



Perspectives

The deVeber Institute for Bioethics and Social Research

Spring 2009

Research and Scholarship for an Informed Social Response to Human Life Questions

Debunking the Myths

The Battle between Politics and Science in Research Studies

Though research studies are meant to be scientific and unsullied by politics, abortion studies often seem to be affected by prevailing biases. At deVeber, we often find the true results of the studies are hidden out of sight in the body of the data, sometimes even in direct contradiction to the study's stated findings. It is sometimes this kind of creative writing that accounts for differing results.

For example, in 2008, new international studies and reviews¹ were released which came to three different conclusions: that abortion negatively impacts women's mental health, that abortion has no effect on women's mental health, and that studies are still too inconclusive to determine whether abortion has an effect on mental health.

Answers are often incomplete, ignored, or even dismissed and covered up.

On the issue of fetal pain, Dr. Paul Ranalli explored a flawed study which contradicts well-established knowledge in this area, and yet is now being widely quoted in the health literature. See "A Medical Detective Story" in this newsletter for more details.

The highly contentious issue of abortion has distorted the science of fetal pain and mental health. Answers in studies are often incomplete, ignored, or even dismissed and covered up. Thanks, however, to your ongoing support, the deVeber Institute works to uncover the facts on these topics, and to offer balanced research despite the political controversy that surrounds it.

1. Fergusson DM, Horwood JL, Broden JM. 2008. **Abortion and mental health disorders: Evidence from a 30 year longitudinal study.** *The British Journal of Psychiatry* 193: 444-451.

Coleman PK, Coyle CT, Shuping M, Rue VM. 2008. **Induced abortion and anxiety, mood and substance abuse disorders: Isolating the effects of abortion in the national comorbidity survey.** *Journal of Psychiatric Research*. Accepted 21 October 2008.

Charles VE, Polis CB, Sridhara SK, Blum RW. 2008. **Abortion and long term mental health outcomes: a systematic review of the evidence.** *Contraception*. 78: 436-450.

Dingle K, Alati R, Clavarino A, Najman JM, Williams GM. 2008. **Pregnancy loss and psychiatric disorders in young women: an Australian birth cohort study.** *The British Journal of Psychiatry*. 193: 455-460.

Top questions that researchers don't ask (but they should)

1. When reporting the reproductive history of a woman, did the patient have a spontaneous abortion or an induced abortion?
2. In psychological research, why is the word trauma used following an abortion for fetal abnormality, but not used for other cases of induced abortion?
3. In research on abortion decision-making for women, what is the role of intimate partner violence?
4. When a young woman who is still a minor is pregnant and requesting abortion, why is the reason for her pregnancy not often reported, and the possibility of abuse or rape not investigated?
5. When studying the risks for preterm birth, why is abortion not often considered as a risk factor?



Prenatal Tests – Hope or Distress?

More Information and Care Needed for Parents and Children after Genetic Diagnosis

As news continues to circulate about the new prenatal genetic tests which are to be released on the market this June², the deVeber Institute continues to research the bioethical and social implications of this test for Canadian society.



In response to our October release “New Prenatal Genetic Testing – Are We Ready?” a Canadian psychiatrist wrote: “I have seen so many women traumatized because they have such anxiety throughout the pregnancy after such encounters of coercion to have genetic counselling from doctors who... have abortion in mind.”

The mother of a child with a disability asked: “How can we ensure that the support needed for families facing a prenatal genetic diagnosis is in place, when this support really needs to be offered from an unbiased position?”

Responses to difficult diagnoses

It has been brought to our attention that research is necessary regarding the medical treatment provided to infants born with conditions which some consider preventable through prenatal testing and termination. Are systems in place to ensure that the information provided to parents is unbiased and that the medical treatment is ethical, given that the majority of society would choose termination for many of these conditions?

Early induction is commonly offered after a positive genetic diagnosis. Parents are given ample support for early induction, including bereavement packages and psychosocial support. However, support for women who wish to carry their child to term is lacking.

“How can we ensure that the support needed for families facing a prenatal genetic diagnosis is in place?”

Perinatal palliative care, which is not yet widely available in Canada, is an effective model for providing care and support to parents who receive a life-limiting diagnosis for their fetus. The provision of such a service enables the woman to have a true choice in these circumstances. Given this choice and the option of support throughout the pregnancy, 40% to 80% of parents choose to continue their pregnancy.³

This care may be a hopeful alternative for women, particularly considering that research has shown that

women suffer long-term psychological distress after terminating their pregnancy due to fetal anomaly⁴. Laurie-Beth, who aborted 10 years ago after her child was diagnosed with Trisomy 13, conveys her grief:

“I understand that those who counselled us thought they were sparing us more pain by helping us to ‘move on’. We were encouraged to put our daughter – Serena Brienne, we named her – behind us, and to try again to have another child, encouraged while being told our daughter would not live. There was no understanding of our loss, my loss, my grief, my guilt – for my feeling like I was giving up on my child – for my not doing everything I could for her.”⁵

Weighing the Scales?

Regardless of the degree of severity of the genetic anomaly that is diagnosed prenatally, further inquiry into the supports for parents before, during, and after decision-making is necessary. Dr. Michael Shevell, a Montreal paediatric neurologist, comments:

“To truly permit choice the counselling made available must be non-directive and value neutral... Yet little attention has been paid to this counselling process and the actual information content there-in. Reasonable concerns exist that a publicly funded program of detection and counselling occurring at a time of funding limitations will be driven by a cost-containment emphasis that may weigh the scales of choice in one direction.”

2. Abraham C, “Simple tests, complex questions.” *The Globe and Mail*. Saturday February 7, 2009.
3. Calhoun BC, Napolito P et al. “Perinatal Hospice: Comprehensive Care for the Family of the Fetus with a Lethal Condition.” *Journal of Reproductive Medicine*. 2003. 58(11):718-719.
Breeze ACG, Lees CC et al. “Palliative Care for Prenatally Diagnosed Lethal Fetal Abnormality” *Archives of Disease in Childhood; Fetal and Neonatal Ed*. 2007. 92(1):F56-58.
4. Kersting, A. et al. “Trauma and grief 2-7 years after termination of pregnancy because of fetal abnormalities”. *Journal Psychosoc Obstet & Gynae*. 2005. 26(1): 9-14.
5. <http://livingwithtrisomy13.org/prenatal-diagnosis-trisomy-13-essay3.htm>.
6. Shevell, M “Eugenics by another name” *Canadian Journal of Neurological Sciences*. 34(4): 494-95.

A Medical Detective Story

What You Felt Before You Were Born

"An unborn child is likely capable of feeling pain from the middle point of pregnancy", Dr. Ranalli said at the deVeber Institute's annual public lecture in October.

New understandings and evidence accumulated over the past two decades show that by the 20th week of gestation, the fetus possesses everything necessary for the fetus to feel pain. However, the systems that help adults inhibit pain are not developed until well after this time period. Therefore it is possible that the fetus may be experiencing extreme pain during an abortion without the internal coping mechanisms that we take for granted.

In North America, however, there is much denial of the subject, according to Dr. Ranalli. A review published in the Journal of the American Medical Association (JAMA) in 2005 purported to claim that a fetus could not feel pain until 29 weeks. The report's conclusion would imply that premature babies born from the time of viability, currently 23 weeks, would be unable to feel pain for the first 6 weeks of their lives. This concept was abandoned over 25 years ago, when neonatologists, recognizing the newborn's ability to feel pain, began giving anesthesia to newborn babies during surgery.

Nevertheless, the article continues to be cited by many as authoritative, a practice Dr. Ranalli believes is intended to provide moral cover for abortion providers. Dr. Ranalli described the article's conclusions as "so ghastly, the effect would be to set back the humane modern practice of child-centered pediatric medicine 20 years."

Dr. Paul Ranalli, MD, FRCPC is a neurologist, a lecturer and clinical instructor at the University of Toronto Medical School, and an Advisor to the deVeber Institute.



To hear more from Dr. Ranalli on Fetal Pain, order your copy of "A Medical Detective Story: What You Felt Before You Were Born." Now available for \$20. Email bioethics@deveber.org or call 416-256-0555.



Caring for the Disabled at the Time of Death

Joy, Challenges, Sorrows at End of Life **By Peter O'Hagan**

Three speakers emphasized to a full house both the joys and sorrows that accompany the caregiver as they journey with the dying. The event was "Compassionate End-of-Life Care for Adults with Developmental Disabilities", an evening co-sponsored by the deVeber Institute and L'Arche Toronto, and held at the L'Arche Gathering Place in Toronto on January 29.

Susan Morgan, a chaplain, spoke about her personal experiences in ministering to the dying, and expressed her concern about when people "retreat" from those who are dying. She insisted on the importance of "presence", reminding her listeners that their role is not only to be doing when attending to a dying person, but also just to be with them, sometimes even in silence.

Dr. Paul Zeni, a family physician and specialist in palliative care, emphasized the importance of a holistic approach to caring for the dying, pointing out that pain management is often the easiest of the many elements of care a patient requires. He discussed the importance of respecting the patient's wishes regarding methods and extent of treatment, emphasizing the need for continual communication between the patient and the caregiver.

The final speaker of the evening, Jane Powell, is an Assistant in the L'Arche community, who has completed a course of study in grief and bereavement at Western University. Her talk was focused specifically on the unique difficulties of caring for those with developmental disabilities as they grow weaker. In particular, she stressed the importance of the continual presence of someone who knows the patient well and is attuned to their particular needs.

Dr. Zeni called the time of death a "special time" as well as a frightening one, a time that holds great rewards for those who help their loved ones approach death with the dignity of fellow human beings.

One attendee gave the following feedback: "Each speaker brought a new dimension of learning to the topic. Each segment was productive and included concepts or practices that will benefit people I support."

All 3 talks are available on one DVD "Compassionate End of Life Care for Adults with Developmental Disabilities." Now available for \$20. Email bioethics@deveber.org or call 416-256-0555.

Why I support the Institute

"It was likely Solzhenitsyn who first warned of a coming "major turning point in world history... where the hierarchy of values which we have venerated... may collapse."... A welcome source of hope has come increasingly from the evidence that your Institute brings to the arena "the high qualities of mind and soul" the great Russian insisted would be vital."

From Don K D Smyth, supporter of the deVeber Institute's summer student research.

Will you help to fund our summer students in 2009?

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We are grateful to:

Philip Sung Design Associates Inc for taking on the deVeber Institute as their non-profit beneficiary.

Blaise Alleyne for his work in updating the design and functionality of the deVeber Institute website

Nathan Welch for providing photography services at our annual public lecture.

Your Donations Making a Difference

Thanks to your ongoing support, we have been able to achieve a number of new accomplishments this past year and extend our reach by:

- Releasing the new DVD "Women's Health at Risk: Abortion and Informed Consent"
- Designing a new website and newsletter to make the research more accessible
- Hosting our Annual General Meeting and public lecture at St. Michael's College, University of Toronto
- Responding to new prenatal genetic testing technology by issuing a press release with recommendations
- Making the Executive Director position full-time
- Hosting community evenings about palliative care

In 2009, with your continued support, we look forward to hosting our first conference, releasing new research on our website, and delivery more community talks.



Reproductive Decisions and Women's Well Being

Current Research and Practical Solutions

Are you concerned about the welfare of pregnant women? Join us on October 2nd, 2009 for a one-day conference in Toronto.

Morning speakers Dr. Deborah Zeni, Elizabeth Ring-Cassidy, and Andrea Mrozek will discuss what abortion means for women, and the latest research on Women's Health After Abortion.

Afternoon speakers will offer practical insights as social service providers who offer counselling and programming for pregnant women or women who have had abortions.

Registration \$75 include lunch.

Call 416-256-0555 or email bioethics@deveber.org today to find out more about special deals for teachers, social workers, nurses, counsellors and students.

We can provide documentation for nurses that can be used for Quality Assurance.

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