évaluant au cas par cas le rapport bénéfice-risque du traitement. Cette décision qui se déploie sur un fond d'incertitude est particulièrement difficile.

Méthodes

L'objectif de ce travail était d'évaluer à l'aide de 3 questionnaires écrits, les aspects organisationnels du service (questionnaire Q1), les stratégies décisionnelles (Q2) et les points de vue et difficultés rencontrées dans cette prise en charge délicate (Q3), chez les neurologues vasculaires français.

Sur 66 unités neurovasculaires contactées, 51 ont répondu et 47 ont accepté de participer à l'étude. Nous avons reçu 37 questionnaires Q1 venant des responsables d'unité et 102 Q2 et Q3 de médecins seniors travaillant dans 38 centres.

Résultats

La décision est prise au cas par cas par 82% des médecins. Les autres utilisent une procédure écrite. La décision est ressentie comme difficile pour 85% d'entre eux et stressante pour 75%. La difficulté est rapportée plutôt au manque de connaissances par les médecins hommes et au risque de handicap par les médecins femmes. Malgré la diversité des pratiques 85% des médecins fixent des limites et ont recours à la collégialité pour décider. Nous discuterons à partir des résultats de cette enquête de l'approche éthique de la décision dans un contexte d'incertitude et d'urgence.

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Clinical Ethics Consultation Relevant to Cardiovascular Surgery: A Turkish Experience in Istanbul

A male patient who was 35 years of age, had admitted to the Department of Cardiovascular Surgery in one of the biggest University Hospitals in Istanbul. His family has applied to the Department of Medical Ethics for ethics consultation.

He was shut below the retropopliteal region of his right leg. A deep venous wounding had occurred. Consequently, the case with a very serious local circulation problem needed a long lasting treatment protocol with possible repetitive operations and a treatment protocol that is very expensive. After the operations, he would need open wound treatment protocol together with plastic surgeons.

The patient does not have any kind of health insurance. He was a gold merchant and he bankrupted. He lost his health insurance (Bag Kur) with the bankruptcy. Since he could not finalize his procedure through the Chamber of Commerce, he could not take advantage of 'Green Card' of poor people.

As regards to medical indications, cure rate of the leg if treated for 3-4 months (back to the normal functioning), was proposed to be over fifty percent. If the expenses were not compensated, amputation would be proposed.

We had a meeting with the responsible physician, and then we applied to administrative office of the hospital and we got 50% discount for the expenses of the treatment.

In this presentation, we will first briefly describe the process of clinical ethics consultations that is considerably new in Turkey. As regards to the case, we will discuss what happened at the end, the consequences of the evaluation of this case, process of clinical ethics consultation, failures and successes. The rationals and decision making process will be justified and compared to different options.

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Getting Ethics into Action. A practice based approach to implementing ethics into a healthcare organization

Creating time and space for ethical reflection in health care organizations often is very difficult. Adding to this difficulty is the fact that suggestions for programs of ethics often are highly theoretical and only loosely connect to the lived practice. As a result ethical consultation is mistakenly seen as something that can be added to the practice instead of morality, and thus reflection on morality, being an integral part of the practice.

We designed a course in which an ethics program is developed in collaboration with an ethical 'steering group'. Members of the 'steering group' join in a research in which they reflect on questions as what ethics can be, what kind of ethics is appropriate for their organization and what possibilities there are for doing ethical reflection in daily practice. The outcomes of these reflections are translated into a plan of (ethical) activity that is both visionary and highly practical. This plan is then executed in the organization.

The course is a practical elaboration of the idea proposed by Walker (1999) in which she argued for the construction of 'a moral space' in organizations. Walker holds the ethical committee responsible for constructing and maintaining that space, while ethical reflection should be done by every person that takes part in practice.

This paper sketches the theoretical background of the course. We also present the outcomes of several running and completed courses and reflect on the effectiveness of the course as a tool to construct a durable moral space in a healthcare organization.

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Sedation in Palliative Medicine

Background: A major goal of palliative medicine is to achieve optimal control of symptoms and pain for the improvement of quality of life under the given conditions. In this context, the physician can be faced with the choice of palliative/ terminal sedation if the patient presents with symptoms like intolerable pain, extreme shortness of breath or existential suffering.

Methods: We investigated the current state-of-the-art of palliative sedation using scientific, political and ethical criteria prevalent in Europe and present the procedure used in our own hospice and hospital nowadays.

Conclusions: Palliative sedation is a procedure of last resort. The indication requires the consent of the patient or of the surrogate decision maker. The indication must be well documented and rational. Palliative sedation enables the patient to have a dignified death. Palliative sedation is clearly differentiated from euthanasia. Palliative sedation can be part of a good care giving for dying patients. It is not a service instrument for inconvenience at the end of life. It is not to be used as a procedure to simplify care giving. The goal of palliative sedation is solely the control of symptoms, to give the patient relief of unbearable suffering.

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The relationships of moral distress, ethical climate, and intent to turnover among critical care nurses

The term "Moral Distress" is defined as the experience of knowing the right thing to do, but being constrained by forces that make it nearly impossible to pursue the right course of action. Moral distress has been anecdotally associated with professional burnout and leaving a position in nursing or the profession itself. The experience of moral distress should be explored in order to understand shortages in the workforce. Ethical climate is an organizational variable which consists of perceptions of practices and conditions within the work environment that facilitate the discussion and resolution of difficult patient care issues and support ethical decision-making in the clinical setting. Intent to turnover is a variable which measures an individual's likelihood of leaving a job. A descriptive, correlational study of moral distress, perception of ethical climate and intent to turnover was done using three Likert-type tools and a demographic data form. The purpose of this study was to explore relationships between moral distress, likelihood of leaving a position and the moderating effects the ethical climate of the work environment. A sample of 100 critical care staff nurses from 2 tertiary care health care institutions in a major metropolitan area revealed several significant findings. Responses were analyzed using descriptive, correlational, regression and path analysis statistics. Information on environmental factors demonstrated that relationships with peers and managers as well as a feeling of competence in one's nursing skills moderated moral distress that was positively correlated with intent to turnover.

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**« Quelle utilité de l'éthique clinique pour l'évaluation des pratiques ? »
Réflexions à partir d'une étude des déterminants éthiques dans la prise en charge du cancer colorectal chez les patients âgés.**

En réponse aux équipes hospitalières préoccupées par une situation récurrente dans leur pratique vis à vis de laquelle elles ne sont pas au clair sur le plan éthique, le Centre d'éthique clinique de l'hôpital Cochin (Assistance Publique-Hôpitaux de Paris, France) met régulièrement en place des études dites de recherche. C'est le cas à propos des cancers colorectaux chez les personnes âgées chez qui on suspecte que les protocoles standardisés de prise en charge sont moins bien appliqués que chez les patients plus jeunes. Plutôt que de considérer rapidement que cette pratique est inéthiques au regard du principe d'égalité de tous à l'accès aux soins, l'objectif de l'étude, associant le Centre d'éthique clinique et les services en charge de ces patients (gastro-entérologie, oncologie, chirurgie digestive, gériatrie), est de mieux comprendre les motifs de ces écarts.

Seront présentés le protocole et ses premiers enseignements après un an de pratique, ainsi qu'une lecture critique de la méthode employée. Quelles sont les limites liées à cette méthode au regard des objectifs poursuivis ? Et du reste quels sont précisément ces objectifs ? Ne s'agit-il que de clarifier les arguments qui fondent la décision ou la méthode permet-elle aussi de mieux assurer le respect des différentes valeurs individuelles engagées ? S'agit-il de mettre en lumière des pratiques éventuellement discutables au plan éthique dans le but d'en débattre, voire de favoriser un changement des comportements ? Le caractère observationnel de l'étude permet-il de répondre à nos attentes ?

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The Dilemma of Consent giving in Clinical Drug Trial in Zambia: A Conflict between Rights and Culture

Some health related studies are undertaken without any form of ethical review, although in almost all studies involving human subjects, there is always a stress on safeguarding the individual rights. How the implementers approach the individual participants, the interpretations and procedures as well as implementation of the policy regarding consent require some attention. The Ndola Demonstration Project (NDP) had revealed that Mother and Child Health (MCH) services were the best organs that targeted women in reproductive age with HIV interventions, as the majority of them visited these health facilities. We argue that in the current era of globalized health care research, good ethical issues must be upheld, irrespective of the community's level of development. Some reasons behind consenting to or not to participate in any drug trial may be socially, culturally or economically driven. These reasons may be at individual level, couple's level and family or community level. Consent is a highly complex tool which is significant in any biomedical research. Apart from linking individuals to each other, it protects the dignity, integrity and safety of participants in the research. If used properly, it allows for the success of the research or intervention and therefore winning the support of the eventual beneficiaries. The refusal to consent participation in one of our study, was culturally and religiously driven on one hand, and also stepped on the rights of pilot members on the other. This paper explains how and why ethics matters in a cultural setting in Zambia.

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Fair allocation of health resources: a qualitative investigation of responses to a quantitative survey

Surveys are often used to elicit public opinions, values and preferences. Economists have used surveys to discern values concerning end-state distributional equity, by presenting a simple resource allocation dilemma and asking respondents to choose a fair allocation. Each choice is consistent with a specific principle (utilitarian, egalitarian, maximin, etc.), and respondents' choices are interpreted as evidence of commitments to these broader principles. Because simple surveys can be administered easily to a great number of people, they are potentially useful for generating empirical information on public values. An obvious drawback of surveys is that they are reductive. The analysis of survey data requires an interpretive leap from what people chose to why they chose it, as well as from values salient in a contrived research context to values salient in the policy world where allocations are made.

Such a survey is underway to understand Canadian values with regard to the just allocation of health resources. In this presentation, we report findings from a collateral qualitative investigation of how survey participants formulate and explain their responses to simple resource allocation dilemmas. We interviewed 39 survey respondents and used modified grounded theory methods to identify themes in the reasoning, imagery, and concepts of fairness respondents applied to judge the justice of health resource allocations. The values at play behind respondents' choices did not always correspond to the principles researchers intended the choices to represent. Respondents identified a wide range of issues they would consider in formulating a just distribution of health resources.

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Can an Ethics Committee Contribute to Reducing Bureaucracy in Managed Care?

Maccabi Healthcare Services is a large HMO in Israel. The CEO initiated the formation of a multidisciplinary ethics committee to assist the senior management in dealing with ethical aspects pertaining to policy issues. Increasing bureaucracy within the institution had become one of the major problem areas requiring a strategic intervention. The EC studied this problem from an ethical viewpoint. Questions raised included: The relationship between administrative and ethical issues; The relevant ethical values of the institution; and How can administrative demands be assessed using ethical standards.

Following initial discussions, the committee defined the differences between essential and non-essential bureaucracy in ethical terms. According to this definition, any activity that does not serve the ethical values of the organization is unnecessary, and any activity that contradicts these values is unethical. In some administrative issues there is an intrinsic conflict – which creates an ethical dilemma - between the organizational need and the ethical interests of those affected by the relevant policy. Such issues frequently have medical aspects, such as the use of generic drugs or the limitation of access to certain providers. Discussion of the abovementioned topics within the EC is aimed to apply ethical thinking at all levels of decision making within the organization.. The use of an ethical decision making flow chart developed by the EC may result in a measurable reduction in unnecessary administrative demands.

The CEO has initiated a sample study of the application of the formula suggested by the EC for the assessment of administrative orders, as part of a strategic plan for reducing bureaucracy.

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Dying from respiratory disease: Constructed reality and the interpretive repertoires of ICU nurses

Given that at least half of all patients with a chronic disease are cared for in an intensive care unit (ICU) within three days of their deaths, there is an urgent need to examine issues related to end of life care for this population. The ethical imperative to create a more inclusive and holistic paradigm of end of life care, one which extends far beyond the walls of the palliative care unit, will continue to intensify as demographics shift in the future. Greater understanding of the facilitators and barriers to providing high quality end of life care in the ICU will be instrumental in ensuring "a good death" in this setting for people with chronic illness.

As part of a larger project examining the quality of dying of people with chronic respiratory disease in ICUs, critical discourse analysis was used to analyze transcripts of three focus groups of front line nurses. Critical discursive theory focuses on what people say, how they say it and to what end the talk is used. This poster identifies the consistent patterns discursively constructed by participants about people dying with chronic respiratory disease in the ICU. Three primary interpretive repertoires of patients with COPD were identified from the discourse analysis: a) the passive COPD patient; b) the pragmatic COPD patient and c) the anxious COPD patient. The ethical implications of this constructed reality may affect nurses' attentiveness to emotional needs, consistency in care provision and emphasis on the curative nature of care.

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Does Ethics Education Influence the Use of Ethics Resources by Practicing Nurses and Social Workers?

Background and purpose: Social workers and nurses in the U.S. today face many ethical challenges in practice. Ethics education and training may provide needed confidence to take appropriate moral action and make use of available ethics resources.

This study investigated the relationship between ethics education and training of nurses and social workers and their use of ethics resources, as well as the perceived usefulness of these resources and reasons given for not using them.

Methods: A mailed survey of U.S. nurses and social workers from 4 states assessed ethics education, use of ethics resources, and perceived usefulness of ethics resources.

Findings: Among responding social workers and nurses, 14% reported having no ethics education (8% of social workers and 23% of nurses), and only 57% had ethics education in their professional educational program. For those whose organization provided ethics resources, the source of ethics education was related to their use of these resources. Those who never or rarely used ethics consultation were more likely to have had no ethics training (86%) than to have had ethics in their professional program (77%), in CE/in-service training (70%) or both (66%). Source of ethics education was not related to perceived usefulness of ethics services, but was related to reasons given for not using resources. Those with no ethics education were most likely to report that they were not qualified, lacked the authority, or found ethics consult services difficult to access.

Conclusion: Ethics education has a significant positive influence on the use of ethics resources by nurses and social workers.

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A Survey of the 'Ethics Climate' in Hong Kong Public Hospitals

To assess the "ethics climate" of Hong Kong public hospitals, the opinion of healthcare professionals (HCPs) including 532 doctors, 1,681 nurses, 394 paramedics and 111 administrative staff in 14 hospitals were surveyed. Ranked in decreasing order of importance, respondents' ethical concerns were: (1) communication and conflict between HCPs and patients/families, (2) respect for patients' rights and values, (3) informed consent, (4) patient confidentiality, (5) DNR orders, (6) end-of-life decisions and (7) inter-professional conflicts. All HCPs, except nurses, believed that both healthcare providers and patients perceive quality of patient care is satisfactory. Nurses assessed patients as demanding (72%) more than doctors (66%). All HCPs agreed that informed consent procedures are followed (70.9%) and patients' autonomy rights recognized (73.9%), but were unsure that patient's choices are always followed (54.9%), especially in treatment termination decisions of end-of-life patients (49.7%). Paternalistic practices are not uncommon (56.9%), and doctors sometimes yield to families who insist on futile treatments (60.7%). Tolerance of professional incompetence (46.3%) and unprofessional conducts (48.9%) are uncommon. Nurses agreed more than other HCPs that communication channels with peers and supervisors are inadequate, and inter-professional conflicts exist. Polarities in opinion between nurses and doctors were common, and they took extreme positions in opposition to each other in 36 ethical issues. Different ranks of doctors and nurses also had different ethical assessments, and nursing managers and senior nurses often held opinion closer to doctors and administrative staff than their junior colleagues, leaving junior nurses potentially isolated and demoralized. (Percentages represent mean degree of agreement.)

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Inclusivity and Engagement: Challenges in Using Theatre as Novel Method of Health Policy Development

Theatre has a long history of engaging the public in controversial moral, social, and political issues. Our CIHR/Health Canada funded study (2005) examined theatre as a method for public engagement in the development of policy on preimplantation genetic diagnosis (PGD). Sixteen performances of the play *Orchids* occurred in Vancouver, Toronto, and Montréal (in French, with collaborator Hubert Doucet), followed by post-performance discussions that elicited audience perspectives on the uses of PGD, and the effectiveness of theatre as a method of public engagement in policy development.

Methods of audience recruitment included invitations to stakeholder communities; posters placed in strategic locations; ads in community and entertainment papers; and a dedicated website. A total of 741 individuals attended *Orchids*, 373 participated in large-audience discussions, and 65 in focus groups. Over 75% of attendees were female, and there were many medical and academic professionals. Approximately 15% had a disability and/or inherited condition. Seventeen audience members and spouse/partners had undergone fertility treatment, and seven had a child as a result of IVF.

In this paper, we discuss some of the challenges we encountered in our efforts to engage large and diverse audiences in this novel approach to health policy development. Assessing audience demographics as well as the diversity of perspectives arising from post-performance discussions, we focus on the question of inclusivity as it relates to methodological and ethical questions (such as recruitment and representativeness). We also consider alternate strategies for maximizing inclusivity and audience engagement to be explored in our future projects.

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Moving Ethics Forward by Building Community Healthcare Capacity

Building a foundation for community-based ethics helps mobilizes the practice of ethics in organizations that would not normally have the internal capacity to develop an Ethics program, and helps foster dialogue where health care resources are limited.

The Sudbury-Manitoulin Ethics Network (SMEN) was established to serve as a District resource for health service providers, agencies and organizations when ethical issues arise. The Network has developed exemplary models for organizational and clinical ethics consultation in diverse healthcare settings. As of 2006, 17 community members of the SMEN, represent and have professional backgrounds which include, philosophy, nursing, theology, quality and risk, administration, and teaching. The mandate of SMEN is to foster an ethical climate and strengthen ethics capacity broadly throughout our organizations through collaboration, shared resources and support.

The Network has become a growing entity as others struggle to build ethics programs. In its short existence, many benefits have been accomplished. This poster will highlight outcomes achieved by the Network, since its inception and identify activities that the network has engaged in that promote education, organization resource, discussion and collaboration. The network has developed internal capacity and synergy by sharing monthly case studies. It has also produced a seven part ethics education videoconference series.

Establishing a community ethics network is a solution to advancing the ethical perspective. The primary ingredients needed are: a common sense of purpose; a sense of synergy; and a willingness to work hard. This is as a positive step in building and strengthening a moral community.

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Exploring Ethical Risk Communication in a Health Context

The practice of risk communication has undergone significant transformations since its inception in the mid 1970's. This paper organizes these developments into three main approaches that reflect other frequently cited chronological characterizations of the field's evolution (Fischhoff, 1998, Covello & Sandman, 2001, Sandman, 1991, Leiss, 1996). The first approach emphasizes expert characterizations of risk for "simple" risk problems (which I call expert driven RC), while the second emphasizes the psychological dimensions of risk for complex risk problems (which I call psychological RC). The third and youngest approach calls for substantial public input throughout the risk analysis process in response to risk problems that involve normative and interpretative ambiguity (which I call holistic RC). Each method has evolved over time in response to the changing nature of risk issues and lessons learned from the field. All are still actively used by ethical risk practitioners for pertinent risk problems.

The two main objectives of this paper are to (1) critically examine the three main approaches to risk communication, and in doing so, (2) help individuals to navigate ethical health risk communication. The practice of risk communication typically concentrates on environmental hazards (chemical plants, radon gas). However, lessons learned through these studies can also be applied to health topics like PGD or SARS through health risk communication (Ball, Evans, & Bostrom, 1998). Examples of health topics will be used throughout this discussion in order to clearly demonstrate these contributions.

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Congestive Heart Failure Offering Individualized Choice Evaluation Study (CHOICES)

End-stage heart failure shortens the duration of life and degrades its quality as shortness of breath, fatigue, and edema worsens. Treatments that extend survival time gain approval and acceptance more readily than those that improve quality of life. Our experience suggests that patients prefer options that improve quality while sacrificing quantity. We asked heart failure patients their preference among three treatment options: current optimal medical management - providing poor quality and limited quantity of life; oral inotropes - pills that improve quality while shortening quantity, as a result have not been made available to patients; and mechanical hearts - implantable devices that improve quality and extend quantity but require cardiac surgery. 92 patients with mild (n=49) and severe (n=43) heart failure completed a treatment preference tool; data were also collected on quality of life, severity of shortness of breath, fatigue, and overall health. Treatment preferences in rank order were: 1. oral inotropes, 2. mechanical heart, 3. medical management. Preferences were not associated with severity of heart failure. Younger patients were more likely to choose aggressive treatment with a mechanical heart. Heart failure patients prefer treatment options that improve quality over quantity of life. The finding of no difference between the mild and severe groups suggests treatment preferences can be decided early in the course of illness. These results cannot predict individual preferences, but should encourage clinicians to discuss treatment preferences with patients early in their course of illness to ensure that treatment goals are congruent with the preferences of patients.

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Implementation of an Ethics service in Mental Health and Addictions Services in the Calgary Health Region

The Calgary Health Region has the largest Mental Health and Addictions Services in Canada this includes area, population accessing the services; and in numbers of staff. Moreover, the demands on the system as a whole are increasing at high rate due to the population boom both in the city itself and in outlying rural areas. Although the mental health service was able access acute care bioethics committees, few acute care consults were requested. The community mental health components (by far the largest number of programs) were generally unaware of ethics services in healthcare. In October 2005, the Mental Health and Addictions executive management agreed to fund a six month pilot project to examine the need for an ethics service and to examine the educational requirements needed to raise ethical decision making capacity amongst staff in all programs and all disciplines. A survey was conducted and program and team focus groups were also held. All managers were interviewed separately. The survey results were informative but also alarming. The results were analyzed to produce a Top Ten List of ethical concerns in mental health. These top ten issues most likely could be extrapolated to other areas of healthcare. In September, 2006 a committee was formed. Membership was based on a modified Hub and Spoke model developed by the Toronto Centre for Bioethics. The committee was also selected individual's experience or education in bioethics, fifty percent of the committee are enrolled in a university level introduction to bioethics course organized, financed, and taught by the Provincial Health Ethics Network, Calgary Health Region's clinical Ethics Service. Examples of the consults so far are: stolen confidential information, use of a placebo in treatment, treatment of Persons with Developmental disabilities in a forensic setting, Public Guardianship, overruling a surrogate decision maker, rural mental health ethics.

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Outil méthodologique d'analyse des mécanismes décisionnels en éthique clinique : place des émotions

Nous présentons un outil méthodologique d'analyse des mécanismes décisionnels en éthique clinique. Il permet d'explorer le régime des justifications auxquelles recourt le praticien, sans en avoir une conscience explicite, en situation de décision difficile.

Il s'agit :

- de mettre en forme la dimension éthique de la décision au moyen de concepts organisateurs reconnus dans la littérature internationale: principe d'autonomie, principe de bienfaisance, principe de non-malfaisance ¹.
- de reprendre ces concepts sur la base d'une exploration des émotions dont nous considérons qu'elles sont indispensables à la prise de conscience de la dimension éthique de la décision ².

Ainsi nous pensons que les principes (qui définissent des valeurs universelles) sont révélés aux praticiens à travers certaines expériences émotionnelles privilégiées. Ce sont en particulier les émotions de respect, de compassion et de crainte. Ainsi la valeur qu'il accorde à chaque principe se révèle au soignant par le biais des émotions ressenties : l'émotion de respect réactive chez celui qui l'éprouve la valeur qu'il attache à l'autonomie, l'émotion de compassion, la valeur qu'il accorde à la bienfaisance, et l'émotion de crainte, la valeur qu'il attribue à la non-malfaisance.

Notre construction méthodologique peut se résumer par la série de questions suivantes :

- Quel était le contexte ?
- Quelles ont été les émotions ressenties ?
- Selon quel ordre les principes, auxquels de telles émotions nous ont rendu sensibles, ont-ils été hiérarchisés?
- Ce mode de hiérarchisation était-il ajusté au contexte ?
- Quels ont été les arguments avancés pour justifier la prédominance du principe retenu?

Nous proposerons un exemple d'analyse d'une décision difficile dans un contexte de diagnostic prénatal pour illustrer notre propos.

1. T.L Beauchamp et J. Childress. Principles of Biomedical Ethics, Oxford University Press, New-York/Oxford, 1994

2. Livet P., Emotions et rationalité morale, PUF, coll. « Sociologie », Paris, 2002.

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Revisiting Patients Responsibilities: The Other Side of Patients Rights

Health practitioners are constantly reminded of their duty to respect the rights of patients. Is it appropriate to ask the patient to fulfill certain responsibilities or expectations?

Many health care institutions have created documents outlining the rights of patients. A review of Patient Rights documents on the internet and amongst Joint Centre for Bioethics-affiliated institutions reveals that very few of these documents set out responsibilities or expectations of the patients and their families.

Patient rights have developed from the trust relationship between the patient and his or her health practitioner, and include the right to:

- be treated respectfully;
- be informed about treatment options, risk and benefits;
- make one's own treatment decisions;
- privacy and confidentiality of personal health information.

Is the other side of the coin patient responsibilities?

The author will review the origins of patient rights from ethical and legal principles, as well as explore events in North American history influencing patient rights. The relationship between patient and health practitioner has changed over the last few decades, from a more paternalistic model to an interactive model. Some authors suggest that adding a contract-like component to the interactive model could improve the relationship by making explicit the need for shared accountability between patient and health practitioner in regard to the patient's health care.

The author will also lead a discussion regarding the following issues:
is a patient able to fulfill expectations?
can a patient negotiate with equal power with the health practitioner?

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Using Technology & Partnerships to Enhance Ethics Knowledge & Build Ethics Capacity in Northern Ontario

The Sudbury Manitoulin Community Ethics Network launched a cost-effective educational videoconference series in October 2006, aimed at helping healthcare professionals working in large and small communities throughout Northern Ontario, to develop capacity and sustain knowledge in ethical decision-making. The "Healthcare Ethics Series" runs monthly using multi-point videoconferencing technology and connects hundreds of healthcare professionals in over 70 health care organizations across Northern Ontario. The series enables participants to identify, understand and make good ethical decisions about clinical and organizational issues and problems. Web-based video archives are also available via the internet and are being accessed by individuals and organizations across Canada.

The aims of the series included:
-reaching large and small organizations across the North to provide foundational Ethics knowledge
-reducing professional isolation and fostering dialogue
-enhancing clinical & managerial practice
-evaluating the use of multi-point video technology as a method of providing continuing Ethics Education.

This poster will highlight the lessons learned in using video technology to provide Ethics Education, and provide preliminary outcome data concerning reach, impact on professional isolation and practice change. The poster will also address the limitations of this approach to fostering dialogue and building capacity.

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Do-Not-Resuscitate Ordering Patterns Between Physician Specialties

BACKGROUND: In 1991, the Patient Self-Determination Act (PSDA) was created to ensure that health care institutions that received federal funding had to inform their patients (pts) about the right to refuse life sustaining care such as cardio-pulmonary resuscitation (CPR). We hypothesized that do-not-resuscitate (DNR) ordering patterns between physician specialties have not significantly changed since PSDA.

METHODS: A retrospective chart review was conducted on 286 of the 296 total adult deaths during 2005 at Indiana University Hospital. Pt information regarding age, sex, race, admitting diagnosis, cause of death, and discharging service was collected. Existence of pt's DNR order status, advance directives (AD), and type of discussions regarding the DNR order were also collected.

RESULTS: Among medicine pts, 77% had a DNR ordered during their terminal encounter vs. 64% of pts on surgical services. Physician specialty also had a significant impact on the average time between hospital admission and DNR order (11 days for internist vs. 21 days for surgeons). Documentation of discussions regarding DNR orders significantly impacted the frequency of DNR orders and the waiting time for DNR orders. Pt-dependent variables such as advance directives status, age, race, and gender had no significant impact on DNR ordering patterns.

DISCUSSION: The results of this study suggest that: 1) DNR ordering patterns are different between physician specialties, consistent with data that pre-dates PSDA; 2) documentation about DNR discussions is associated with increased frequency of DNR orders and decreased waiting times; and 3) pt-dependent variables had no significant impact on DNR ordering patterns.

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Is the global rationing debate a non-debate? Contesting some uncontested claims in the current health care rationing literature

During recent decade, the academic debate about finding ways to ration health care more efficiently and explicitly evolved rapidly. Although the explicit rationing experiments in Oregon and New Zealand had only limited success, many countries across the globe placed rationing firmly on their political agenda (Honigsbaum et al. 1997, Oberlander 2001, Ham & Robert 2003). In numerous academic conferences and publications regarding the subject, supposed gap between needs and resources leading inevitably for rationing care became soon taken as an axiomatic fact (e.g. Coast et al. 1996, Daniels & Sabin 1998, Butler 1999, Coultier & Ham 2000, Ubel 2000). Some critics did, however, try to point out that sheer questioning of this axiom should not e.g. lead to rejection of otherwise qualified epidemiological and other papers by scientific journals. In addition, critics claimed that the rationing debate consists largely of assertion and political analysis, but little empirical work. Certain idioms of rationing research, such as limitless demand for health services, were also challenged in articles and editorial letters (e.g. Smith et al. 2000, Frankel et al. 2000 and 2001, Loudon and Webster 2001). However, recent publications take inevitability of rationing as granted. Central theses of rationing proponents are currently almost universally accepted (Aaron et al. 2006). In my research I have systematically analyzed health care rationing literature in order to find out whether critics erred and this general acceptance is solidly grounded. My results show that certain problematic ideological factors, political viewpoints and non-scientific aspirations have shaped the rationing research.

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« **Implications éthiques des biotechnologies appliquées à l'agriculture. Analyse du discours de la presse écrite en Argentine** »

L'Argentine est un des trois premiers producteurs d'OGM au monde, avec les États-Unis et le Canada. Pourtant, ce qui est étonnant dans le cas de l'Argentine, c'est l'absence de dialogue public sur l'élaboration de normes socio-éthiques qui guideraient l'utilisation de ces produits. Cette étude s'intéresse particulièrement à la façon dont les questions socio-éthiques liées aux biotechnologies ont été abordées dans les médias écrits en Argentine dans les dernières années (1999 - 2006). En Argentine, comme ailleurs, les médias influencent l'opinion publique et agissent comme déclencheur du processus par lequel les individus appréhendent, modifient et articulent leurs perspectives idéologiques sur la réalité. En analysant les manifestations du discours portant sur les biotechnologies appliquées à l'agriculture, soit les idées qui y sont produites, reproduites et véhiculées par la presse, nous nous rapprochons des représentations sociales. Comment la dimension éthique s'est-elle manifestée dans le contenu de la presse ? Quels sont les sujets abordés, qui sont les acteurs mentionnés? Sont-ils les mêmes qu'au Canada, qu'en Europe et aux États-Unis? Y a-t-il un biais en faveur ou en défaveur des biotechnologies dans la presse ou toutes les positions sont-elles présentées? Cette recherche contribuera à mettre en évidence certaines tendances dans l'évolution du discours public. Quelles sont les biotechnologies les plus controversées ? Quelles sont les questions qu'elles soulèvent et les attitudes qu'elles induisent? Ont-elles changé pendant la période étudiée? Cette étude permettra de dresser un portrait général qualitatif du discours public en Argentine afin d'identifier les visions socio-éthiques sous-jacentes ainsi que les valeurs sociales qui sont touchées par les biotechnologies.

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Surgeon-patient communication: precept and practice

Background: Adequate information flow between physicians and patients is fundamental to building a strong relationship and vital to enhancing trust and confidence of patients in physicians. This paper presents the result of a study that examined information flow between surgeons and patients in Nigeria.

Methods: By means of self-administered questionnaire, we obtained information from consultant and trainee surgeons in three tertiary medical centres in southwestern region of Nigeria. The questionnaire focused on how and what they communicate with patients about disease diagnosis, management, operative procedures and prognosis among others.

Results: 102 surgeons completed the questionnaire. Of these, 87 (85.3%) were males and 60 (58.8%) were aged between 31 and 40 years. Forty four (43.1%) of them were consultants while 55 (54.0%) were registrars. Sixty three surgeons (61.8%) said they have not been providing adequate information before treatment nor give sufficient details while obtaining consent for surgical procedures ($p < 0.01$). While 48% of them said it was unethical to withhold relevant information from patients at the request of family members, 18.6% said it was ethical. However 92.1% of all respondents often withhold information from their patients at the request of family members ($p < 0.01$). More than half (57.8%) of the surgeons do not routinely discuss operative findings with their patients ($p < 0.01$). Almost half 48 (47.1%) of them considered it very important that all surgeons should undergo compulsory communication skills training.

Conclusion: Most Nigerian surgeons do not discuss sufficiently with their patients. There is a need for training of surgeons on value of communication.

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An audit of health products and services marketed on chiropractic websites in Alberta and consideration of these practices in the context of chiropractic codes of conduct and ethics.

Background: Chiropractic's success as a health care profession is evidenced partially by the rising number of practitioners. Paradoxically, this success may start to cost the profession, as the number of consumers may not be increasing proportionally, yielding less income for practitioners. Some chiropractors are responding to these pressures by retailing health products and services

Objectives: To describe the extent to which Alberta chiropractors with websites sold health products and offered fee discounts/service inducements. To consider these practices in the context of chiropractic codes of conduct and ethics.

Methods: Chiropractic websites in Alberta were identified using the online Telus Business Finder and cross-referenced with the Yellow Pages print directories. Websites were searched and an inventory of the advertised health products was made. Fee discounts and service inducements were also recorded.

Results: 56 websites were reviewed. Almost two thirds of the websites advertised health products for sale (N=37: 64.9%). Orthotics were sold most often (N=29 practices; 51.8%), followed by pillows/supports (N=15: 26.8%), vitamins/nutritional supplements (N=15; 26.8%) and exercise/rehabilitation products (N=10; 17.9%). Ten practices (18%) offered some type of inducement. These included discounted treatment packages (N=2; 3.6%), free gait/posture analyses (N=3; 5.4%) and free general consultations (N=2; 3.6%).

Conclusions: Website marketing of health products and services by chiropractors in Alberta is common. Such practices raise ethical considerations for the profession including conflict of interest and patients' best interests. Professional guidelines vary on the acceptability of these practices. Consumer and practitioner perspectives and practices regarding retailing need to be further examined.

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Currents of hope: Bioethics and international print media coverage of neurostimulation techniques**Background**

The application of neurostimulation techniques in neurological conditions like Parkinson's disease has generated "currents of hope." Building on this success, there is significant interest for the use of neurostimulation in psychiatric disorders namely major depression and obsessive-compulsive disorder. These innovative neurosurgical practices raise important ethical and social challenges in matters of resource allocation, informed consent for vulnerable populations, and conflicts of interest. The examination of the media offers a window into forces that shape public understanding of science and the social reality of research.

Aims

Characterize media coverage with a focus on ethical, legal and social issues;
 Identify potential pitfalls for informed consent and patient-provider relationships.

Methods

Guided keyword search function of the LexisNexis Academic database for major newspapers.
 Systematic content analysis including ethics issues, benefits and reporting practices.

Results

Results of this study show that:

- public discussion on the ethical, legal and social issues of neurostimulation techniques is less frequent than in media coverage of genetics research;
- ethics coverage does not include extensive discussion of issues of resource allocation and fair access in spite of the important costs of neurostimulation devices.
- benefits are often saliently featured in headlines suggesting new therapies or cognitive enhancement, possibly increasing existing pressures and related conflicting professional commitments.

Conclusion

A better appreciation of existing public understanding of neuroscience and its potential impact on ethics and healthcare for vulnerable populations is necessary to adequately prepare for the extension of neurostimulation to a broader range of conditions.

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Ethics: It's All About the Journey

Bioethics plays a major role in the consciousness of front-line staff as they grapple with issues of holistic care. These issues include admission and discharge criteria and system responsiveness, patient consent and capacity, power of attorney for personal care, advance care planning, family dynamics revolving around coping with chronic illness and end of life care and the refusal of life sustaining treatment.

This poster presentation will depict the journey, taken by a small complex continuing care and palliative care hospital with limited resources, from an emerging consciousness of bioethical considerations implicit in its daily life down a path of milestones reached to make those considerations explicit. Those milestones represent a recognition that the organization had an ethical imperative to provide formalized training and processes to facilitate ethical decision-making by patients, families, and staff. The journey begins with the constitution of an ethics committee focused primarily on reviewing research proposals and grows into the Board of Trustees mandating an active, interdisciplinary Ethics Committee. This poster will further portray the evolution of the committee's influence in promoting knowledge about ethics, developing a core of staff trained in the history and philosophical constructs informing ethics and ethical decision-making; the establishment of an ethical decision-making framework, the organization and implementation of an interdisciplinary ethics consultation team and on-going ethics education open to all staff. A case study consultation and action plan will demonstrate the success of this organization in making ethics matter.

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Epilepsy surgery as an example for ethical considerations in elective interventions

Elective interventions as a rule aim at the improvement of non-life-threatening conditions in contrast to emergency interventions with the aim to avert danger and save lives. Elective interventions constitute from a legal point of view "bodily harm" (§223/230 of German Penal Code) in cases where patients are not fully aware of non-surgical alternatives and have not given informed consent to the surgery. Therefore, the enlightenment of the physician is the most crucial factor in the decision-making of the patient and his/her family. With respect to epilepsy surgery extensive presurgical diagnostics together with comprehensive information about probable consequences of the surgery are indispensable for the physician in charge. Risks of the interventions and available non-invasive alternatives have to be outlined according to the guidelines of the associations concerned with epilepsy surgery. In contrast to the usual procedure (enlightenment and surgical intervention at the same day) elective surgery demands enough time between enlightenment and decisions for the patient to consider alternative treatments. In the Epilepsy Center Bethel 2100 epilepsy patients had had elective surgical interventions up to now (1366 therapeutic, 247 diagnostic, 133 palliative as callosotomy, VNS).

The enlightenment procedure will be demonstrated including the potential risk-utility-ratio and the non-invasive alternatives. The ethical dilemmas of the physician as well as the patients will be illustrated with cases. Outcome and postoperative evaluation demonstrate that extensive presurgical enlightenment and discussion with the patients led to minimizing risks, optimizing quality and subjective contentedness with the procedure. Ethical considerations in the process of decision-making are outlined.

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Être consultant en soins palliatifs pédiatriques : dilemmes éthiques rencontrés dans la pratique quotidienne

L'équipe de consultation en soins palliatifs du CHU Ste Justine a été mise en place en 1999. Le modèle d'équipe interdisciplinaire consultante a été choisi afin de répondre aux besoins des six catégories d'enfants qui devraient bénéficier de soins palliatifs selon la classification du ministère de la Santé du Québec. Ces enfants se retrouvent dans les différentes cliniques et unités de soins du centre hospitalier.

Une équipe de consultants qui se déplacent vers les équipes traitantes permet à plus d'enfants de bénéficier de l'approche palliative adaptée à sa condition. Une prise en charge conjointe avec l'équipe traitante favorise le continuum entre le curatif et le palliatif mais entraîne aussi des défis supplémentaires. L'équipe de soins palliatifs fait des recommandations qui sont appliquées par l'équipe traitante.

Au cours des six ans années de pratique quotidienne, les membres de l'équipe ont fait face à de nombreux dilemmes éthiques. À l'aide de divers exemples, recensés dans la pratique clinique, je vais exposer ces différents dilemmes et discuter des différentes méthodes de résolution de problèmes que l'équipe utilise et ce, en respectant le contexte de soin spécifique à chaque enfant.

Nina Preto, Dr. Susan Cox, Dr. Michael McDonald, Dr. Pat Kaufert, Dr. Joe Kaufert, Dr. Catherine Schuppli, Kim Taylor, Natasha Damiano, Lisa Labine,**The W. Maurice Young Centre for Applied Ethics**

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Centering the 'Human Subject' in Health Research: Understanding the Meaning and Experience of Research Participation

Although volunteers play a key role in health research, little is understood about the human subject's experience. Increasingly complex forms of research that complicate the ethical review process and fragment the researcher-research subject relationship support the call for more evidence in this area. Our study explores the meanings and experiences of being a research subject from the subject's standpoint. In phase one, key issues and perspectives on the experiences of human subjects in health research were identified through a systematic literature review and interviews with human subjects, health researchers, REB members, as well as scholars & experts in the area of research ethics. In phase two, this data will inform the selection of four case studies, which will be closely analyzed to further develop the issues and themes that emerged from the interviews. In depth interviews and focus groups will be conducted with the human subjects, researchers and research workers involved with each of the case studies, and with members of the research ethics board that approved the study. This is in part to identify salient differences in how research participation is understood and experienced, and to uncover assumptions that are held about those experiences by the research team or those involved in research oversight. Phase three will involve focus groups with research subjects, researchers, REB members, scholars and policy experts to seek feedback on our findings. This poster will provide an overview of the study and highlight initial phase one findings, focusing on the scholar and policy expert perspectives.

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A qualitative study of prognostication and end-of-life decision-making in critically-ill neurological patients

Background: The training of specialized "neurointensivists" introduces knowledge, approaches and, possibly, a new vision of intensive care for critically ill neurological patients.

Goals of the study

Identify differences between general medical intensivists (GMI) and neurointensivists in matters of prognostication, assessment of long term functional outcomes, and quality of life.

Identify key factors in end-of-life (EOL) decision-making for severely brain-injured patients.

Methods: Brief questionnaire based on a clinical vignette followed by a semi-structured interview to explore factors influencing prognostication and decision-making.

Results: Eight neurointensivists and 10 GMIs from two US tertiary hospitals participated. Key findings, illustrated by qualitative examples, include:

Inter-specialty differences

Neurointensivists were more optimistic than GMIs regarding chances of survival, long term functional outcomes, and quality of life;

Three general medical intensivists recommended withdrawal of life support early on for the patient in the case.

Overall differences regardless of specialty training

There was reluctance of physicians to acknowledge the impact of personal background and work environment on EOL decision making in spite of peer-review evidence suggesting otherwise;

There was substantial variability in the verbal articulation of prognosis; qualitative assessment of quality of life; and description and prediction of impairments.

Conclusion

There are both inter-specialty as well as overall differences in EOL decision making for critically ill neurological patients. The existence of diverging views among intensivists with different training may complicate communication and yield varying opinions on outcome, quality of life and EOL care. Its impact on family decisions and patient outcome needs to be further investigated.

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End of Life (EOL) Communication: What do Intensivists Document?

Physician communication affects family satisfaction with EOL care. Structured communication interventions have been shown to decrease non-beneficial treatments and length of stay in the ICU. **Objective:** To describe the documented characteristics of EOL communications between physicians and patients and/or surrogates. **Methods:** We reviewed the charts of all consecutive patients who died in our ICU between January and June 2006. We recorded characteristics of each documented EOL communication using data collection forms developed from a literature review of structured communication interventions and Robert Wood Johnson Foundation Critical Care Peer Workgroup domains of quality EOL care. **Results:** We included 113 patients with 273 documented EOL communications (range 0-10 / patient). Median time from ICU admission to first communication was 16 h (interquartile range 4-48 h). Nurses (14%), social workers (< 1%), chaplains (< 2%), referring physicians (86%), and intensivists (78%) attended meetings. Patient capacity was documented in (<1%), and substitute decision makers (SDM) were specified in (4%). Diagnosis was recorded in (68%), with explicit survival estimates mentioned in (19%). Options for continuing, withholding or withdrawing life support were documented in (52%). **Conclusions:** Physicians document EOL communication with patients and/or family members soon after ICU admission, but infrequently document non-medical team member attendance, capacity assessment or identification of a SDM. Most documented communications report discussions about diagnosis and options for life support but few mention survival estimates. A structured approach to document EOL communication may improve reporting of domains of quality EOL care known to be relevant to patients and families.

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Biotechnology Innovation and Health System Sustainability: An Ethical Approach to Priority Setting

Ethics is crucial in addressing the challenge presented by the pursuit of biotechnology innovations and maintaining health system sustainability. In 2002 the Canadian federal government established an innovation strategy intended to establish Canada as an international leader in innovation i.e., the application of knowledge to service delivery and product development resulting in economic and social benefits. In 2003 Canada budgeted \$11 billion towards investment in R&D and innovation. This has increased costs to the health system through short-term investment. Additionally, potential long-term costs exist through increased public demand of new innovations. Health spending per capita increased in Canada by 4.2% between 1998 and 2003. Health spending continues to grow thus challenging the sustainability of the Canadian health system. Sustainability refers to ensuring the long term availability of adequate resources to enable access to quality services. The issue of maintaining sustainability within the health system given the government's increased spending on innovation makes priority setting crucial.

The application of fair and legitimate priority setting i.e., the distribution of goods or services among competing programs and people, is one strategy that can assist in ensuring a sustainable health system while pursuing biotechnology innovation. This presentation will 1) review the role of biotechnology in health innovation; 2) discuss how innovation challenges health system sustainability; and 3) provide recommendations for resolving the tension between health care innovation and sustainability. An ethical lens is imperative in confronting the tension between innovation and sustainability.

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Informed consent and stimulant medication: Adolescents' preferences for information and understanding of information

Introduction: For informed consent to be valid, an individual must have (1) the capacity (or ability or competence) to consent, (2) received an adequate disclosure of the relevant treatment information, and (3) consented voluntarily and freely.

Common law decisions in Canada have established that there is no minimum age at which individuals are able to consent and no age below which they cannot consent. Rather, capacity to make a decision depends on ability. This study examines the ability of adolescents with Attention Deficit/Hyperactivity Disorder (ADHD) to understand information needed for consent and their preferences for information disclosure.

Method: Experienced physicians, lawyers, bioethicists, parents and teenagers reviewed this material. Adolescents with ADHD, parents and clinicians were recruited. Participants received a structured disclosure on informed consent, information about the benefits and risks of stimulant medication, rated what information they felt should be disclosed on the disclosure form, completed a questionnaire on attitudes to informed consent disclosure and their understanding of the information.

Results: Physicians', teenagers', and parents' preferences for information disclosure are described. Teenagers' understanding scores were lower than adults' scores. However, some teenagers' understanding scores were equivalent to that of parents.

Conclusions: Clinicians' personal views about information disclosure may differ from their patients' views. While teenagers' understanding was on average lower than adults, many teenagers' understanding was similar to parents. Thus clinicians should assess adolescents' ability to understand information necessary for consent on an individual basis.

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Ethical decision- making in patients who cannot communicate: Problems arising in a long-term ventilation unit

An increasing number of people depend on mechanical ventilation. Problems that cause breathing failures are, for example, progressive neuropathies, muscle diseases, illness of the lung, or brain damage with dysfunction of the respiratory center.

The medical prognosis for this heterogeneous patient group is uncertain. It depends on the underlying disease and the intensiveness of nursing and medical care. It is often possible to administer the ventilation treatment for many years.

Many of the patients are completely awake (conscious). They must understand that their situation will not improve. In contrast, the situation often deteriorates with worsening of the underlying disease. The quality of life is very limited not only because of the almost complete dependence on nursing care 24 hours a day.

The tracheal tube causes a significant problem in the ability of the patient to communicate. Instead of normal communication the patients have to express their wishes and needs through facial expression or (if possible) gestures.

Many nurses and physicians, despite this significant limitation of communication, wish to ascertain patient's wishes in respect of limitation of therapy, DNR orders, or life sustaining treatment.

But sometimes the emotional strain for patient and therapists seems to be unacceptable high.

Is it better to avoid discussing these questions because of the complexity of the mentioned problems? Is there a way to accomplish successful communication?

The author has experience in treating long term ventilated patients in a specialized unit over 3 years. He will give case reports and discuss successes and failures in communication.

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Ethics rounds or ethics consultation in Sweden? How much input should the ethicist have? - Nurses' and physicians' experiences

Objective: To evaluate one ethics rounds model by describing nurses' and physicians' experiences of the rounds.

Methods: Ethics rounds in the form of interdisciplinary team conferences concerning dialysis patient care problems, led by philosopher-ethicists, were tested at three Swedish hospitals. The philosophers were instructed to promote mutual understanding and provide training in moral reasoning through the identification and analysis of the ethical problems, without resolving them. This in order to decrease the risk that an outside expert would remove responsibility from the person with the formal decision-making responsibility. Seven physicians and 11 nurses were asked to narrate their experiences of the rounds, which were then analysed using content analysis.

Findings: Participants described both positive and negative experiences. Good rounds included stimulation to broadened thinking, sense of connecting, strengthened confidence to act, insight of moral responsibility and emotional relief. Negative experiences were associated with a sense of unconcern and alienation, as well as frustration with lack of solutions and a sense of resignation that change is not possible. The findings suggest that the ethics rounds above all met the need of a forum for crossing over professional boundaries. The philosophers seemed to have an important role in structuring and stimulating reasoned arguments. A conspicuous finding was the nurses' frustration with lack of solutions and also the appreciation of help with problem solving, which was in fact not part of the goal of the rounds.

Conclusion: In assisting healthcare professionals, the results suggest to find a balance between ethical analysis, conflict resolution and problem-solving.

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Ethical Issues of Qualitative Health Research: Patients and Practitioners as Subjects and Gatekeepers or Contextual Contributors?

Qualitative health research offers opportunities to investigate complex and vital issues from the patient perspective. Study findings can be used to inform health policy, improve health practice and enhance patient experiences. As health researchers we have a responsibility to generate valid data, which respect individual patient experience, attempt to maximise benefits and reduce harms to health care consumers, and aim to build a highly effective and fair health care system. In this study we interviewed 10 people with newly diagnosed rheumatoid arthritis (RA) and, using a topic guide, we explored their illness experiences of self-management, diagnosis and professional support. We embraced a genuinely collaborative approach in our study design, applying the concept of 'relational autonomy'. From the earliest stages of the study, we worked as a team with RA patients and health practitioners to make research decisions about: access and recruitment of study volunteers; topics and language for the interview agenda; nature of support offered for patient study volunteers, and dissemination of the findings. In qualitative health research, respect for individuals' experiences extends beyond attending to the accounts of study volunteers, and minimal communication with health professionals in their role as gatekeepers. It requires researchers to consult relevant groups and individuals as study contributors, and treat their perspectives, experience and knowledge with respect. Although collaboration can be challenging, to overlook such communication is an infringement on patient and health professional autonomy. In this qualitative pilot study we provide a concrete example of relational autonomy, and its application.

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A case of Organ Transplantation from Istanbul. Would ethics consultation change the coercion or voluntariness?

A woman, who is 40 years of age, married and has three children, has been followed up by nephrology department of a big hospital for three years. Later on, she had the symptoms of renal insufficiency with the indication of dialysis.

Her physician, who was known to have a dominant and positive role in the patient-physician relationship in the clinics, offered the possibility of renal transplantation from one of the patient's brothers or sisters. She had six brothers and sisters, all of whom had a positive tissue match with the patient.

The patient chose the youngest brother as the donor candidate. As regards the institutional protocol, he was sent to psychiatry and ethics consultation. He seemed at first sight volunteer and came to interviews with a relative, never alone. A resident physician and a registered experienced nurse in the psychiatry department had the feeling that he was coerced for the transplantation and his IQ test that was performed in the psychiatry department showed an IQ value below 70 which is the indication of a level below the minimum requirement for a regular perception level of a healthy individual.

Is the behaviour of the brother morally irresponsible? Is the woman selfish? Or does coercion exist? We plan to describe and discuss the process and values for a donor candidate for renal transplantation in Turkey and evaluate the role of ethics consultation for organ transplantation.

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Enhancing Patient and Family Care Through Clinical Ethics Consultation

The IWK Health Centre is a tertiary care centre for the care of women, children, youth and their families. In the fall of 1999, the Department of Bioethics, Dalhousie University, conducted a needs assessment of health professionals at the IWK Health Centre.

Professionals identified a need for support in responding to the ethical issues they encounter in their practice. The Health Centre Ethics Committee developed a consultation process to enhance clinical care and its outcomes through the provision of specialized facilitation, education, advice and information. The process assists in identifying, analyzing and resolving ethical uncertainty or conflicts that arise for health centre staff, physicians, volunteers, patients and families. When issues of uncertainty or conflict develop, it is important for all involved to be heard, listen to other perspectives, learn about other relevant information, and work together for resolving issues. The process is designed for patient or population specific care concerns and/or complex situations where, for example, team members may hold different views about the most appropriate plan of care.

The clinical ethics consultation committee was then created by inviting professionals across the Health Centre who had an interest in and capacity for facilitating ethical discussion amongst their colleagues to submit an application. The planning team interviewed the applicants, and ten successful candidates were selected. These individuals underwent intensive orientation as part of the ethics collaboration with the Department of Bioethics and continue to receive ongoing support and mentoring.

This presentation will outline clinical ethics consultation at the IWK, the selection process for clinical ethics consultants in more depth, as well as the continuing education, mentoring and support for consultants and overall coordination of the consultation process. In particular, the experiences of the clinical ethics consultants, staff and partners at the Department of Bioethics will be highlighted.

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The Functioning of a Clinical Ethics Committee in an Acute Care Hospital

The past thirty years have seen a widespread proliferation of clinical ethics committees in Canadian hospitals. These committees were initially established as a mechanism to deal with ethical dilemmas in patient care. While the literature acknowledges the widespread existence of clinical ethics committees, very little evidence is available to assess their functioning and /or value to health care professionals or their impact on patient care or caregivers.

In light of these findings, the authors conducted a qualitative descriptive research study of a clinical ethics committee in a large teaching hospital. This study was part of a larger study of clinical ethics committees in four Canadian hospitals. The data collected for this research study will be incorporated into the data set of the larger study.

The purpose of this study was to develop a structural and contextual description of a clinical ethics committee; to identify current issues that the clinical ethics committee is dealing with; and to describe the types of activities/recommendations that result from committee discussions.

Data sources for this study included audiotapes and minutes of committee meetings, committee terms of reference, committee membership and committee structure within the organization. The presenter will describe the findings of the study and its implications for the establishment and development of effective Clinical Ethics Committees within Acute Care Hospitals.

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The Cascade Education Campaign: An Effective Bioethics Education Program

To provide ethics education to Burnaby Hospital's staff and community, our Ethical Resources Committee developed an inexpensive, entertaining and effective program – the cascade education campaign.

The first stream of the cascade is Graffiti Education. Dozens of Fortune cookie-sized graffiti stickers with a brief perplexing slogan are posted in both conspicuous and surprising locations throughout the hospital, including light switches, elevators, washrooms and computers.

The graffiti is meant as a teaser - a piece of a puzzle that both staff and public ponder and discuss. For our campaign on resuscitation issues, the graffiti read, "DNR is not DNC". The Graffiti Education Stream continues for one to two weeks.

Table Tent Cases comprise the next wave. On cafeteria tables, table tents display a fictional ethics case. In the resuscitation campaign, we circulated three separate scenarios highlighting different issues in resuscitation orders.

The Table Tents invite readers to consider their answers and to proceed to our committee's Bulletin Board Display, where they will find a discussion on the cases and relevant ethical issues.

This wave is reinforced by our *Everyday Ethics* newsletter, which discusses the ethical issues in more detail. The newsletter is circulated throughout the hospital.

The illustrative cases, discussions and content of the newsletter are reflected on our Intranet Website with references for further ethics education. The chair of our committee writes a regular newspaper column. The same theme is therefore covered in a related article appearing in the community newspapers of Greater Vancouver.

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Attitudinal barriers towards medical students with "disabilities"

BACKGROUND: There is limited research regarding the acceptance of Canadians with "disabilities" in the medical school admission process, during their medical training, and as good physicians.

METHODS: A total of 993 students in Medicine (427), Law (358), Occupational Therapy (OT) (90), and Social Work (SW) (118) at the University of Western Ontario, responded (RR 69.3%) to an anonymous questionnaire seeking to identify attitudes regarding medical students with "disabilities", including admission policies. REB approval was obtained. A *p*-value less than 0.01 was deemed significant.

RESULTS: The prevalence of self-identified "disability" was 4.9% overall, and 3.2% among medical students. Half of the "disabled" students (16/33) had chosen to disclose their "disability" to their administration, before or after acceptance. Medical students were less likely than OT students to believe medical students with "disabilities" could succeed as medical students (*p* = 0.009) or should receive accommodation (*p* < 0.001), and preferred disclosure of "disabilities" when applying to medical school (*p* = 0.004). Medical students were also less in favour of an "undifferentiated" medical graduate, i.e. a student willing and able to enter any field (*p* < 0.002).

CONCLUSIONS: Medical students with "disabilities" face attitudinal barriers within the medical community.

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Ethical Challenges of New Advances of Biotechnology and Islamic views in Iran

New advances of biotechnology have faced the world toward some bioethical challenges which need global responses to determine how these technologies could be implemented safely. Without doubt, these advancements could lead to irreversible disasters if not limited by ethical guidelines.

Impacts of the biotechnological advancements would not be the same in different communities. Whereas concerns about subjects' rights, autonomy, and informed consent, privacy, patenting and ownership of genetic material, eugenics, selective abortion, development of biobanks, the commercialization of products including property rights, genetically modified foods, using of new Assisted Reproductive Technologies (ARTs), stem cell research and cloning are some of the most important issues in this field, some other issues such as justice and resource allocation are more prominent in some countries.

According to considerable progresses of biotechnology in Iran, bioethical issues have been considered by Iranian ethicists, religious scholars, lawyers and policy-makers in recent years. In this manuscript we aim to state some bioethical activities in Iran and the most important debates in this field considering Islamic points of view.

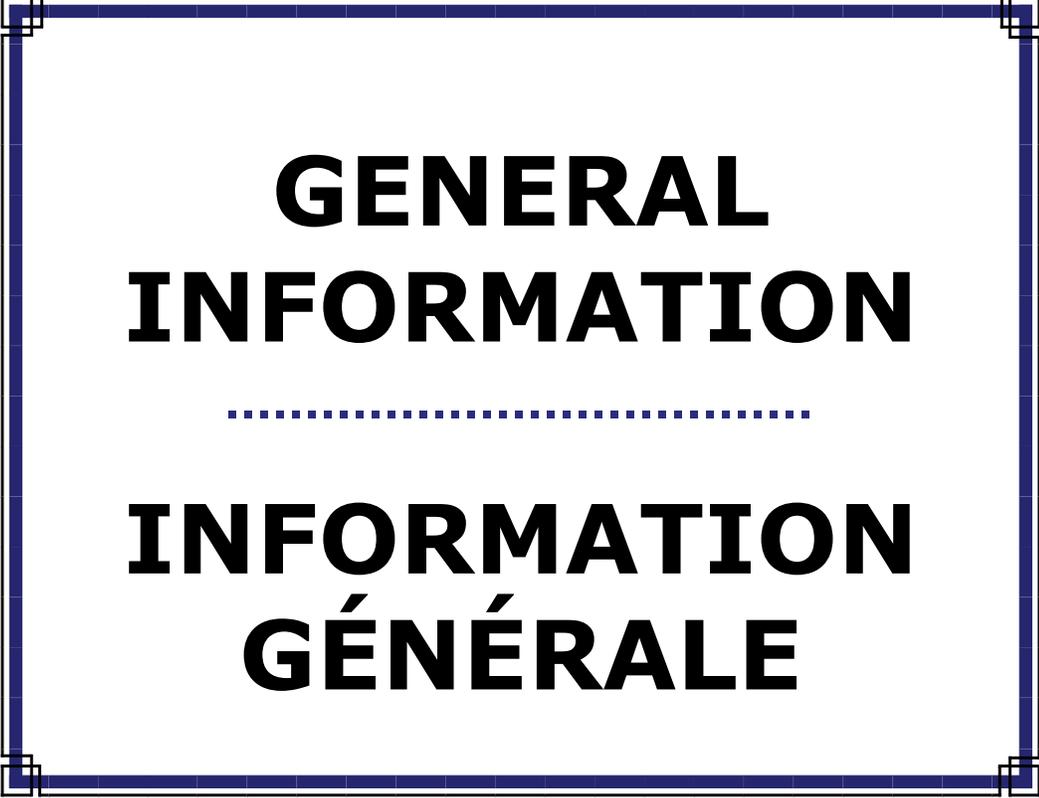
Keywords: bioethics, medical ethics, biotechnology, genetics, Assisted Reproductive Technologies, stem cell research, cloning, Islam, Iran

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Bioethics and primary healthcare: an approach for principlism, virtue, casuistry or care?

Ethical problems in primary healthcare are not the critical, dramatic and rare cases usually found in hospitals and suitable for principlism approach due to requiring immediate decisions. A real issue to studies in ethics matters is to deepen the understanding about the interface between bioethics and primary healthcare, concerning its' peculiarities. This is an empirical, qualitative, descriptive ethics study carried out to identify and compare ethical approaches used by primary health care professionals in ethical decision making. Research subjects were eighteen nurses and seventeen physicians of the Family Health Program in the city of Sao Paulo, SP, Brazil. In semi-structured interviews they were asked to recommend a solution to hypothetical scenarios and to justify their choices. Nurses and physicians, in general, are concerned about preserving the rights of the individuals, but they do this in such a way that they protect the relationships, in a mixture of principlism and ethics of care approaches. They also used procedures of reasoning based on paradigms and analogies, resembling casuistry. The results point out that health work is still perceived as a practice that involves standards of excellence and the achievement of internal goods. In contrast to high-technology settings, primary healthcare deals with less dramatic, more complex issues and different values which might complicate ethical decision making. The subtlety of the ethical problems in primary healthcare might make them difficult to discern and may lead to disastrous consequences for patients, families and communities.



**GENERAL
INFORMATION**



**INFORMATION
GÉNÉRALE**

General Information / Information Générale

18th Annual Canadian Bioethics Society Conference

Created in 1988 from the fusion of the Canadian Society of Bioethics and the Société canadienne de la bioéthique médicale, the Canadian Bioethics Society has over 600 current members. Members include both individuals and organizations from a wide variety of fields including medicine, nursing, law, theology, philosophy, allied health, anthropology and public health, who share a common interest in bioethics and in the human dimensions of health research and practice. This annual conference is intended as a forum for dialogue, discussion and debate across a broad range of bioethics issues. This conference will be of interest to current and future members of the CBS, as well as any other individuals or organizations interested in bioethics issues.

3rd International Conference on Clinical Ethics and Consultation

The growth of ethics committees and formal clinical ethics services has accelerated in North America and has spread to Europe and other parts of the world during the last two decades. The 1st International Assessment Summit on Clinical Ethics Consultation was held in Cleveland in 2003 co-organized by the Department of Bioethics at the Cleveland Clinical Foundation and the Institute for Applied Ethics and Medical Ethics at the University of Basel, Switzerland. The 2nd International Conference was held in Basel, Switzerland in 2005. The 2007 Toronto Joint Ethics Conference will mark the third such event with a specific focus on clinical ethics. This cross-national, cross-cultural conference will further promote discussion of the process, prospects and problems of clinical ethics and consultation and will provide an educational opportunity for individuals and healthcare organizations to learn about ways to improve the functioning of their ethics consultation services.

Study Credits

Certificates of attendance can be picked up at the registration desk. The number of education hours for each conference and daily attendance is provided on the reverse of the certificate. Information for Canadian physicians about applying for Continuing Medical Education Credits is also included on the reverse side of the certificate.

18ième conférence annuelle de la Société canadienne de bioéthique

La Société canadienne de bioéthique, avec ses 600 membres environ, a été fondée en 1988 à la suite de la fusion entre la Canadian Society of Bioethics et la Société canadienne de la bioéthique médicale. Elle regroupe des individus et des organismes oeuvrant dans des domaines aussi variés que la médecine, les soins infirmiers, le droit, la théologie, la philosophie, l'anthropologie, la santé publique, etc. Ces personnes et ces organismes ont en commun de s'intéresser aux enjeux liés à l'éthique et à l'aspect humain de la recherche et de la pratique dans le domaine de la santé. Cette conférence annuelle se veut un forum favorisant le dialogue, la discussion et le débat concernant un large éventail d'enjeux en bioéthique. Cette conférence saura intéresser les membres et les futurs membres de la SCB, mais aussi toutes les personnes s'intéressant aux questions de bioéthique.

3ième conférence internationale sur l'éthique clinique et la consultation

Depuis les vingt dernières années, le nombre de comités d'éthique et de services d'éthique clinique a augmenté de façon importante en Amérique du Nord, de même qu'en Europe et dans d'autres pays du monde. Le premier sommet international sur la consultation en éthique clinique a eu lieu à Cleveland en 2003. Il fut organisé conjointement par le département de bioéthique de la Cleveland Clinical Foundation et par l'Institut d'éthique appliquée de l'Université de Bâle en Suisse. La deuxième conférence internationale eut lieu en 2005, à Bâle, en Suisse. La conférence conjointe en éthique de 2007 sera le troisième événement du genre à avoir comme objectif spécifique l'éthique clinique. Cette conférence transnationale et interculturelle permettra de pousser la réflexion sur les méthodes, l'avenir et les problèmes de l'éthique clinique et de la consultation. De plus, elle sera une occasion de formation pour les individus et les organismes de santé qui souhaitent améliorer le fonctionnement de leurs services de consultation éthique.

Crédits de formation

Les certificats de présence à la conférence sont disponibles au comptoir d'inscription. Vous trouverez, à l'endos du certificat, le nombre d'heures de formation valable pour chaque conférence et pour chaque jour. Les médecins canadiens pourront également trouver l'information nécessaire pour les crédits de formation continue à l'endos du certificat.

General Information / Information Générale

Simultaneous Translation



Headsets are available for use at sessions in the Grand Ballroom. To obtain a headset, please complete the information on the envelope provided in your conference package and **insert a valid credit card or driver's licence, before visiting the attendant's table.** If you are unable to pick-up or return your headset at the scheduled times, please seek assistance at the registration desk.

Traduction simultanée



Des casques d'écoute sont disponibles pour les sessions de la salle Grand Ballroom. Pour vous procurer un casque d'écoute, S.V.P., veuillez fournir les informations sur l'enveloppe incluse dans la pochette de la conférence et y **insérer votre permis de conduire ou une carte de crédit valide avant de vous adresser au comptoir des prêts.** Si vous n'êtes pas en mesure de retourner votre casque d'écoute à l'intérieur des heures d'ouverture, S.V.P., veuillez vous adresser au comptoir d'inscription.

Timetable for Pick-up and Return of Headsets

Wednesday	Pick-up: 6:00 to 7:15 p.m. Return: 8:30 to 9:00 p.m.
Thursday	Pick-up: 8:45 to 9:15 a.m. 11:30 to 12:15 p.m. 3:30 to 4:15 p.m. Return: 5:30 to 6:00 p.m.
Friday	Pick-up: 8:45 to 9:15 a.m. Return: 5:00 to 5:30 p.m.
Saturday	Pick-up: 8:45 to 9:15 a.m. Return: 5:00 to 5:30 p.m.
Sunday	Pick-up: 8:45 to 9:15 a.m. Return: 12:00 to 1:00 p.m.

Horaire pour emprunter et retourner les casques d'écoute

mercredi	Emprunt: 18h à 19h15. Retour: 20h30 à 21h
jeudi	Emprunt: 8h45 à 9h15 11h30 à 12h15 15h30 à 16h15 Retour: 17h30 à 18h
vendredi	Emprunt: 8h45 à 9h15 Retour: 17h à 17h30
samedi	Emprunt: 8h45 à 9h15 Retour: 12h à 13h
dimanche	Emprunt: 8h45 à 9h15 Retour: 17h à 17h30

Message/Information Boards

A message/information board for posting and receiving messages will be located adjacent to the registration desk. Last-minute changes to the program will also be posted. Velcro is available at the registration desk.

Tableau d'information et de messages

Un tableau sera placé sur un mur près du comptoir d'inscription pour ceux et celles désirant afficher des messages ou de l'information. Les changements de dernière minute au programme seront aussi affichés à cet endroit.

Bookstore - Hours/Location

The bookstore hosted by the University of Toronto is located in the foyer near the Grand Ballroom. Hours of operation are between 8:00 and 4:30 p.m. on Thursday (May 31), Friday (June 1), and Saturday (June 2).

Librairie—heures d'ouverture et emplacement

La librairie est située dans le hall, juste à côté de la salle Grand Ballroom. Les heures d'ouverture sont de 8h à 16h30, le mardi 31 mai, le vendredi 1^{er} juin et le samedi 2 juin.

Educational Vendors - Hours/Location

On Friday, June 1 from 9:00 to 5:00 p.m., exhibitors will be located in the Trinity V Ballroom.

Établissements d'enseignement - heures d'ouverture et emplacement

Les exposants seront situés dans la salle Trinity V Ballroom, le vendredi 1^{er} juin de 9h à 17h.

General Information / Information Générale

Dining/Local Attractions

Information about dining options and local attractions is available at the registration desk and with the hotel concierge. Local bioethicists have compiled a list of their favourites for your dining pleasure. A selection of Baldwin Street restaurants located within a 15 minute walk of the hotel is offering a 10% discount that can be obtained by showing your conference name tag.

Poster Exhibits

The CBS Poster Exhibit will take place on Thursday, May 31, the Visual Postcard Exhibit will take place on Friday, June 1 and the ICCEC Poster Exhibit is on Saturday, June 2. Poster exhibits will be in the foyer outside the Grand Hall Ballroom from 9:00 a.m. to 5:00 p.m. Posters should be set up between 7:30 and 8:30 a.m. and removed between 5:00 and 5:30 p.m. You should plan to be at your poster during the morning break.

Souper/Activités

Vous pouvez demander des informations concernant les restaurants et les activités à faire à Toronto au comptoir d'inscription et aux responsables de l'hôtel. Les bioéthiciens de Toronto vous ont préparé une liste de leurs endroits favoris. Certains restaurants du village Baldwin, situés à 10 minutes de marche de l'hôtel, offrent un rabais de 10% sur les repas des participants à la conférence. Vous n'avez qu'à montrer votre porte-nom de la conférence.

Présentations par affiche

Les présentations par affiche de la SCB auront lieu le jeudi, 31 mai; l'exposition de carte postale aura lieu le vendredi, 1^{er} juin; et les présentations par affiche de la CIECC auront lieu le samedi 2 juin. Les affiches seront exposées dans le hall, juste à côté de la salle Grand Ballroom, de 9h à 17h. Les affiches doivent être installées entre 7h30 et 8h30 et elles doivent être enlevées entre 17h et 17h30. Les présentateurs devraient être à leur affiche pendant la pause de l'avant-midi.

2007 Joint Ethics Conference - Evaluation Form (English)

Your feedback about the 2007 Joint Ethics Conference is invaluable. It will help those who are planning upcoming Canadian Bioethics Society(CBS) Conferences and International Conferences on Clinical Ethics Consultation (ICCEC) to ensure that future conferences meet and exceed your expectations. Please complete only those sections that you are comfortable completing.

I attended the following:

- Canadian Bioethics Society Conference (May 30 to June 1, 2007)
 International Conference on Clinical Ethics Consultation (June 1 to June 3, 2007)
 Both (May 30 to June 3, 2007)
 Other _____

I am from:

- Canada
 Europe
 United States
 Other Nation _____

I fit best in the category(s) of:

- Academic
 Health Care Professional
 Clinical Ethicist/Bioethicist
 Student
 Media
 Member of the General Public
 Other _____

I found about the conference through:

- Conference Website
 CBS Communications (E-mails/Newsletter)
 ICCEC Communications (E-mails)
 Word of Mouth
 University of Toronto Joint Centre for Bioethics Listservs
 MCW Listserv
 Other _____

Please rate each of the following by drawing a circle around the number that best represents your response.

	Very Poor	Poor	Good	Very Good	Excellent
Overall organization of conference	1	2	3	4	5
Sessions began and ended on time	1	2	3	4	5
Overall quality of plenary sessions	1	2	3	4	5
Amount of time allotted for plenary sessions	1	2	3	4	5
Overall quality of concurrent sessions/workshops	1	2	3	4	5
Amount of time allotted for concurrent sessions/workshops	1	2	3	4	5
Overall quality of poster presentations	1	2	3	4	5
Amount of time allotted for viewing poster presentations	1	2	3	4	5
Opportunities for networking	1	2	3	4	5
Play "I'm Still Here"	1	2	3	4	5
Dinner at the CN Tower	1	2	3	4	5
Quality of translation (written materials)	1	2	3	4	5
Quality of interpretation (verbal)	1	2	3	4	5
Educational vendors	1	2	3	4	5
Bookstore	1	2	3	4	5

	Very Poor	Poor	Good	Very Good	Excellent
Program booklet	1	2	3	4	5
Meeting facilities	1	2	3	4	5
Variety, quality, and quantity of food	1	2	3	4	5
Range of available accommodation	1	2	3	4	5
<i>If you are a student, please rate the following activities:</i>					
Student Meet & Greet	1	2	3	4	5
Student General Meeting	1	2	3	4	5
Student Mentor Breakfast	1	2	3	4	5
Student Dinner	1	2	3	4	5
Overall, I would rate this conference as (please circle your response):					
Outstanding		Better Than Most		Average	
		Below Average		Unsatisfactory	
Please provide comments about keynote speakers.					
Please provide comments about concurrent sessions.					
What did you like best about the conference?					
What needs to be improved for future conferences?					
Do you have any suggestions for themes, topics or speakers for future conferences?					
Are you planning to attend the next CBS conference in St. John's, Newfoundland & Labrador? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know					
Are you planning to attend the next ICCEC conference in Taiwan? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know					
Any other comments?					

Conférence conjointe en éthique 2007 - Formulaire d'évaluation

Votre opinion sur la conférence conjointe en éthique 2007 nous est chère. Elle aidera ceux et celles qui organiseront les futures conférences de la Société canadienne de bioéthique (SCB) et les conférences internationales sur l'éthique clinique et la consultation à faire en sorte qu'elles remplissent toutes vos attentes. S.V.P. veuillez remplir les sections du formulaire. Il n'y a aucune obligation de remplir toutes les sections. Vous pouvez remplir seulement celles dont vous avez envie.

J'ai assisté à:

- Conférence annuelle de la Société canadienne de bioéthique (30 mai au 1^{er} juin 2007)
 Conférence internationale sur l'éthique clinique et la consultation (1^{er} au 3 juin 2007)
 Aux deux (30 mai au 3 juin 2007)
 Autre _____

Je viens du/de/des:

- Canada États-Unis
 Europe Autres pays _____

La catégorie qui me caractérise le mieux:

- Universitaire Média
 Professionnel de la santé Membre du public
 Éthicien clinique/bioéthicien
 Étudiant Autre _____

J'ai entendu parler de cette conférence:

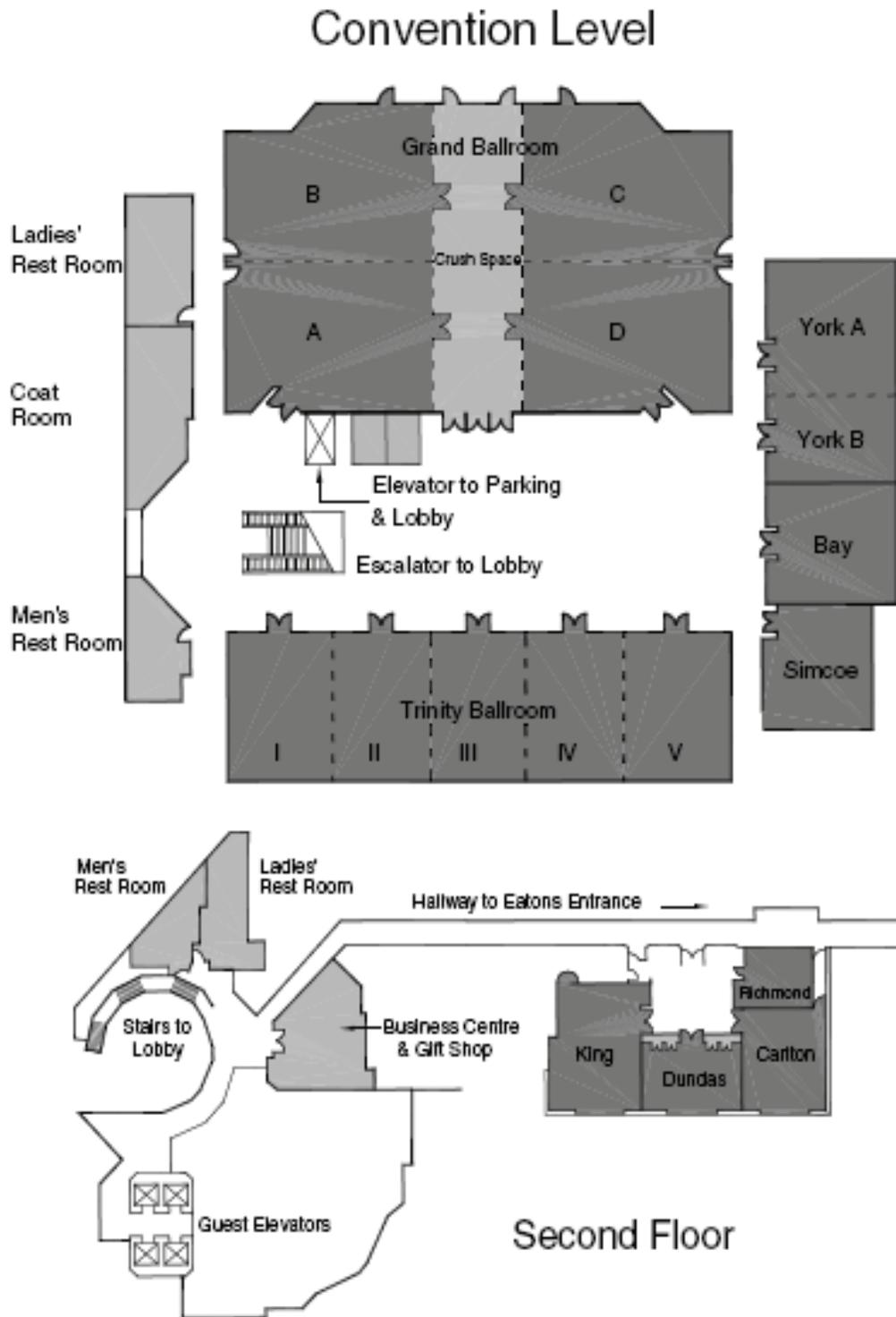
- Site Internet Liste d'envoi du *Joint Centre for Bioethics*, U de Toronto
 Communications de la CBS (courriels/Bulletin) Liste d'envoi du MCW
 Communications de la CIECC (courriels)
 De bouche à oreille Autre _____

Encerclez le chiffre qui correspond le mieux à votre évaluation :

	Très faible	Faible	Bon	Très bon	Excellent
L'organisation générale de la conférence	1	2	3	4	5
Les séances ont commencé et se sont terminées à l'heure	1	2	3	4	5
La qualité des séances plénières	1	2	3	4	5
Le temps alloué aux séances plénières	1	2	3	4	5
La qualité des séances simultanées et des ateliers	1	2	3	4	5
Le temps alloué aux séances simultanées et aux ateliers	1	2	3	4	5
La qualité des présentations par affiche	1	2	3	4	5
Le temps alloué aux présentations par affiche	1	2	3	4	5
Les occasions de réseautage	1	2	3	4	5
La pièce de théâtre « <i>I'm Still Here</i> »	1	2	3	4	5
Le souper à la Tour du CN	1	2	3	4	5
La qualité de la traduction (écrite)	1	2	3	4	5
La qualité de la traduction simultanée (verbale)	1	2	3	4	5
Les kiosques des établissements d'enseignement	1	2	3	4	5
La librairie	1	2	3	4	5

	Très faible	Faible	Bon	Très bon	Excellent
Le livret de la conférence	1	2	3	4	5
L'équipement et les services	1	2	3	4	5
La variété, la qualité et la quantité de la nourriture	1	2	3	4	5
Le choix et la disponibilité de l'hébergement	1	2	3	4	5
<i>Si vous êtes un étudiant, S.V.P, évaluez les activités suivantes :</i>					
Activités d'accueil des étudiants <i>Meet & Greet</i>	1	2	3	4	5
Assemblée générale des étudiants	1	2	3	4	5
Petit déjeuner avec mentors	1	2	3	4	5
Souper des étudiants	1	2	3	4	5
De façon générale, j'évaluerais cette conférence comme étant (encerclez votre réponse) :					
Exceptionnelle		Meilleure que la plupart		Moyenne	
			Sous la moyenne		Insatisfaisante
S.V.P., veuillez nous faire des commentaires sur les conférenciers invités.					
S.V.P., veuillez nous faire des commentaires sur les séances simultanées.					
Qu'avez-vous le plus aimé à cette conférence?					
Qu'est-ce qui devrait être amélioré lors des prochaines conférences?					
Avez-vous des suggestions de thèmes, de sujets et de présentateurs pour les prochaines conférences?					
Prévoyez-vous assister à la prochaine conférence de la SCB à St-Jean, Terre-Neuve et Labrador? <input type="checkbox"/> Oui <input type="checkbox"/> Non <input type="checkbox"/> Ne sais pas					
Prévoyez-vous assister à la prochaine conférence ICCEC à Taiwan? <input type="checkbox"/> Oui <input type="checkbox"/> Non <input type="checkbox"/> Ne sais pas					
Autres commentaires?					

Map of Conference Facilities / Carte des salles de la conférence



Acknowledgements/Remerciements

The Planning Committee gratefully acknowledges contributions by the following:
Le comité organisateur remercie chaleureusement les donateurs suivants:



University of Toronto
Joint Centre for Bioethics



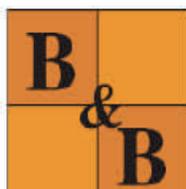
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada



BORDEN
LADNER
GERVAIS



Snow's Victory
Florists



Brown & Burnes
Barristers at Law

