Physician Assisted Death/Suicide and Mental Illness
Sheila Lacroix, Centre for Addiction and Mental Health (CAMH)

An information request I posted on SALIS-L last December generated so much interest that I was asked to prepare a report of my findings to share with SALIS members. It was about whether or not there are any studies or position papers that address the opinions of psychiatric patients, or their advocates, on access to medical assistance in dying (MAID), also referred to as physician-assisted death (PAD). Very little literature exists; the role of psychiatry is generally directed to assessing competence in MAID cases for the relevant illness. Given the current situation in Canada, I wanted to elaborate on the topic.

Canada is currently at a crossroads. In 2015, the Supreme Court of Canada decriminalized MAID, but a gap has been left until legislation is drafted to control and set standards. The Supreme Court deadline of one year for parliament to draft legislation and a regulatory framework was extended by

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SALIS/AMHL 2016
Welcome to Denver!
May 4-7, 2016

A Broader Vision: The Value of Multidisciplinary Lenses

Time to start packing your suitcases, folks, because the 2016 SALIS/AMHL conference is just 3 weeks away! If you haven’t checked in on the conference website lately, you might want to take a peek. We now have a draft of the program available, which includes exciting invited speakers like:

- Jeffrey Beall, associate professor at Auraria Library (UC Denver), critic of the open access movement, and keeper of the oft-used-by-librarians “Beall’s List of Predatory Open Access Publishers;”

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a further four months, to June 2016. A joint parliamentary committee was formed to make recommendations. Its report, *Medical Assistance in Dying*, was released February 2016, and calls for MAID to be accessible in publicly-funded health care institutions for Canadians with terminal and non-terminal medical conditions that cause enduring and intolerable suffering. People with psychiatric conditions are included for eligibility if they meet criteria set in the Supreme Court’s decision, which includes being competent or capable to make decisions.

This might look straightforward in theory, but not so in practice. There continues to be a flurry of discussion in the public forum as a result of the committee’s recommendations, so this article is definitely timely.

After reviewing the literature, not much was found about the work or recommendations of psychiatric advocacy groups. Also, there is not a lot of literature about MAID for those suffering from non-terminal medical conditions such as mental illness and addiction. The bulk of the literature addresses those suffering from terminal illnesses, such as ALS or advanced cancer, or the complexities of advanced directives for Alzheimer’s patients. In such cases, MAID is, in effect, hastening dying when death is imminent.

Depression, comorbid with other medical conditions such as AIDS, has also been studied and documented. Treatment of comorbid depression has been found to positively affect the quality of life of those with a terminal illness. There was also ongoing debate for many years on the ethics of force-feeding anorexic patients; a decision in a medical setting made to stop eating could be considered assisted dying. But what about non-terminal patients who are in constant emotional or physical pain?

From my readings, three issues come to the forefront.

**The Recovery Model.**

Our health care model in Ontario, Canada and elsewhere now embraces the recovery model. This recognizes that the lives of those suffering from mental illness and/or addiction can improve, and that the desire to die may be transient. It might be a rocky road with ups and downs, but there is hope for a better life. We witness and celebrate our patients’ recovery at CAMH all the time. A downside is that society and governments still don’t provide enough treatment and supports to promote rehabilitation. This should continue to be a priority. MAID could seem at odds to the recovery model, posing a conflict of interest for the psychiatrist or other mental health professionals trained to prevent suicide (Appel, 2007).

Insufficient medical care and psychosocial supports, such as adequate housing, have been highlighted in recent media reports and opinion pieces. The recovery model and MAID may not be mutually exclusive, but most would agree the recovery model emphasizes the bigger picture of care essential to supporting those suffering from mental illness and addiction.

**Stigma.**

It is interesting how the language is changing. More frequently we see “assisted dying” instead of “assisted suicide,” although the latter, “suicide, assisted,” is still the Medical Subject Heading (MeSH) assigned by the U.S. National Library of Medicine to index literature on this topic. Those of us in the field are acutely aware that stigma still affects attitudes towards mental illness and addiction.

Although one can readily imagine a terminally ill person saying farewell, surrounded by loved ones, we can't bear the vision of a lonely distraught mentally ill person ending his or her life, usually alone, often violently. Suicide remains a frightening and stigmatizing word, typically associated with mental illness. As the former scenario is usually associated with one dying from a somatic, incurable illness and the latter with one involved in a mental health crisis, could this support attitudes that exclude the mentally ill from MAID? A person experiencing extreme suffering from mental illness may want to die, but not by suicide. Will the more rational, clinical “assisted dying” construct embrace the needs of those previously moved to suicide or will it create yet more stigma by separating the pain and suffering of the mentally ill from that associated with somatic illness?

**Free Will and Accessibility.**

Canadian novelist Miriam Toews’ book *All My Puny Sorrows* tells the story from the point of view of the sibling of a beautiful and brilliant musician who struggles with her sister’s plea for assistance to end her life. Toews’ novels borrow from her own life experiences. She is from a family affected by mental illness; both her father and her sister died through suicide. In spite of the disturbing content of her books, she has an endearing writing style that somehow makes her tragic stories

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palatable.

I thought of this novel when I read one of the few studies that addresses MAID for the mentally ill (Thienpont et al., 2015). Under Belgium’s euthanasia law, in effect since 2002, unbearable psychological suffering resulting from a mental disorder is a valid basis for MAID, but with stricter criteria than for somatic illness. Thienpont and his team studied case notes of 100 consecutive cases of patients who requested MAID as a result of “unbearable and untreatable psychological suffering due to psychiatric illness.” Of these, 48% of the requests were accepted.

This study is worth a read, and fortunately is published in an open access journal. The authors address the issue of the concept of unbearable suffering, and how it remains to be adequately defined. One outcome is interesting; 11 of those approved for MAID decided to postpone or cancel. Of these, 8 responded that knowing this option was available gave them peace of mind. It is also interesting to note that most of the 100 candidates suffered from either treatment resistant mood disorder and/or a personality disorder.

A very recent paper from the Netherlands (Kim et al., 2016) also provides data from narrative summaries on 66 MAID psychiatric patients, 6 of whom were substance abuse cases. These studies are based on very limited data and small samples, so it is premature to draw any real conclusions. It might be worth exploring why some mental disorders are more prominent within the cases. This makes a case for a robust reporting arrangement in Canada to help monitor and inform practice.

Only the Benelux countries, The Netherlands, Luxembourg, and Belgium, support MAID for psychiatric patients, so there is not much precedence or research to guide policy. Looking at sparse current data, MAID requests from psychiatric patients are a small percentage of total requests: 3% in Belgium (Thienpont et al., 2015).

Like many ethical issues, it cannot be viewed in black and white —there are different lenses that must be respected. All we can hope for is a humane and just system, meeting the range of needs of patients, caregivers, and health care professionals, and that MAID, which seems to be moving towards legitimacy in Canada, will be just one of many options on the continuum of care.

The release of Medical Assistance in Dying has provided a structure for opening up the discussion; the media continues to be flooded with editorials, letters and positions from organizations, professional associations, religious groups, and members of the public. The next four months, not to mention the next few years, will be challenging! The author thanks Kevin Reel, Ethicist and Interim Discipline Co-Chief for Occupational Therapy at CAMH, for reviewing this paper and providing insightful comments and support to address this challenging subject.

Bibliography


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SALIS News, Vol. 36, No. 1

Julie Netherland, Director of the Office of Academic Engagement for Drug Policy Alliance;

Dana Abbey, NN/LM Colorado coordinator and Health Information Literacy Coordinator at the Univ. of CO Health Sciences Library.

Presentations from SALIS and AMHL members on a wide range of fascinating topics will complete the agenda. Once in Denver, you’ll also find tons of things to do, and the weather will (should/better!) be fantastic. Hope to see you there!
Donations have come in this year—thank-you to Nancy Sutherland, Peggy Oba and Anonymous for their generosity.

There will be a presentation on Digs at the SALIS-AMHL Conference in Denver, coming up in about three weeks, and a workshop for those of you who are serious about our efforts and want to learn more or join the team.

There is much to learn, and it provides a great experience, not just with the project, but with interacting with other SALIS members and colleagues in a giving back, public good spirit.

If you are unable to come to the conference, and would like to know more about the presentation and workshop, there will be a write-up for SALIS News Summer issue and we will try to keep you informed in other ways as well. Christine Goodair is tweeting about us via the SSA Society for the Study of Addiction, and it has been a top tweet.

Please tell your patrons about the project, and show them The SALIS Collection.

There is more activity happening with the Digs Project, but the bottom line is we need more books and docs, and more funding. Please, if you have not yet gotten involved with this project, what are your reasons?

We especially need historical and pre 1995 materials---those government docs that were not born digital, and need to be digitized. Or maybe you have digitized materials and would be willing to send us a copy to upload to the SALIS Collection, making them more universally available.

We now have 644 items in The SALIS Collection, but need to raise more funds to digitize the rest of the NIAAA Library.

Also, as mentioned in the last update, we would like to start collecting more of the Other Drug literature, i.e.:

- Marijuana
- Cocaine
- Opiods
- Psychedelics
- Methamphetamine
- Smoking and Tobacco.

The SALIS Collection: Alcohol, Tobacco, and Other Drugs

The SALIS collection includes key seminal, full-text books, reports, documents, and other literature on the study of addiction, including alcohol, tobacco, other drugs, and related topics.

Donate at: http://salis.org/digitizationproject.html

https://archive.org/details/salis
The other day, when viewing the condensed shelving of my library’s many 4x6 inch daily meditation books, my thoughts kept moving to the “world” of books published within the addictions field. How many alcohol/drug/addiction titles exist? Who publishes them? What are the trends? It seemed a worthy topic to explore . . .

There were 9,260 books published in the United States in 1907. In 2010, there were 328,259 books published traditionally, plus about 3.8 million published non-traditionally or on-demand! In all of modern history, 130 million books have been published. To look at that another way, the number of words in the English language is estimated to be 1,019,729 words, which equates to 127 books for every word in the English language (Chernoff)!

In 2013, the top two countries in the number of books published were China (440,000) and the United States (304,912). Total new titles and re-editions published that year worldwide: approximately 2,200,000 (Wikipedia).

Who publishes all these alcohol/drug/addiction books?

Just as I did not find an estimate of the number of addiction books, I also did not find a single article examining the addictions book publishing field, nor an overview/history of specific addiction book publishers. No articles were found despite scouring the literature in databases such as Academic Search Premier and Library, Information Science, and Technology Abstracts. Because so few publishers have a distinct focus on addiction/recovery, it is a challenge to find any aggregated addiction/recovery publishing data over the years (HBFF, 2014). There are also very few publishing journals per se which would include this type of overview article. Two key industry publications would include Publishers Weekly and Library Journal.

All publishers face dramatic changes in the external environment: the transition from a print publishing company to a media company, the utilization of increasing distribution channels, the reach to multiple markets, e-books versus print books, print on demand, accessible publishing, green publishing, and expanding topics—often with an international audience in mind.

Publishers with a self-help/addiction/recovery focus to at least some of their titles would include Capizon Publishing, Central Recovery Press, Conari Press, Guilford Press, HarperElixir, HarperOne, Hazelden Publishing, Health Communications Inc., and New Harbinger. Diversification, rapidly changing technologies, and even higher standards of customer expectations also have huge impacts to all these publishers.
In their 2014 annual report, Hazelden Publishing listed:
- 41 new products,
- 45 new distributed products,
- 8 new services and trainings,
- 19 new e-books,
- 5 new mobile apps,
- 12 translation rights, and
- 11 new subscriptions.

Now back to those small meditation books. The first “modern” addiction meditation book was *Twenty-Four Hours a Day*, by Richmond Walker, published in 1954 by Hazelden Publishing. It has sold over 9 million copies to date, and continues to be a best seller. It is also now available as an app from iTunes/Apple App Store.

Other “addiction meditation book” statistics include:
- 47 active meditation titles from Hazelden Publishing;
- 200,000 print copies of meditation books sold annually;
- 25,000 e-book meditation titles sold annually;
- 9 meditations titles available as apps, with annual sales of 25,000;
- Hazelden Publishing also has a free meditations app called *Inspirations*, with 41,000 downloads in 2015, and life-time downloads of 100,000.

It is interesting to note that the number of print meditation books sold is far larger than the number of e-book meditation books sold.

Two free apps, Inspirations and Today’s Gift, exemplify Hazelden Publishing’s mission to share their products to a diverse and extended audience, their responding to customer demand for access via changing technology (mobile devices), and their desire to share the hopeful and inspirational message of recovery freely into the public good:

**Inspirations** (available for Apple and Android) is a free collection of daily meditations.

**Today’s Gift** is a free email service of the Hazelden Betty Ford Foundation through which an uplifting, thought-provoking, self-esteem-building message is sent daily to those who subscribe. [http://www.hazelden.org/web/public/todaysgift.page](http://www.hazelden.org/web/public/todaysgift.page)
Mary Kelly attended the NIAAA Advisory Council Meeting, Friday February 12, 2016 representing SALIS, as a Liaison member of NIAAA. Using the SALIS newsletter article, The SALIS Collection Hits Its Goal and Keeps on Going! by Andrea Mitchell (v. 35(4)), Kelly briefed NIAAA Director, Dr. George Koob, and senior staff on the status of the SALIS Digitization (Digs) Project with the Internet Archive and its growing list of titles, thanks to the financial and resource support of NIAAA and others.

NIAAA staff made several suggestions such as linking to the SALIS Internet Archive from the Collaborative Research on Addiction (CRAN) and encouraging us to find and upload materials that address disparities in minority health. Another staff suggested that we inquire about including the materials from the Fetal Alcohol Syndrome Disorder (FASD) Center for Excellence, whose website will be going dark in the near future.

These suggestions, contact information, and other recommendations for future meetings with NIAAA were sent to Andrea Mitchell, Digs Project Director.

Dr. Koob also directed two staff members at the meeting to contact NIDA and encourage that institute to support SALIS and upload drug abuse related materials to the Internet Archive.

Mary Kelly, recently retired from JBS International, Inc. attended the NIAAA Advisory Council Meeting in place of Dr. Nita Bryant, who was not able to attend because of a family emergency.
Members’ Corner
Compiled by Diane Van Abbe
Membership & Outreach Committee

Leslie Marlow
Director, Library Services & Knowledge Mobilization
Nevada Prevention Resource Center (NPRC), University of Nevada, Reno
lmarlowe@casat.org
http://www.NevadaPRC.org

How long have you been a member of SALIS?
Just over 1 year.

What organization do you work for and what is your position?
Nevada Prevention Resource Center at the University of Nevada – Reno. I am the Associate Project Coordinator.

How has being a member of SALIS enriched your life?
I learn a lot through the various emails. I also was able to use the SALIS Collection at the Internet Archive to help me with an MLIS course that I took.

Hobbies outside of work:
Currently: Hiking, crocheting, writing, reading, volunteering.

Favorite food:
Hmmm . . . easier to answer what I don’t like. Unfortunately, I like most baked goods.

Favorite book:
Many favorite books. I have always loved Gone With the Wind and Marjorie Morningstar as a couple of examples. I read a wide variety of materials in most genres.

Is there anything else you would like SALIS colleagues to know about you?
Libraries are a second career that I started while trying to raise children. My primary career has been as an attorney. I am still an active member of the Florida Bar but stopped working full-time in law in 2005 due to the needs of my children, the youngest of which just reached 18 in 2015.

Want to nominate someone to be profiled in Members’ Corner? Email Diane Van Abbe at diane.vanabbe@camh.ca.

SALIS Election 2016
Compiled by Nominations Committee members Judit Ward, William Bejarano, and Chad Dubeau

Chair Elect

Barbara Seitz de Martinez
PhD, MLS, CPP
Deputy Director and Head Librarian
Indiana Prevention Resource Center, School of Public Health
Indiana University – Bloomington

Dr. Barbara Seitz de Martinez is Deputy Director (since 2005) and Head Librarian (since 1990) at the Indiana Prevention Resource Center, part of the department of Applied Health Science, IU School of Public Health. She holds a PhD in Communication and Culture with a minor in Latin American Studies from IU.

She initiated GIS in Prevention (IN) County Profiles as a library service in 2002; created an Hispanic-Latino portal to substance abuse and health related topics in the 1990s; introduced a searchable database of resources for Veterans in 2009; launched a virtual HOME library (exporting records from InMagic into Access) in 2009; and has continued to expanded the site over the years, adding many topical e-Resource databases, including an extensive collection of online videos and webinars.

Another area of research interest is cultural competency and health disparities. She has presented papers on topics related to these themes at NPN, APHA, SALIS (Substance Abuse Librarians and Information Specialists), and at IN, WI, and OK state prevention conferences.

She has the world’s sweetest husband, six children, and a plethora of grandchildren and great grandchildren in Nicaragua. She has two cats and loves to go on walks, dance, and do step classes. She chaired for many years and continues as a board-member of Bloomington-Posoltega (Nicaragua) Sister Cities Committee, and is a board-member of Indiana Latino Institute.

A member of SALIS since 1990, she has served as Chair (1997-1999) and Secretary (2011-2013), and hosted the 21st Annual SALIS Conference in 1999.

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Christine Goodair, BA (Hons), FRSA
Programmes Manager
(Substance Misuse) St. George’s, University of London

Christine has been a member of SALIS for more than 10 years and has been SALIS secretary and Chair. She is currently a member of the Advocacy Group and involved in the SALIS Internet Archive Project, and writes regularly for SALIS News. Christine was very active in ELISAD the European sister organisation which merged with SALIS a few years ago. Standing to be a member-at-large Christine hopes to bring a European perspective to SALIS underpinning its stance as being an international organisation. She has worked in drug information services but is now in the academic sector, based at St George’s, University of London, managing research projects on substance misuse. Christine continues to have an information role with the Society for Study of Addiction and is responsible for maintaining the resources section of their website as well as running their current awareness service via Twitter.

Isabelle Michot, MS
Observatoire Français des Drogues et des Toxicomanies (OFDT) - French Monitoring Centre for Drugs and Drug Addiction, Saint-Denis, France

After a master's degree in biology, Isabelle Michot has specialized in scientific and technical information. She has worked eight years as an information specialist in an association that funds research on alcohol and joined afterwards OFDT in 2004. OFDT’s documentation center is dedicated to its staff of researchers and its partners. It is considered as the AOD national resource center in France. Isabelle works on the online catalogue, conducts literature searches and bibliographies and supports her colleagues for their publications. She also occasionally replies to media requests. She is a member of a French public health network, producing bibliographic records for its database and a member of the writing committee of a French journal on drugs (Swaps). She has been an ELISAD member from 2005 onwards – the 23rd ELISAD annual meeting has been hosted by OFDT in 2011 – and she is a SALIS member since 2008.

Sonja Mertz, MLIS
Prevention Research Specialist
Minnesota Prevention Resource Center (MPRC)

Sonja Mertz, MLIS, has been the Prevention Research Specialist at the Minnesota Prevention Resource Center (MPRC) since March 2013. In this role, she manages the MPRC’s website – updating ATOD online resources, creating state-wide event materials, and adding news and research items. Sonja inherited a catalog-less library when she began at MPRC, so the past two years have been spent organizing, weeding, and cataloging each item. Midway through this process, MPRC decided to eliminate its clearinghouse of ATOD materials and downsize the physical library items. Sonja has since then been making collection decisions and reallocating items to other organizations in Minnesota. Before coming to MPRC, Sonja completed a practicum at the University of Minnesota Biomedical Library. While completing her library degree at St. Catherine University, Sonja worked as a research assistant for that institution’s Holistic Health Department. Being a member of SALIS has been an important part of Sonja’s work at MPRC and in the ATOD field, in general. She would be honored to serve as a Member-at-Large and contribute to this invaluable organization.
New Books
By Andrea L. Mitchell, MLS, Librarian

+ government document
* non-English title

Buy books at Amazon.com to support SALIS!


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Have You Seen?

NIH recently held a two-day summit titled “Marijuana and Cannabinoids: A Neuroscience Research Summit,” featuring presentations from experts in the field addressing the endocannabinoid system, impact on brain development and function, psychosis and addiction, policy research, and the therapeutic potential of cannabis in treating epilepsy, MS, pain, and PTSD/anxiety.

Videocasts of both days are available for viewing online:

Day one: https://videocast.nih.gov/summary.asp?Live=18464&bhcp=1