

SEMINAR SERIES
GLOBAL PERSPECTIVES ON DISABILITY, HUMAN RIGHTS AND
ACCESSING JUSTICE
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Disability, Dignity and End-of-Life Care

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Moderator:

Prof. Colleen Sheppard (Director, CHRLP & Professor, McGill University Faculty of Law)

Resource Persons:

Dr. Justine Farley, MD (Director, Palliative Care Team, St. Mary's Hospital, Montreal)

Mr. Joseph Arvay, QC (Farris Law, Vancouver)

Mr. Derek J. Jones (Lecturer McGill University Faculty of Law & Member, McGill Research Group on Health and Law & Centre for Human Rights and Legal Pluralism)

Commentator:

Dr. Jonas-Sébastien Beaudry (Boulton Research and Teaching Fellow, McGill University Faculty of Law)

Organized by:

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McGill Human Rights Working Group – Disability and the Law Portfolio

Summary of Seminar

Professor Colleen Sheppard introduced the topic for the workshop by observing that many countries are currently debating issues related to end-of-life care. Noting that Quebec has introduced legislation on “dying with dignity” and that there is ongoing litigation in British Columbia regarding the right to assisted suicide, the topic is timely. She clarified that the purpose of the seminar was to explore issues at the intersection of law, medicine and ethics: issues relating to human rights, dignity and end of life care. The intent would be to reflect in particular on the impact of these issues on the rights of persons with disabilities. The seminar would look at the broad topic of end-of-life care and not simply focus on the assisted suicide debate.

Dr. Justine Farley focused her presentation on defining what palliative care is, and used an example to illustrate the concept. With reference to the World Health Organization's definition of palliative care, Dr. Farley explained that it is an approach that addresses the quality of life of patients and their families who are faced with the prospect of a life-threatening illness. Regarding dying as a normal process, palliative care aims to provide relief from pain and other

distressing symptoms while integrating both the spiritual and the psychological aspects of human experience.

Dr. Farley framed her presentation around the case of a patient, “Don,” who at 59 years old suffers from colon cancer. Using the case as an example, Dr. Farley walked the group through the various stages of palliative care treatment. Dr. Farley emphasized that palliative care takes a team approach, with other health and non-health professionals forming part of the treatment team. Dr. Farley explained and discussed care planning, symptom management, family involvement and the planning of the dying process with the patient. At the end of her comments, Dr. Farley expressed some concerns about Bill 52 as proposed by the Quebec government. She indicated that she is concerned that many people do not understand what we are speaking about in regard to dying and end-of-life care. She is also concerned about the impact the proposed legislation could have on the budget for elderly care and resources for other health services.

Joseph Arvay, counsel for the applicants in [Carter v. Canada](#), began his comments by taking up the theme of palliative care. He stated that palliative care was front and centre in the case and that most (though not all) palliative care physicians were opposed to physician-assisted dying.

Mr. Arvay spoke about his experience litigating the issue of physician-assisted suicide (PAS). He observed that the arguments he was most concerned about were those presented by disability rights groups who opposed his clients’ application. He commented that the arguments put forward by the disability rights groups were founded on a particular theory of disability rights and not the actual experiences of persons with disabilities. The view of the main disability rights organizations is based on the social model of disability, which is to be contrasted with the medical model. The social model holds that while people may have physical impairments, it is really society that disables them (*i.e.* while a physical disability *actually* disables, society allows for design that *functionally* disables). The disability rights groups, according to Mr. Arvay, suggest that if the state permits physician-assisted suicide it essentially endorses the view that a disabled person is “better off dead.” The concern of the rights groups is that society and the medical community will adopt this message and that persons with disabilities themselves will eventually internalize it. Mr. Arvay’s response was that the court should not reject physician-assisted suicide based on this hypothetical argument.

Mr. Arvay also discussed how people with disabilities fall into three categories: those born disabled, those disabled in the prime of life and those who develop degenerative diseases later in life. He noted that it is the first category of individuals who seem most strongly opposed to PAS, as their experience of disability is fundamentally different from those who become disabled later in life. The second group is most affected by the argument based on the social model, but the concerns of the disability rights groups could be countered by imposing a significant waiting period on PAS. According to Mr. Arvay, this would allow the second group to put themselves in the same position as the first and thus make an informed decision about PAS. Finally, in Mr. Arvay’s view the prohibition against PAS has the harshest effect on the third group. For this group, being disabled is the reality of living with a serious medical condition that they view as intolerable. In his opinion, the “better off dead” argument is patronizing and infantilizing, and he rejected the idea that this group might be “brainwashed by ‘ableist society’”.

Derek Jones suggested that to complement evolving standards of palliative care and the deep challenges of PAS, Canada may draw on over three decades of international interdisciplinary experience to address end-of-life issues. He indicated, for example, that the reading materials discussion of "Baby Doe" regulations and litigation in the U.S in the 1980s ask whether it is discriminatory not to treat babies born with severe, often life-threatening disabilities. Beyond decisional accountability issues, such cases raise potent questions, including:

- Who is a “person with disability” if death confronts many of us who move from ability to disability near the end-of-life?
- In policy and cases, how do we prioritize and reconcile autonomy and substitute decision-making, discrimination and sanctity of life, risks of abuse and protection of the vulnerable?

The international experience, he noted, indicates society has basic processes for studying and answering such questions. These include the courts and the legislative process, deliberative democracy and public referenda, institutional and national interdisciplinary ethics committees. For example, as a member of some McGill hospital clinical ethics committees, he has seen the committees serve as policy advisors, sounding boards and conflict resolution bodies for divided families, for divided treatment teams, and in family versus hospital disputes over “tragic-choices” in end-of life cases.

Mr. Jones concluded his comments by recounting a notable experience with a durable power of health care attorney/advanced directive he had drafted under U.S. law for a family member disabled by a chronic ailment. Conversations a decade before had led to periodic revision of the document. Ultimately, the process and document enabled his dying family member, siblings and health professionals to manage difficult decisions towards a dignified death. He recommended more familial, clinical, interdisciplinary, public and legal discussion of disability, dying and death.

Finally, Dr. Jonas-Sébastien Beaudry offered comments on the broader concepts of dignity and the value of human life. Dr. Beaudry observed that these concepts can be muddy but they get to the crux of the issue. He stated that both sides of the debate use the concept of dignity as a basis for their arguments. In the debates around end-of-life care, dignity seems to mean two different things. Dignity can mean the autonomy of the person, implying that dignity means respecting the wishes of someone. Or dignity can be defined as the value that a human being has. Pointing out that both sides of the debate invoke the concept of dignity in support of their position, Dr. Beaudry suggested that when the idea of dignity is invoked, its meaning ought to be clear. Dr. Beaudry concluded his thoughts by suggesting that the voices of persons with disabilities should be “structurally integrated in the debate.”

At the end of the presentations, the period of open discussion addressed several questions: What role do or should resources and fiscal issues play in care of patients with disability in end-of-life care? Does denial of PAS constitute discrimination against those individuals whose disability will prevent them from stopping treatment or actively terminating their lives in the face of relentless suffering? Do elder neglect laws adequately protect and care for seniors, in nursing homes, who are disabled by age and physical ailment near the end of their lives?