November 9, 2016

Health Care Consent, Aging and Dementia: Mapping Law and Practice in British Columbia

BACKGROUNDER

Introduction

The Canadian Centre for Elder Law (“CCEL”), in collaboration with the Alzheimer Society of British Columbia (“The Society”), is embarking on a project which examines the law, policy and practice of consent to health care in the context of ageing and dementia. This 16-month project funded by the Law Foundation of British Columbia will involve extensive comparative legal research on informed consent and interrelated areas of the law, as well as community and key stakeholder consultation. The work will be informed by an expert interdisciplinary advisory committee and will culminate in a report identifying areas for law and practice reform and at least one plain language educational resource on health care consent rights.

Objectives

This project aims to:

• Document the experiences of people with dementia, their substitute decision-makers and the people who support them, with respect to use of medication and consent in BC;
• Summarize the law in BC with respect to health care consent;
• Map knowledge, policy issues, and legal concerns related to the use of antipsychotics and anti-depressants for people with dementia;
• Bridge a wide variety of social policy research with implications for legal practice;
• Identify differing and innovative approaches taken in other jurisdictions in Canada and the United States as well as the United Kingdom and Australia vis-à-vis law and policy around health care consent, particularly with respect to older adults;
• Suggest potential areas for law reform in BC;
• Raise further awareness on the right to informed health care consent among British Columbians;
• Produce a foundation of research that will support the key people engaged in this issue to appreciate the topic from a perspective that respects the rights of older adults, people with dementia, substitute decision-makers, family members and those who support people receiving treatment; and
• Publish at least one public legal education resource for people with dementia, substitute decision-makers and/or loved ones focused on helping people to understand their rights.

Project Methodology:

The Project will involve the following activities:

• Establishing a diverse project advisory committee that will meet approximately six to eight times to guide the work of the CCEL and The Society as needed on this Project;
• Interviewing a range of experts on the topic of medication, informed consent and older adults with dementia;
• Holding a series of focus groups providing people living with dementia, family members and substitute decision-makers with an opportunity to share their experiences in relation to informed consent, medication and treatment for adults living with dementia;
• Undertaking a comprehensive review of relevant legislation and jurisprudence in BC;
• Completing comparative research considering key jurisdictions in Canada and abroad, such as Ontario, the United Kingdom and Australia;
• Completing a literature review on the subject including social science academic material from journals and reports as well as publications from the legal community;
• Producing a report that makes recommendations for law reform for BC following a summary of:
  o The views and concerns of key professional stakeholders on the subject of medication, use of chemical restraints and treatment of older adults with dementia;
  o Findings from our interviews with people with dementia (who have capacity to consent to participate), substitute decision-makers, family members and those who support them regarding medication, use of chemical restraints and treatment of older adults with dementia;
  o Relevant legislation; and
  o Legal models and legislative provisions from other jurisdictions of note;
• Reviewing existing public legal education resources on the right to informed consent to health care and developing a straight-forward plain language resource for BC.

Rationale for the Project

Provincial and territorial data from Statistics Canada 2011 Census shows that BC has one of the largest growing populations of seniors in Canada. As our population continues to age many British Columbians will be affected by dementia. Although difficult to estimate, research suggests that between 60,000 and 70,000 British Columbians have dementia\(^1\), and many more are affected by dementia as caregivers, supporting family members, friends and loved ones.

\(^1\) Medical Service Economic Analysis, Health System Planning Division, Ministry of Health, Dementia (age 45+ years only) January 17, 2011, project 2010_372. Centre for Applied Research in Mental Health and Addictions, Simon Fraser University, 2006.
In recent years a number of studies have raised concerns regarding potential overmedication of older adults, especially the use anti-psychotics and anti-depressants to manage behaviours associated with dementia. For example, a 2011 Ministry of Health report revealed both significant use of antipsychotics and concerns regarding lack of appropriate consent to treatment and engagement of family in developing care plans. Then in 2015 the BC Seniors Advocate identified the overuse of both antipsychotics and antidepressants in residential care as an area of great concern, reporting that only 4% of seniors in residential care have a diagnosis of a psychiatric disorder, yet 34% of this client group are prescribed antipsychotic medications. The use of antipsychotics in residential care is primarily in response to the increasing number of residents with dementia. According to the 2015 BC Seniors Advocate’s report, it is estimated that up to 51% of residents in BC care facilities are taking nine or more different medications.

Chemical restraints are any form of psychoactive medication used not to treat illness, but to intentionally inhibit a particular undesirable behaviour or movement. Antipsychotics may be classified as a chemical restraint if their prescription is not intended for the treatment of schizophrenia or a related disorder.

There are many concerns with the use of chemical restraints in residential care, including:

- Antipsychotic medications are not intended to treat the symptoms of dementia and there is not robust evidence to support their use;
- Seniors who have a large number of prescription medications prescribed to them are at an elevated risk of adverse events, in part because potential side effects and drug interactions are often not explained to them, or their substitute decision-maker; and
- Side effects of antipsychotics range from unpleasant to debilitating and can potentially lead to misdiagnosis of conditions, such as Parkinson’s, resulting in even more incorrectly prescribed drugs.

Overall, despite a general knowledge that all antipsychotics, whether typical or atypical, are associated with increased morbidity and mortality in persons with dementia and should be used with caution, antipsychotics continue to be prescribed.

In response, resources have been developed to support enhanced practice. In particular, BC Care Providers Association published a Best Practices Guide for Reducing Anti-Psychotic Drug Use in Residential Care

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5 Seniors Advocate, “Placement, Drugs and Therapy”.
in 2013,9 and the BC Ministry of Health published Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care in 2012.10 However, there remains a need to develop a rights-based understanding of health care consent to supplant the dominant health care orientation. There is also a need to develop resources to assist health care decision-makers, health care staff, older adults and their loved ones to understand the scope of the right to informed consent.

The use of prescription of medication to manage symptoms of dementia raises legal issues related to health law, substitute decision-making legislation, workplace safety and human rights. Decisions regarding medication have a significant impact on quality of life and life expectancy, and older people and substitute decision-makers often do not appreciate the right to ask questions, explore alternatives and provide consent. Older people living with dementia are a vulnerable, growing subset of BC’s population; however, ultimately the issue of consent to health treatment matters to everyone, and the research of this project will support a robust understanding of the right to informed consent in BC which will benefit anyone receiving treatment or consenting to treatment on behalf of another. In particular, project findings will be of benefit to people living with disabilities other than dementia, as people in other communities, such as the community living sector, suffer from exclusion from health care decision-making due to assumptions around mental capacity and lack of respect for the right to informed consent.

Legal Background

Health Care Consent Law

In British Columbia, the law of health care consent for adults is governed primarily by the Health Care (Consent) and Care Facility (Admission) Act (“HCCA”).11 Pursuant to this Act, every adult is presumed capable of giving, refusing and revoking consent to health care12 and a health care provider cannot provide health care without first obtaining the adult’s consent.13 Health care is defined as “anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other purpose related to health...”.14 The legislation sets out the elements and scope of consent15 and the three limited exceptions to the requirement to obtain the consent of the adult: incapacity16, emergency17 and preliminary examination.18 Importantly, the legislation also sets out in descending order of hierarchy who may act as a temporary substitute decision-maker in cases of incapacity. The Act is said to be a codification of the common-law doctrine of “informed consent”.

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10 BC Ministry of Health, supra note 4.
12 HCCA, s. 3. See also Representation Agreement Act, s. 3.
13 HCCA, s. 5.
14 HCCA, s. 1.
15 HCCA, ss. 6-9.
16 If patient found incapable, may obtain consent from SDM: s. 11 (personal guardian or representative) and s16 (TSDM) HCCA.
17 Urgent or emergency health care: “in order to preserve the adult’s life, to prevent serious physical or mental harm or to alleviate severe pain”, s. 12 HCCA.
18 To “undertake triage or another kind of preliminary examination, treatment or diagnosis”, s. 13 HCCA.
The *Residential Care Regulation* deals with consent in the context of the use of chemical restraints.\(^{19}\) Only a few Canadian provinces have enacted health care consent legislation, the remainder preferring to rely on the common law doctrine.\(^{20}\)

A full examination of health care consent laws in British Columbia requires a review, not only of the common law doctrine of informed consent and statutory consent laws, but of the broader legal framework. This project endeavours to contextualize consent laws within this broader legal framework by also considering the following interrelated areas of law:

**Capacity and Substitute Decision-Making**

Where adults are found incapable, health care providers must obtain consent for health care decisions from their substitute decision-makers or make decisions in accordance with any advance directive. Advance directives provide legally binding instructions to health care providers regarding which health care a person consents to in the future should they become incapable and they are governed by the HCCA. Substitute decision-makers may be:

- Representatives under the *Representation Agreements Act*
- Temporary substitute decision-makers under the *Health Care (Consent) and Care Facility (Admission) Act*
- Committees of the person under the *Patients Property Act*

**Mental Health and Involuntary Committal Laws**

In British Columbia, a patient in need of psychiatric care can be involuntarily committed to a designated psychiatric facility and treated without their consent: pursuant to s. 31(1) of the *Mental Health Act*, treatment of an involuntary patient which is authorized by the director of the facility is "deemed to be given with the consent of the patient".\(^{21}\) This provision effectively enables adults with dementia to be admitted to residential care facilities and to be prescribed antipsychotic medications without the consent of the adult or their substitute decision-maker. This “deemed consent” provision is at odds with legislation in other provinces, such as Ontario, whereby consent must be given by the adult, or by the adult’s substitute decision-maker.\(^{22}\) The ability to use chemical restraints under Ontario is very limited. The “deemed consent” and related provisions are currently subject to a Charter challenge in the Supreme Court of BC.\(^{23}\)

**Health Care Regulation and Professional Responsibility**

In addition to provincial health care consent laws, regulated health care professions are required to comply with their governing bodies’ codes and standards, and are guided by internal guidelines produced by them. Some such governing bodies have standards and/or guidelines specifically addressing

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\(^{19}\) *Residential Care Regulation*, ss. 73-75.

\(^{20}\) Ontario, British Columbia, New Brunswick, Prince Edward Island and Yukon have health care consent statutes.

\(^{21}\) *Mental Health Act*, R.S.B.C 1996, c. 288, s. 31(1).


\(^{23}\) Mary Louise Maclaren, D.C. & Council of Canadians with Disabilities v. Attorney General of BC, Supreme Court of British Columbia; See also <http://www.clasbc.net/charter_challenge_forced_psychiatric_treatment>
consent to health care, such as the College of College of Registered Nurses of British Columbia. Others, such as the College of Physicians and Surgeons of BC, do not.

International and Domestic Human Rights and Discrimination Law

Canada is a signatory to the International Convention on the Rights of Persons with Disabilities, which broadly speaking promotes individual autonomy, the freedom to make one’s own choices, full participation, equality and non-discrimination, and in particular, under article 12, enshrines the right of people with disabilities to participate in decisions about their own lives. Further, British Columbian human rights law prohibits discrimination on the basis of age, disability and gender, amongst other grounds. In the context of a vulnerable population of older adults living with dementia, the interplay of disability, discrimination law and health care law is evident. Consequently, applying a human rights lens to a review of health care consent law as it affects older adults may provide an important perspective on this issue and help illuminate areas where people living with dementia are treated differently from people living with other forms of disability or other health conditions.

Workplace Safety Laws and Staffing Regulations

Employers have a statutory obligation under occupational health and safety laws to ensure the safety of all employees. Employers have an obligation to undertake a violence risk assessment and are responsible for educating and training workers in violence prevention strategies and informing workers of what they need to do if a resident becomes violent. In addition, the Residential Care Regulation sets minimum standards for staffing coverage and training—which must be appropriate to meet the needs of persons in care—as well as requires designated programming for the physical, social and recreational activities for persons in care. The relationship between staff safety, staffing coverage and training is highly relevant in the context of evidence which suggests that best practice for treatment of behavioural symptoms of dementia is “comprehensive, individualized assessment in order to provide person-centred care, with family and professional caregiver education and support”.

Project Committee Members

As with many CCEL projects, an advisory committee will provide ongoing project guidance regarding research and consultation methodology, key stakeholders and recommendations to flow from research. The advisory committee members are:

Alix Adams, Manager, Palliative and Dementia Care, Seniors Services Branch, Ministry of Health

26 Workers Compensation Act, R.S.B.C 1996, c. 492, s. 115
27 Occupational Health and Safety Regulation, B.C. Reg. 296/97, s. 4.27 to s. 4.31.
29 Residential Care Regulation, ss. 45 & 55.
Tara Fitzgerald, Quality Leader, Seniors Care, BC Patient Safety & Quality Council

Isabel Grant, Professor, Peter Allard School of Law, University of British Columbia

Laura Johnston, Staff Lawyer, Community Legal Assistance Society

Michael Kary, Director of Policy and Research, BC Care Providers Association

Alison Leaney, Provincial Coordinator, Vulnerable Adults Community Response, Public Guardian and Trustee

Marth Jane Lewis, Executive Director, BC Centre for Elder Advocacy and Support

Barbara Lindsay, Director, Advocacy & Education, Alzheimer Society of BC

Isobel Mackenzie, BC Seniors Advocate

Jim Mann, Person living with dementia

Dr. Deborah O’Connor, Professor, School of Social Work, and Co-director, Centre for Research on Personhood and Dementia, University of British Columbia

Lisa A. Peters, Partner, Lawson Lundell LLP and Chair, BC Law Institute

Michael Vonn, Policy Director, BC Civil Liberties Association

Penny A. Washington, Partner, Dispute Resolution & Litigation, Bull Housser

About the CCEL

The CCEL carries out scholarly research, writing, analysis and community engagement relating to legal and policy issues that impact older adults. As part of its work the CCEL consults with stakeholders, collaborates with numerous community agencies and publishes legal, policy and practice resources including recommendations for law reform and public information materials. The CCEL is a division of the British Columbia Law Institute, BC’s non-profit independent law reform agency.

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