

JEMH Update

The Journal of Ethics and Mental Health is pleased to present this issue which offers a range of peer reviewed articles, frontline perspectives and book and media reviews, as well as other interesting contributions. As a result of technical difficulties, this is the only issue of the Journal this calendar year. We anticipate resuming our normal publication schedule in 2011.

Please note that the Journal of Ethics in Mental Health will be holding our annual ethics and mental health conference in Kelowna, British Columbia, May 12th to 14th, 2011. The theme of the conference is “Ethical Challenges in Service Delivery and Design”. A call for papers and presentations has been issued. Additional information about this conference is available on the JEMH web site at: <http://www.jemh.ca>

On behalf of the Journal’s Board of Directors, I wish to express my sincere appreciation to the many volunteers and contributors who make the publication of our Journal possible. In particular, the members of the International Editorial Board have provided remarkable assistance to the content and quality of the Journal. Thank you.

Ron Ballantyne MSW MBA
Editor-in-Chief
e-mail: BallantyneRon@rogers.com

LETTERS

Dear Mr. Ballantyne

Thank you for publishing the article, "Direct Intervention in the Brain: Ethical Issues Concerning Personal Identity" by F. Focquaert and D. DeRidder in the November 2009 issue. It led me to rethink what personal identity is about, vis-à-vis my own history of who I am as context for this reflection, combined with research leading to the French philosopher, Paul Ricoeur, and his writings, especially his three volume opus, *Time and Narrative* (1983-1985). Though this work is certainly pertinent to the article's topic, neither these books nor any other of his works were cited in the article mentioned.

My main point in response to the authors, though: Their perspective is not global enough for their conclusion to be convincing, "Overall, from a cost/benefit perspective, the possible benefits of DBS [deep brain stimulation] for treatment-resistant neurological and neuropsychiatric disorders outweigh the possible harm of narrative identity change."

The crux here: The authors limited personal identity to *idem-identity* or sameness of person in space time, i.e., its persistence, at the expense of *ipse-identity*, or ipseity -- selfhood entertaining questions such as "Who am I?" and "Does there need to be an other for me to be the one I really am?"

Surprisingly, however, this is not necessarily a negative criticism of the authors' point of view.

That is, when *ipse* is added to *idem* in one's assessment of cost/benefit or risk/benefit to personal identity of a particular medical intervention such as neuromodulation via a subcortical implant, it's possible that it is not the medical practitioner who has ultimate control of the outcome but the person being treated, who may decide years later that he or she can no longer bear up to a regimen of direct -- or even indirect -- brain stimulation. Such action may even be unexpected by the attending physician, yet can arise from the initiative a human person takes for himself or herself *ipse* to choose instead a completely different approach to having a more functional and meaningful life.

I speak from personal experience, as under the Americans with Disabilities Act, I am disabled, having had struggled in the workplace with depression, anxiety, and OCD, for example. Nonetheless, I decided not to undergo shock therapy, and after years of being on prescribed medications and taking talk therapy, stopped doing that, too. What happened from taking initiative for my own 'treatment' was actually the discovery that I had tried so hard to be someone I really was not. My "sameness" over time had been a seemingly intractable desire to make my own life, choose my own identity, until circumstances finally led to a freely taken decision to give up all I had worked my entire adult life to achieve and be, and to start all over with the one I really

am. No narrative story spoken by anyone else could have revealed this one to me, no psychoanalysis, no relief of the incessant pain experienced emotionally and in many other ways. What did it was an awareness of what had really happened to me, including injury experienced at other people's well intentioning hands. Thus the DSM-IV in effect amounted to a medical Gulag from which I emerged not only a seared survivor, but now someone who does have a life after all, who knows he is loved -- who is fully human.

Accordingly, my narrative identity *has* changed, has conformed itself to my *ipse* identity as true, real, substantial being. Correspondingly, my symptoms have changed, too -- they are gone, even that nasty, seemingly intractable one of restless leg syndrome.

Life and love in relationships with others, those are more convincing as gold standards for analyzing ethical -- actually, moral -- issues regarding effects of medical interventions on personal identity and its expression in space-time, issues really brought to the fore when one's mental health hangs in the balance.

Thank you.

Sincerely,

Harold M. Frost, III, Ph.D.

President & Owner
Frosty's Physics, LLC
P.O. Box 135
Sheffield, VT 05866 U.S.A.

Visiting Scholar
Department of Chemistry
Dartmouth College
Hanover, N.H., USA

E-mail: halfrost@charter.net

Influenza Pandemic, Mental Illnesses, Addictions

Barbara Russell, MBA, PhD

Ethicist Centre for Addiction and Mental Health

Toronto, Canada

ABSTRACT

While public health ethics typically deals with issues wherein individual well-being competes with the population's well-being, it also deals with competing groups' well-being. Public health responses to the Chicago heat wave and Hurricane Katrina were strongly criticized, in part, because certain groups of people experienced far greater and longer-lasting losses compared to others. Differences in experience were largely due to socio-economic-political disadvantages or vulnerabilities. This article is written in light of the recent first and second "waves" of the H1N1 pandemic in Canada. Its focus is on people living in the community with a mental health or addiction problem during the pandemic and, more specifically, in the context of supplies of anti-viral medications and vaccines being limited. The article explores how certain social justice concerns may increase the risks of serious illness or death for these people and the kinds of compensatory responses that might be implemented.

Key words: influenza; mental illness; addictions.

Since mid-2008, healthcare organizations, governmental offices and the media have directed more and more attention to public health and public health ethics in the guise of responding to the possible global spread of the avian flu virus and then an actual pandemic of swine flu. Ethics related questions have included individuals' right to be free of others' demands, individuals' duty to protect the public, healthcare workers' duty to place themselves at risk in caring for the ill, healthcare organizations' duty to keep workers as safe as possible, governments' duty to purchase and distribute sufficient effective anti-viral medications and vaccines, and developed countries' duty to help developing countries combat the virus' spread.

In a post-Katrina article, communications PhD candidate Brabham notes that

discussions about Hurricane Katrina's aftermath have expanded to include design failure in the spheres of economics, federal and local governance, policing and public safety, recovery logistics, and even race relations, at long last connecting the current problems diachronically with events long past.¹

Instead of "planning and preparedness," he suggests "design and recalibration" to help emphasize the necessity of explicitly establishing foundational considerations and of testing these foundations as events unfold and new knowledge emerges. Calhoun also notes that a rhetoric of preparedness can distract attention away from needed work on systemic problems.²

It appears that Canada's second wave of swine flu has ended. This is therefore an opportune time to examine what has been done and debated thus far because serious infectious diseases are ever present. Influenced by Brabham's suggestion, this paper examines "foundations" relevant to access to anti-viral medications and vaccines and seeks a possible recalibration of distributive priorities vis-à-vis people living with a serious mental health or addiction problem.

Vulnerability:

What constitutes vulnerability? *Vulnus* is a Latin noun for "wound."³ As an adjective, it can mean the potential to be harmed or to suffer a loss. Vaughan and Tinker explain vulnerability as "increased potential loss in a hazardous situation, including reduced capacity to respond effectively."⁴ Zion et al say that people are vulnerable when they "lack basic rights and liberties that make them particularly open to exploitation."⁵ The WHO's Council for the International Organization of Medical Science's Guidelines describe vulnerable people as "those who are relatively or (absolutely) incapable of protecting their own interests. More formally, they may have insufficient power, intelligence, education, resources, strength or other needed attributes."⁶ Reviewing recently published books about the sociology of disasters, Tierney characterizes decades of research as a growing "vulnerability science" wherein a disaster should no longer be considered as simply the outcome of a physical or natural event.⁷ Instead, it is the outcome of factors about the person experiencing it, his physical and environmental surroundings, the general population, government, and societal organization.

Yet some people question the concept's salience. Luna identifies various negative consequences from its use: to be vulnerable or belong to a vulnerable group can mean that a person is perpetually, inescapably, and definitively deemed vulnerable.⁸ This can result in other people labeling and pitying her, which is demeaning. "Don't think that 'someone is vulnerable,'" says

Luna, “but look at the ‘particular situation that *makes* or *renders* someone vulnerable.”⁹ She is made vulnerable because of other people’s actions, organizations’ actions, or her circumstances. For instance, Kipnis identifies seven types of vulnerability of children who are being considered as potential subjects of research.¹⁰ Luna recommends characterizing the concept of vulnerability in terms of layers in order to metaphorically reinforce its multiplicity, co-occurrence, inessential-ness, and disparate causes.

Levine et al hold that despite its frequent use, vulnerability as a concept has escaped adequate critique in terms of its meaning and validity in ensuring that appropriate protections are in place for research subjects.¹¹ The term now is applied to most groups of research subjects, is applied equally to all subjects within a group, and tends to focus on only one attribute. The authors suggest that researchers and Research Ethics Boards consider instead which protocols require “special scrutiny” because of the ethical challenges involved.

Turning to influenza pandemics and the question of antivirals and vaccine access for people with mental health concerns, the discussion that follows will refer to risk, not vulnerability, for three reasons. First, “the current healthcare system has placed the source of vulnerability [to be] *within* the individual,” says Saunders in reference to hurricane Katrina’s impact.¹² Similarly, Calhoun worries about trends of making individuals fully responsible for preventing certain harms from occurring, and thereby fully liable, when in fact systemic factors contribute significantly to these harms.² Just as autonomy should be considered a relational, rather than independent capacity, so too should vulnerability.^{2,6} Second, to me, “risk” seems a less paternalistic word. Third, current pandemic planning already attends to biophysical risks of becoming seriously ill or dying from the H1N1 virus. I will argue that factors relevant to mental health and addictions should be considered on par with these biophysical risks when setting priorities for accessing scarce or limited preventive and treatment measures. Accordingly some risks will reflect biophysical realities. Others will reflect economic, political, and sociological realities. As Schrecker notes, acknowledging “true” reality means including “competing everyday survival needs” too.¹³

Social justice exists when the burdens and benefits of communal life are shared equitably and when each person counts equally in terms of recognition, voice, and well being.^{14,15} Conducting a “social autopsy” on the 1995 Chicago heat wave, Klinenberg pointed out that “the processes through which [almost 70016] Chicagoans lost their lives followed the entrenched logic of social and spatial divisions that govern the metropolis.”¹³ Social justice worries arose again after Katrina devastated the U.S. Gulf Coast and New Orleans in 2005.^{1,7,12,17-20} Because “policies that fail to take account of the realities of individuals’ lives and the social contexts in which they live cannot hope to succeed”²¹, governments, social service organizations, clinicians, and academics have become more concerned about the predicted impact on at-risk groups when an emergency or disaster occurs.

In a 2007 study by Uscher-Pines et al, most of the 37 national influenza pandemic plans studied linked vulnerability to biophysical factors that increase the likelihood of acquiring or transmitting the virus.¹⁵ Only ten plans referred to groups with special needs or socially disadvantage. Just two plans discussed

barriers to accessing vaccines or anti-viral medications. Laurence Gostin, a law professor at Georgetown University who has written extensively on global and public health, law and ethics, states that,

swine flu is largely innocuous for otherwise healthy people but potentially deadly for those with the compounding health problems likely in poor, minority, and indigenous populations. The response to swine flu is quintessentially a problem of social justice.²²

Fortunately, demands to address social justice concerns have increased, as evidenced by the *American Journal of Public Health* recently publishing a series of articles on swine flu and the specific needs of different at-risk groups, including people who are Aboriginal or other ethnicities, publicly housed, single parents, low income workers, incarcerated, refugees/immigrants, farm workers, or living with a disability.^{4,20,23-28}

“Redesigning” Serious Illness and Death:

The Public Health Agency of Canada’s “Canada Pandemic Influenza Plan for the Health Sector,” which guided provincial plans, has three overarching goals: to try to reduce the (1) number of deaths, (2) occurrences of serious illness, and (3) economic and social disruption.²⁹ What counts as “serious illness”? An influenza virus can make breathing very difficult (due to pneumonia) or cause protracted nausea/vomiting or a high fever. Such reactions can, in turn, cause substantial physiological damage and increase the likelihood of death. These are serious reactions and so people at high risk of experiencing them warrant early access to preventive and treatment measures. I want to suggest that in the context of an influenza pandemic, harms should not be limited to the physical. Psychologically-related harms should count, too. Moreover death should not be presumed to be due only to cardiovascular complications. Death due to suicide should count as well. In the next section, five hypothetical though realistic scenarios are presented to help illustrate how mental illnesses and addictions involve added risks that fair priority setting should take into account explicitly.

“Recalibrating” Access to Anti-Viral Medications and Vaccines:

Schrecker states that “only after resource scarcities have been identified as the consequence of either specific policy choices or more general social arrangements can appropriate ethical arguments be constructed.”³⁰ Fair prioritization may be needed even if there is no absolute scarcity. The public’s response to their provincial public health offices’ and ministries’ decisions about who could get the H1N1 vaccine in what order attests to the importance of fairness even if resources are limited only temporarily. Our federal and provincial governments committed to purchasing enough anti-viral medications and vaccines for H1N1 for every Canadian who wanted them. Yet the realities of manufacturer production and transportation schedules, governmental distribution schedules, and clinic/hospital schedules still necessitated prioritizing access for different groups of people.

In this context of supplies being limited for several weeks to a few months, the first scenario involves “Joe” who recently resumed living in the community after spending three months in a psychiatric hospital. He had been re-hospitalized, initially on an involuntary basis, because he repeatedly walked into busy roads and intersections in response to the voices he heard. His discharge is conditional in the sense that Joe is “on” a community treatment order as a new measure to help transition him *and* the healthcare/social systems towards a more sustainable and enjoyable life for him. Community resources committed to help him include a bi-weekly hour long appointment with a community general practitioner who also does psychotherapy, an emergency number for a local crisis center, connection with a local pharmacy that has his prescriptions for a psychotropic medication and an anxiety medication, and enrollment in a community program for its social connections.

Imagine that the H1N1 pandemic looms large with a predicted infection rate of 20% of the general population. It is foreseeable that many commercial businesses and non-commercial programs will curtail their services or temporarily close for the pandemic’s duration. While Campbell et al’s article²⁶ focuses on congenital and developmental disabilities and injuries, we need to consider how someone living with a mental illness might be impacted. If Joe’s GP switches her practice to focus only the physical effects of H1N1, psychotherapy appointments will be discontinued. The pharmacy may reduce its hours or close temporarily. Because H1N1 is a community-based virus, agencies will suspend social gatherings. Supports meant to help Joe live with schizophrenia in the community will vanish. If a CTO’s conditions are not fulfilled, however, this can constitute adequate grounds to re-hospitalize Joe against his wishes and despite him fulfilling his CTO responsibilities. Here, the pivotal risk factor for becoming seriously ill is a legally binding dependence on others.

Shouldn’t involuntary hospitalization mean someone is becoming or is seriously ill? If the answer is “yes,” pandemic priority setting efforts should include people “with” CTOs among those at-high-risk of serious illness, especially if a pandemic could last for months. Interventions to help avoid such risks from materializing would therefore include: GPs would still provide counseling to this group of patients. Community pharmacies would dispense enough medications to last for the “wave’s” duration. Phone-in lines should be set up by community agencies to help keep these people connected.

In terms of anti-viral medications and vaccines, they should be offered early to the GP and community agency staff providing phone support. The community pharmacist would be offered access later because needed psychiatric medications should have been proactively dispensed to Joe and other CTO people. Joe would be offered early access only if he has physical risk conditions (e.g., COPD), otherwise he would wait along with others who are not at high risk. In keeping with Campbell et al’s suggestions to compensate for socially constructed difficulties experienced by disabled groups, what if Joe suffers from severe paranoia or depression such that going somewhere unfamiliar for anti-viral medications or vaccinations is virtually out of the question? If he is also at high risk of serious illness or dying if he acquires H1N1, these therapies should be provided to him at home or at other familiar settings.

The next scenario focuses on people with mental health concerns who are assisted by assertive community treatment teams. This seems quite similar to the situation of people living in the community whose discharge is conditional on a CTO. Like CTOs, ACT teams are meant to offer less restrictive supports and interventions compared to hospitalization. ACT teams typically see people each day or every few days, help with daily activities, accompany them to important appointments, verify and encourage them to follow the prescribed treatment regimen, and generally help them gain knowledge and develop habits needed for living in the community. For some people living with a mental illness, an absent ACT team because team members are ill with the influenza virus could mean that their psychiatric illness worsens to the point of involuntary hospitalization. In some instances, involuntary hospitalization qualifies as an ethically proportional response because the person is at high risk of attempting suicide (i.e., death due to causes other than cardiovascular or pulmonary failure). Consequently ACT team members should be among those who can access anti-virals and vaccines relatively early because their work helps prevent “serious illness or death due to H1N1.”

What if Joe lives with his mother and 26-year-old sister who provide ongoing support and monitoring to help him control the negative symptoms of his schizophrenia? Absent such support, it might be quite predictable that he will become confused and disorganized and at risk of harm to himself or others which, in turn, could justify involuntary hospitalization. If Joe’s mother or sister is at high risk of becoming ill or dying if infected with H1N1, the criticality of their support strengthens the case for them to access anti-virals and the vaccine early. Among the criteria to access ICU ventilators developed by a group at Hamilton Health Sciences is the criterion of dependent relationships.³¹ I think their criterion sets too low a standard. So why is it acceptable in terms of Joe’s family? Part of the unfortunate reality of living with a mental illness is discrimination and stigma, risk factors absent in most other illnesses. Because of misinformation, fear, ignorance, or bias, other people probably would be unwilling to fill in on behalf of ill family members to support Joe.

The fourth scenario involves “Jane” who is recovering from six years of heroin use. This addiction qualifies as a serious illness because it significantly impairs a person’s abilities to live well, causes physical damage, and increases the likelihood of death due to the dangerous quality of street drugs. At a nearby methadone maintenance program, Jane receives injections daily. Subsisting on panhandling proceeds and occasional gifts of money from her older brother, she shares a cheap apartment in an impoverished, violent area where drug dealing is routine. The wait time for a rent subsidized apartment in a safer area is years. Even if she stayed in a shelter, drugs may still be available. If Jane misses a couple of days of the methadone, she is at risk of resuming heroin use because her living situation triggers and yet can easily fulfill her cravings. Consequently she is at high risk of serious illness if the methadone program closes during the pandemic. Since permission to administer methadone requires special training, alternative sources may be few. Pandemic planners should therefore slate program staff for early access to anti-viral medications and the vaccine to help ensure clients have reliable access to methadone. Since many people with mental health or addictions problems live in congested or substandard settings and have low incomes, concerns identified by Bouye et al²⁰ are also relevant.

In the last scenario, it is easy access to technology that constitutes the risk factor. Early access to anti-viral prophylaxis and vaccines for staff of a problem gambling program would be ethically justified, I believe, just as it is for methadone program staff. Why? First, I contend that problem gambling qualifies as a serious illness because of the significant harms suffered. Second, in an influenza pandemic, casinos likely will close because they are social gathering places and communal association increases the virus' spread. Alternative modes of gambling, however, are readily available electronically today. If a problem gambling program is discontinued for the duration of the pandemic, "Bob" has no counseling and monitoring support. If he has a computer at home, it would be easy to turn to or resume gambling online, an activity that is available 24/7. In a short period of time, Bob's untreated or unsupported illness could cause him serious harm in terms of losing large amounts of money.

Conclusion:

This article's purpose is to help provide more detailed consideration of mental illnesses and addictions in the context of an influenza pandemic. Characterized as a "redesign," including these health problems along with the currently accepted physical health concerns (e.g., cardiovascular disease, COPD, diabetes, pregnancy) contributes to discussions as to what counts as serious illness and which types of death are to be prevented. Characterized as a "recalibration," the above scenarios contribute to discussions about defensible proactive measures to institute when supplies of anti-viral medications and vaccines are limited, given the added risks associated with having a mental health or addiction problem (or as some would prefer to say, given the increased vulnerabilities of people living with a mental illness or addiction).

In September 2009, the *Globe and Mail* published an article by a member of the aforementioned Hamilton Health Sciences team that developed added priority setting criteria should the H1N1 pandemic result in demand for limited ICU resources exceeding supply.³² The *Globe* article and coincident healthcare journal article³¹ were valuable contributions to efforts to respond fairly to the pandemic. Valuable in terms of sharing the team's justification of more criteria to help ensure tragic decisions were, at a minimum, fair. The articles' authors hoped that publicizing their efforts would fuel more public discussion and collaboration on such an important issue. This article is written with the same hope.

References:

1. Brabham DC. (2006) Noticing Design/Recognizing Failure in the Wake of Hurricane Katrina. *Space and Culture* 9 (1): 28.
2. Calhoun C. (2006) The Privatization of Risk. *Public Culture* 18 (2): 257-63.
3. Levine C, Faden R, Grady C, Hammerschmidt D, Eckenwiler L & Sugarman J. (2004) The Limitations of "Vulnerability" as a Protection for Human Research Participants. *American Journal of Bioethics* 4 (3): 47.
4. Vaughan E & Tinker T. (2009) Effective Health Risk Communication about Pandemic Influenza for Vulnerable Populations. *American Journal of Public Health* 99 (S2): S324.
5. Levine et al, see note 3, 45.
6. Luna F. (2009) Elucidating the Concept of Vulnerability: layers not labels. *International Journal of Feminist Approaches to Bioethics* 2 (1): 124.
7. Tierney K. (2006) Foreshadowing Katrina: recent sociological contributions to vulnerability science. *Contemporary Sociology* 35 (3): 207-12.
8. Luna et al, see note 6, 121-39.
9. Ibid, 129.
10. Kipnis K. (2003) Seven Vulnerabilities in the Pediatric Research Subject. *Theoretical Medicine* 24 (2): 107-20.
11. Levine et al, see note 3, 44-9.
12. Saunders JM. (2007) Vulnerable Populations in an American Red Cross Shelter after Hurricane Katrina. *Perspectives in Psychiatric Care* 43 (1): 30; italics added.
13. Schrecker T. (2008) Denaturalizing Scarcity: a strategy of enquiry for public-health ethics. *Bulletin of the World Health Organization* 86 (8): 600.
14. Kayman H & Ablrh-Odjidja A. (2006) Revisiting Public Health Preparedness: incorporating social justice principles into pandemic preparedness planning for influenza. *Journal of Public Health Management and Practice* 12 (4): 373-80.
15. Uscher-Pines L, Duggan PS, Garoon JP, Karron RA & Faden RR. (2007) Planning for an Influenza Pandemic: social justice and disadvantaged groups. *Hastings Center Report* 37 (4): 32-9.
16. Kaiser R, Le Tertre A, Schwartz J, Gotway CA, Daley WR & Rubin CH. (2007) The Effect of the 1995 Heat Wave in Chicago on All-Cause and Cause-Specific Mortality. *American Journal of Public Health* 97 (S1): S158-62.
17. Mills N. (2006) John Steinbeck's Hurricane Katrina Lesson. *Dissent* 53 (4): 97-8.
18. Colten CE. (2006) Vulnerability and Place: flat land and uneven risk in New Orleans. *American Anthropologist* 108 (4): 731-4.
19. Elliott JR & Pais J. (2006) Race, class, and Hurricane Katrina: social differences in human responses to disaster. *Social Science Research* 35 (2): 295-321.
20. Bouye E, Truman BI, Hutchins S, Richard R, Brown C, Guillory JA & Rashid J. (2009) Pandemic Influenza Preparedness and Response Among Public-Housing Residents, Single-Parent Families, and Low-Income Populations. *American Journal of Public Health* 99 (S2): S288.
21. Mastroianni AC. (2009) Slipping through the Net: social vulnerability in pandemic planning. *Hastings Center Report* 39 (5): 11.
22. Gostin LO. (2009) Swine Flu Vaccine: what is fair? *Hastings Center Report* 39 (5): 10.
23. Hutchins SS, Fiscella K, Levine RS, Ompad DC & McDonald M. (2009) Protection of Racial/Ethnic Minority Populations During an Influenza Pandemic. *American Journal of Public Health* 99 (S2): 261-70.
24. Groom AV, Cheyenne J, LaRoque M, Mason C, McLaughlin J, Neel L, Powell T, Weiser T & Bryan RT. (2009) Pandemic Influenza Preparedness and Vulnerable Populations in Tribal Communities. *American Journal of Public Health*. 99 (S2): S271-7.
25. Truman BI, Tinker T, Vaugh E, Kapella BK, Brenden M,

- Woznica V, Rios E & Lichtveld M. (2009) Pandemic Influenza Preparedness and Response Among Immigrants and Refugees. *American Journal of Public Health* 99 (S2): S278-83.
26. Campbell VA, Gilyard JA, Sinclair L, Sternberg T & Kailes JL. (2009) Preparing for and Responding to Pandemic Influenza: implications for people with disabilities. *American Journal of Public Health* 99 (S2): S294-300.
 27. Steege AL, Baron S, Davis S, Torres-Kilgore J & Sweeney MH. (2009) Pandemic Influenza and Farmworkers: the effects of employment, social, and economic factors. *American Journal of Public Health* 99 (S2): S308-15.
 28. Maruschak LM, Sabol WJ, Potter RH, Reid LC & Cramer EW. (2009) Pandemic Influenza and Jail Facilities and Populations. *American Journal of Public Health* 99 (S2): S339-44.
 29. Public Health Agency of Canada. (2005) The Canadian Pandemic Influenza Plan for the Health Sector. www.phac-aspc.gc.ca/cpip-pclcpi. Accessed December 6, 2009.
 30. Schrecker, see note 13, 601.
 31. Frolic A, Kata A & Kraus P. (2009) Development of a Critical Care Triage Protocol for Pandemic Influenza: integrating ethics, evidence and effectiveness. *Healthcare Quarterly*: 12 (4): 54-62.
 32. Frolic A. H1N1 Triage: hope for the best, plan for the worst. *The Globe and Mail* September 18, 2009.

Acknowledgements: None.

Competing Interests: I am an Associate Editor of the JEMH but had no involvement in the blind review process for my submission.

Address for Correspondence: barbara_russell@camh.net

Neuroenhancement: Warning, Autonomax may be Necessary

Sara Waller PhD

Associate Professor of Philosophy, Montana State University

Bozeman, MT, USA

Carmela Epright PhD

Associate Professor

Department of Philosophy, Furman University

Greenville, SC, USA

ABSTRACT

This paper argues that neuroscience has great potential to increase free will rather than condemn us to determinism. If human freedom depends on such factors as: having the intelligence and rationality to understand the physical, social and moral consequences of one's actions; being aware of what choices are available and viable; being without emotional illness and compulsion; etc., then brain based treatments can expand human freedom. We present several hypothetical cases in which treatments appear to increase experienced free will. In the first case, a prescription for *Epistimidol* increases the IQ and information-seeking drive of a woman with initially low normal intelligence. In the second case, a man with *Dysthymia* is treated with *Optimistimine* and becomes more outgoing and receptive to others. These and other cases suggest that experiential freedom can be pharmaceutically enhanced by an expanded ability to deliberate and understand the nature of choices and their consequences.

Key words: neuro-enhancement; ethics; pharmaceuticals; treatment; free will; determinism.

Introduction

There is no shortage of commentary on the possibility that findings from neuroscience threaten to reduce or eliminate free will in the metaphysical sense (e.g., Gazzaniga, 2005; Tancredi, 2005; Glannon, 2009). We will contend with this possible loss of *metaphysical freedom* by offering a notion of *experiential*

freedom and an experientially constructed self that consists in its range of choices plus the depth of its ability to understand choice making, probable consequences of choices, and the relationship between choices, experiences, and the self. Even if this experienced freedom and the self that emerges from it exists due to deterministic interactions between treatments and the organism, dismissing such freedom as illusory or existentially irrelevant is to miss a very important aspect of our social, intellectual and political lives.

The solution we present is related to Hilary Bok's (2007) characterization of decision-making in a deterministic world. On her view, free will may be illusory, but our efforts are not irrelevant and should not be dismissed. She explains:

If it is determined that there will be coffee tomorrow morning, then that does not mean that I do not have to make any; it means that it is determined that I will make some . . . If I {grind the coffee beans and put water in the coffee maker} I am not engaging in efforts that determinism has shown to be unnecessary, but {rather} doing what needs to be done in order to have my coffee . . . because my choices, my efforts, my deliberations, and my mental life are part of the natural world, determinism does not imply that they are irrelevant to what ultimately happens, nor that I do not need to bother with them.¹

This paper highlights the importance of human choice, effort, and deliberation in spite of a possibly deterministic universe. Indeed, we suggest that a deterministic universe removes a coherent notion of a human self, but that an experientially constructed self can replace the metaphysical self; and can, like Dennett's "center of narrative gravity" serve to individuate agents from one another and from the rest of the causally interactive universe. We will carry out our argument for the thesis that an *experientially constructed self and its concomitant experience of freedom* can be enhanced by

neuro-chemical interventions through a presentation of several fictional case studies that are not too far-fetched given recent advances in current pharmaceutical science.²

Preliminaries: The Self and Free Will

For the purposes of this paper we will distinguish between two conceptions of free will. The first, *metaphysical free will*, requires the absolute ability to control one's own actions, to choose, to decide, etc. It is this form of free will that recent findings in neuroscience suggest could be false. The second conception of free will, *experiential free will*, consists in the experienced, lived ability to choose, to have control over one's actions, and to initiate action – as perceived by the chooser. Experiential free will, we argue, can be expanded via pharmaceutical and other interventions by, for example, increasing intelligence and the capacities for rational thought and impulse control. Such an increase, *ceteris paribus*³, naturally enhances one's understanding of the likely consequences of actions, increases one's awareness of viable choices, and eliminates compulsion and coercion based on ignorance of options and misunderstanding of consequences. While experiential freedom (and the choices leading up to and actualizing the treatment) may be deterministically caused by drug-brain interactions, this freedom is the foundation for the human self as separate from its environment and thus a human self that can act, think and choose.

A determinist might suggest that experienced freedom is an illusion not worth contemplating. But we argue that experiential freedom is not trivial even in such a deterministic universe. While it is certainly true that experiences may not be veridical, and that I, for example may think, given the right prescription, that I can joyously fly with the condors when in fact my unassisted human body cannot, the possibility that I may be misled or the victim of illusion does not change the importance of my experience. Descartes, after all, found a rather good argument for his existence upon reflecting on the possibility that all of his thoughts and experiences may be subject to deception. The fact that we do experience the world, even if inaccurately, brings with it individual and personal uniqueness that cannot be found by noting the boundaries between our bodies and the air around us, or our mouths and our food. Experiential freedom changes our experienced self, and we argue in the next paragraph that the experienced self is far more “real” and important than the metaphysical self in terms of individuation and personal identity.

Traditional discussions of free will and decision-making are predicated upon a distinction between a (metaphysical) self that chooses, and a world that then is changed by those choices. A self, according to the tradition, only has free will when it is free of external constraints, for example, one does not freely choose to sign a document with a gun pointed to one's head. The notion of external constraints incorporates an assumption that there are things that are clearly external to the self, that can be acted on, or act upon, the self. But in the deterministic metaphysical world that neuroscience seems to offer us, there is no clear distinction between the internal ‘core’ self and the environment it supposedly responds to or controls. Given a fully physical, determined system, any additive to the brain becomes part of the brain, and was always

fated to become part of the brain. Thus, traditional notions of external and internal freedom or constraints have no basis. The dividing line between the metaphysical self and the rest of the world is ultimately erased entirely. Pharmaceuticals and other treatments have a profound effect on what we would consider to be the self (personality, thoughts, choices, actions, etc.) and if the world is determined, then the metaphysical self is causally bound to take them. That self is deterministically comprised of the materials contained within the prescription even before the prescription is ingested because the self cannot avoid ingesting them at the pre-appointed time. The line causing some things to appear to be external to the self (e.g. medication) and others to appear to be internal to the self (e.g. personality) is an illusion founded in viewing the self from one time perspective (pre-treatment) or another (post-treatment). Thus the notion of an individual metaphysical self that acts on an external world, a self that does, or does not, have free will in the traditional sense, needs to be revised.

In a deterministic world there is no self that chooses in the metaphysical sense. And yet, humans contemplate our temporally bound viewpoints on that self in order to re-understand the self as illusory, and humans consider such contemplation important. Humans often take their choices to be a (if not the) unifying factor of the core self – the self that understands and decides upon its actions, responds, chooses and changes in response to various experiences in the world. Thus experienced freedom creates the only self worth having, and even if that freedom is illusory, our individual experience of such deception delineates our boundaries from the boundaries of other creatures and objects in the universe.

Pink (2004) gives us an excellent example of creatures that are, as far as we can tell, lacking the potential for experiential freedom, and so will never build a unifying self. Sharks, like humans, are part of the natural world, and so are fully determined in a metaphysical sense (and, we add, have no real selves that are separate from the features of the environment they are destined to ingest, and the consequent reactions to them). Sharks also (probably) have primitive experiences, beliefs and desires, such as the sensation of blood in the water, felt hunger, and a belief that the food is over here, etc.,. However, we are still not eager to say that sharks freely choose to do anything. They are not rational; they do not deliberate or weigh their options; they do not learn (much) about their worlds; they do not have a broad, abstract understanding of their lives and how their choices might impact them. Sharks are bound by their drives and do not develop themselves as agents; they do not experience themselves as Dennett's “centers of narrative gravity.”

In this paper we suggest that some pharmaceutical treatments can raise some humans above shark-level choice making. The case studies begin with some common notions of the freely choosing self and what most of us take to be its important if not essential components, such as intellect, mood and personality, moral understanding, and self-esteem. If these factors are mutable with pharmaceutical tools,⁴ then the core self that makes choices is also changeable. If this is true, then that current neuroscientific assumption that the metaphysical self (defined and delineated by the structural features of the brain and thus predetermined in a strong sense) is the only possible understanding of the self, is false.

The Cases

Case 1:

Sam has an IQ of about 85 and has not been exposed to many world experiences, or much education. Working with limited cognitive capacity and limited information and experience, he tends to see the world very simply and strictly, and often makes choices about his life based on false dichotomies and a poor understanding of the consequences of his options. He begins a treatment program in which our new drug, *Epistemidol*, which raises his IQ and motivates him to seek information and experiences. New neurons grow, new dendritic branches form, and he finds himself to be both curious and outgoing. His brain is further stimulated by the enriching new experiences, which in turn opens further opportunities for choice and change. Choices before him expand, because he understands more about the world and about himself. Did *Epistemidol* increase his free will?

In an absolute, metaphysical sense, the answer is ‘no.’ Now, as always, he is comprised of causal relationships between physical elements and chemical reactions in his brain. He is choosing newly and differently only because he is at the end of a causal chain of events that brings him greater capacities for choice. However, if we consider his experience of freedom, the answer is clearly ‘yes.’ He understands more about choices, choice making, and the consequences of his choices. He has more ability to make rational choices because he is in possession of a greater number of rational faculties (the ability to process facts, knowledge of logic and inference, etc.) It is nearly impossible to deny a change in his experience of freedom, and the illusion has its own causal efficacy in the metaphysical world. For example, it is generally assumed that people with greater capacities for choice are not merely different, but they are more responsible. The notion that those with greater cognitive capacities are more responsible and have greater freedom to either act or refrain is embodied in the laws of many countries. Legally, we consider those who are more knowledgeable and more intelligent to be more responsible for their actions. For example, children are not tried as adults, in part because we believe that they do not understand the world, and the consequences of their actions, in the same sophisticated way that adults do. Likewise, the mentally retarded are (ideally) not held responsible for their crimes in the same way that those of normal and higher intelligence are.

Sam has opportunities to expand himself through his choices that he would not have had without *epistemidol*. Whether or not he was fated to take it, if it did not exist, his self and life as experienced would be profoundly different. The prescription was a necessary condition for his personal development through the new presentation (and selection) of personal choices available to him. As there is no physically individuated, metaphysically defined Sam, the Sam that matters – Sam as he experiences himself and as he deliberates and chooses, is profoundly different. This is the only “real” Sam there is, and *epistemidol* was a necessary part of his development.

Case 2:

Marcus has an above average IQ and plenty of life experience, as well as Dysthymic Mood Disorder, specifically manifesting in low

energy, low self-esteem, hypersomnia, poor concentration, and difficulty making decisions. These mood afflictions have caused him to lose his job and have reduced the quality of interactions with his family and friends. His depression reduces his interaction with the world, which reduces the choices presented to him. He also has little motivation to make choices and stick to them, and worse, he refuses to consider new choices because he does not have the energy or confidence to see them as live options. He begins to take our new drug, *Optimistimine*, and gains energy, concentration, and the ability to make decisions. He sleeps less, and uses his time to research new options for his life. He becomes more outgoing, and does more things. As a result, his self-esteem rises. These combined factors produce more options in his life, and he actively makes decisions and follows through on his chosen courses of action. Did *Optimistimine* increase his free will?

Again, the experiential answer is ‘yes,’ because he has more options and more ability to act on them. He is able to rationally consider his choices rather than remain in a state of being undermined by his low self-esteem. So, if he has more choices, is more cognizant of them, understands their relative viability better, and is better able to act on them, it appears that his free will has increased – certainly his domain of action in the world has increased. The experiential self, though constructed by (and ultimately indistinguishable from) physical causal chains, emerges as more in control of its environment, and thus distinct from it. Marcus now has the energy to make coffee, even if he was fated to do so. Indeed, we cannot distinguish the enthusiastic, active Marcus from a combination of *Optimistimine*, time, and Marcus’ brain. We have no method for answering the question “Who is the real Marcus – the depressed withdrawn fellow, or the industrious, cheery fellow?” for Marcus was determined to take *optimistimine* and so to change his moods and behaviors accordingly.

Case 3:

Charlene is responsible for three aggravated assaults for which she was convicted. She served 16 years in jail for her offenses. She has an explosive temper, and a manipulative personality. She has few friends, and her family avoids her because of her propensities to lie, cheat, steal and threaten others. Given *Eudaimonia*, she is less impulsive, violent, and manipulative and she has developed a sense of empathy. As a result she is less likely to place herself in situations in which she has altercations with others. Her new, more empathic personality helps her to create friendships based on trust and mutual concern rather than manipulation; which in turn helps her to make choices that do not call for lying, cheating, or theft. Unlike our hero in “A Clockwork Orange,” Charlene is not rendered helpless by her treatment; she is simply more able to control her impulses and cares more about other people; she can make new kinds of choices.

Have we increased Charlene’s freedom? One might argue that this depends upon whether or not one believes that doing the right, socially acceptable action is freer or inherently better than doing evil. However, our point is not to defend a moral system but to suggest that Charlene *is* more free – not because she makes the choices that we want her to make, but because she now *has* choices instead of being determined to act by the anti-eudaimonic processes of her brain. Indeed, it is our view that she is actually experiencing making moral choices *for the first time*. She is finally

free to manipulate or not, react violently or not, exhibit concern for others or not.

Case 4:

Sophia is a woman of above average intelligence who is seeking a Ph.D. in philosophy. She has a sub-clinical degree of anxiety and depression – her most significant complaint is that she often experiences writer's block. Sophia is reasonably attractive and has a normal social life; she dates occasionally and has an average amount of friends and fairly good access to choices, experiences and opportunities. In short, she is smart enough, happy enough, attractive enough, social enough and engaged enough to have or to construct a meaningful life. However, Sophia learns about *Autonomax* – a drug with the combined features of *Epistimidol*, *Optimistimine*, and *Eudaimonia*, and very much wants to take it.

After two months on this medication her IQ has increased 20 points, she is happier and more confident than she has ever been. She is not only more productive – in this short time she has completed an academic paper and a new chapter of her dissertation – she is more social and engaged. Her confidence and productivity⁵ open new doors to social interaction and her empathetic, enthusiastic personality offers her even more opportunities to expand her horizons. Is she freer? Experientially, yes, and those experiences are what comprise the experienced self, the only thing that distinguishes us from the causal events that create and destroy us.

Thus, we claim that human free will as experienced is enhanced by neuro-chemical interventions. While changes in brains, personalities, intellects, decisions, and actions are necessary consequences of the medications discussed, the subjects who have enjoyed increased understanding, motivation, self control, and so on have ultimately enjoyed an increase experienced decision making ability. While it may seem difficult to quantify something like *freedom*, our guess is that measuring it by the sheer number of choices one can *actually take advantage of* in the pragmatic, lived world, is not a bad starting point. This is what makes us more interesting than sharks, and what distinguishes a human life from a causal chain of physical reactions between bodies. By this measure, the treatments have increased freedom, even if they have done so through deterministic causal mechanisms. But this just is an increase in experiential freedom, freedom for which *Autonomax* may be necessary.

Warning

And, yes, this story comes with a warning. Necessary conditions for personal change fit nicely with the deterministic worldview advocated by neuro-scientific findings. While our case studies above were people who, in a deterministic world, needed one chemical in order to have new experiences and transform their inner narratives, we want to point out that in some cases the prescription may be merely sufficient for such transformation, and so it may be replaced by other causes. One can imagine a case in which a very young girl growing up in isolation in an abusive household, a girl who, given those circumstances is quite fated to become socially dysfunctional and a marginal contributor to

society, is forcibly abducted by do-gooders, brought to a highly socialized, nurturing environment, and set free. The girl, through the ordinary course of causal mechanisms, grows up to be an emotionally well, highly social neurobiologist, who develops pharmaceuticals such as *Autonomax*. The sufficient condition for her expanded choice set, and her expanded experience of self was fulfilled by abduction rather than prescription. While we delight in her expanded self and vast experiential set of choices, we might do well to hesitate before we legalize abduction and kidnapping, or applaud the blatant disregard of the choices of another, even if the choice set from which they were drawn seems limited to us. What we believe to be a necessary condition for personal growth, and what is a sufficient cause for the same, may be as illusory, and as important, as the selves we experience every day.

End Notes

1. Bok, Hilary. (2007). The Implications of Advances in Neuroscience for Freedom of the Will. *Neurotherapeutics*. July. pp. 557. (555-559.)
2. We would like to highlight that these case studies are indeed science fiction. We feature, and discuss, what we imagine to be very positive aspects of futuristic pharmaceuticals, and do not discuss potential detrimental or dangerous side effects. Such considerations are important, and worthy of a separate discussion beyond the scope of this article.
3. We will assume that the patient is not suffering from a condition in which expanded choices, or increased knowledge of the world, actually increases his or her anxiety or stress so much that the patient is unable to take advantage of the new knowledge and choices. Thanks to the commentator at the 2009 [Brain Matters: Neuroethics Conference](#) for raising this important point.
4. We recognize that the line between remedial, therapeutic use and enhancement is thin, controversial, and perhaps nonexistent. Further, we recognize that the enhancement of some people can radically disadvantage those without access to similar enhancements, and thus, the experiential freedom of large groups of less fortunate people may be compromised if such treatments are not fairly, or even universally, distributed.
5. We note that in our capitalistic culture, productivity *in fact* often opens doors, expands social and career-oriented choices, and makes one feel confident. We do not endorse this as necessarily an ethically good, or right way to live, and are troubled by the common cultural emphasis on the creation of product and the marketability of the self. But we recognize that within such a culture, selves who are marketable and productive will probably be successful, sought after, and thought of as desirable. This indicates a significant danger for pharmaceutical neuro-enhancement: *enhancement* is something that is profoundly relative to cultural values, and if we are all enhanced to succeed in a certain culture, there will be no one left to offer a critique of those values and corresponding enhancements, or to offer other values as viable options. While enhancement may increase freedoms within a specific, value-laden context, it may simultaneously limit

freedom by making us poorly suited to other contexts oriented around different values.

References:

- Bok, Hilary. (2007). The Implications of Advances in Neuroscience for Freedom of the Will. *Neurotherapeutics*. July. pp. 555-559.
- Dennett, Daniel. (1992). Self and Consciousness: *Multiple Perspectives*. In F. Kessel, P. Cole and D. Johnson, eds. (Hillsdale, NJ: Erlbaum & Associates).
- Glannon, W.(2009). Our Brains are Not Us. *Bioethics*. Vol. 23 (6): 321-329.
- Gazzaniga, M. (2005). The Ethical Brain. pp. 102. (NY: Dana Press)
- Pink, T. (2004). *Free Will: A Very Short Introduction*. pp. 24. (Oxford: Oxford University Press).
- Tancredi, L. (2005). *Hardwired Behavior*. pp 11. (Cambridge: Cambridge University Press).

Funding and Support: *Sara Waller would like to thank the College of Arts and Sciences at Case Western Reserve University and the Department of History and Philosophy at Montana State University, Bozeman for research time and travel funding that supported the development and completion of this paper.*

Acknowledgements: *None.*

Competing Interests: *None.*

Address for Correspondence:

Sara Waller PhD
 PO Box 172320
 Montana State University
 Bozeman, MT, USA 59717-2320
e-mail: *sara.waller@montana.edu*
sarawallerphilosophy@gmail.com

M. Carmela Epright, PhD
 Department of Philosophy
 Furman University
 3300 Poinsett Hwy
 Greenville, SC, USA 29617

Informed Consent and Disclosure of Information for Stimulant Medication: An exploratory study of teenagers', parents' and physicians' preferences for information disclosure

Debbie Schachter MD MSc FRCPC

Child, Youth and Family Program,

Centre for Addiction and Mental Health, Toronto.

Assistant professor, Department of Psychiatry, University of Toronto.

Member, Joint Centre for Bioethics, University of Toronto, Canada

Irwin Kleinman MD FRCPC

Psychiatrist, Mount Sinai Hospital, Toronto.

Assistant professor, Department of Psychiatry, University of Toronto.

Member, Joint Centre for Bioethics, University of Toronto, Canada

ABSTRACT

Objective: This study explores the information teenagers, parents, and physicians want included in an information disclosure for stimulant medication treatment of Attention Deficit Hyperactivity Disorder (ADHD).

Method: 30 physicians, 30 parents of youth with ADHD, and 30 youth with ADHD, ages 12-16, were surveyed about their information preferences.

Results: The majority of participants wanted general information about ADHD, and a general statement about rare risks included. With respect to specific rare risks associated with stimulant medication, half of participants wanted information about arrhythmias, seizure and stroke included. For the other rare risks, there was a range of responses across all groups.

Conclusions: About half of parents and teenagers want disclosure of cardiovascular and cerebrovascular events. Physicians cannot assume that their personal information preferences reflect that of their patients; they need to understand their patients' information needs when informing them about the benefits and risks of medications.

Key words: informed consent; stimulant medication; ADHD; information disclosure.

Introduction

Informed consent should be obtained prior to all medical interventions. Disclosure of relevant information is an essential component of informed consent. The disclosed information should specify the nature of the proposed treatment, its anticipated benefits, material risks and side effects, the alternative treatment options and the likely outcomes of not accepting treatment. (Grisso and Appelbaum 1998; Rozovsky and Rozovsky 1990; *Health Care Consent Act, 1996, S.O. 1996, C. 2, Sch. A.*)

Historically, the disclosure standard was information professionals felt should be disclosed, known as 'the professional standard of disclosure'. (Grisso and Appelbaum 1998) With court decisions, the standard evolved into 'the reasonable person standard'; the information that the reasonable person in the patient's situation would want to know to make an informed decision. (Beauchamp and Childress 2006; Dickens 2002; Grisso and Appelbaum 1998; *Reibl v Hughes, [1980] 2 S.C.R. 880.*)

Information disclosure is important for child and adolescent psychiatry because many families have concerns regarding psychoactive medications; invalid myths and assumptions need to be dispelled. Much has been written in the press regarding psychopharmacologic treatment of adolescent psychiatric

disorders. (Harris 2004a; Harris 2004b; Kirkey 2007; Kluger 2003; Schlozman 2005) possible overuse or inappropriate use of stimulant and antipsychotic medications, (Kirkey 2007; Kluger 2003; Marshall 2000; Philip 2007), and adverse side effects including the potential cardiovascular effects of stimulant medications (Food and Drug Administration 2007; Harris 2004a; Harris 2004b; Health Canada 2007; Nissen 2006). Accurate information is needed to inform families.

However, the 'reasonable person standard' has not been operationalized for the adolescent with ADHD. What information does the 'reasonable adolescent or parent' want disclosed? Early studies revealed patients wanted more information than physicians thought they wanted, particularly about treatment risks. (Faden et al. 1981) Surveys indicate that the majority of adult patients do not endorse physician discretion in information disclosure, and prefer information about all side effects to be disclosed, no matter how rare or serious. (Ziegler et al. 2001) Among adult medical patients, 80% wanted to know about side effects that occurred less frequently than 1/100,000; younger patients and those less educated wanted more information than other groups. (Ziegler et al. 2001) In contrast, among patients with rheumatoid arthritis, females, younger or more educated patients wanted more information than older or less educated individuals. (Neame et al. 2005)

Studies using non-clinical subjects reveal preferences for disclosures that explain medications' side effects, actions and impact on lifestyle. (Berry et al. 1995) Characteristics of these subjects (ie age) as well as the medication side effects (number, risk, and severity) influence the perception of disclosures. (Berry 2004; Berry et al. 2002) Younger adults are less satisfied than older adults with information disclosure, perceive risks as less likely to happen, and may be more likely to take medication. (Berry et al. 2002) Adults' risk perception is increased when the medication is intended for a young child compared to themselves. (Berry 2004) These studies suggest that the patient's age influences the perception of the information disclosure.

The present study examines the information teenagers with ADHD, parents of minors with ADHD and physicians think should be disclosed as part of the informed consent process for stimulant treatment of ADHD.. This data was collected as part of a larger study in order to design an information disclosure suitable for teenagers with ADHD.

Method

Participants: Participants included physicians, parents of youth with ADHD and youth with ADHD. Physicians were child psychiatrists or pediatricians, with at least 5 years clinical experience, relevant academic publications or clinical experience with at least 10 clients per year with ADHD. Physicians were interviewed in 2004-2005.

Parents of children with ADHD and youth between 12-16 with ADHD were recruited from advertisements in physician offices, ADHD websites, and the X, a fully X affiliated teaching hospital in an urban setting. Participants recruited from X or their affiliated

child psychiatrists' office had a clinical diagnosis of ADHD based on the DSM-IV. Participants recruited from advertisements had diagnoses confirmed by either a written note from their physician or following administration of the parent module of the Diagnostic Interview Schedule for Children (Shaffer et al. 1993; Shaffer et al. 1996; Shaffer et al. 2000). Half the patients participated in 2004-05 in the first phase of a larger study on informed consent helping to develop a disclosure form. In 2008, the second half of the sample was recruited to specifically examine participants information preferences.

Procedure: Participants received a written description of the theoretical information patients should receive in order to make a treatment decision. Subjects then read a disclosure form addressing benefits and risks of stimulant medication. Subjects then rated, using a Likert scale, which additional items they felt should be included in the disclosure.

Instruments:

Disclosure The disclosure form included information about common side effects, and the potential effects on growth, tics, blood pressure and pulse, and the risk of psychosis in patients taking stimulant medication. Frequencies were represented quantitatively and qualitatively in order to ensure that participants interpreted qualitative descriptors consistently. The reading level of the disclosure form was grade 6 to ensure readability (Davis et al. 1994; Davis et al. 1990)

Questionnaire about additional information: Additional information to be included in the disclosure was evaluated using Likert style questions. (Items were rated as strongly agree, agree, neutral, disagree, strongly disagree). Additional items included more information about ADHD and its treatment, and detailed information about rare side effects obtained from a literature review. The package was pre-tested on 15 participants (2 child psychiatrists, 3 pediatricians, 5 parents, and 3 children, and 2 experts in bioethics) and revised. Data from these subjects are not included in this paper.

Socioeconomic status (SES): The Blishen Index uses parental occupational status to code for socioeconomic status SES (Blishen et al. 1987) .

Research Consent: X's Research Ethics Board approved this project. Consent was obtained from physicians, parents and consenting teenagers. Teenagers who read the consent form and said they understood it consented to study participation. Teenagers who did not state that they understood the form assented to study participation. All subjects received a monetary honorarium as compensation.

Data Analysis: Data were analyzed using statistical packages available on SPSS. Data from the original participants on whom the package was pre-tested are not included in this study report. Since not all parents and adolescents were part of dyads, paired analyses were not conducted to compare the views of parents and adolescents.

Results

Thirty physicians (15 child psychiatrists and 15 pediatricians), 30 parents, and 30 teenagers participated in this study.

Physicians mean age was 49.9 (SD=8.4), mean medical school graduation year was 1978 (SD = 8.1) and mean SES was 101.32; 62% (N=18) were male. Teenagers mean age was 13.0 (SD = 1.0), mean grade was 7.7 (SD =1), 83.3% (N=25) were male, 56.7% (N=17) were taking a stimulant medication, and 1 (3%) was taking another psychoactive medication. Parents mean age was

44.9 (SD=5.9), mean SES was 50.0 (SD=9.7), mean educational level was 16.1 years (SD=3.2) and 13% (N=4) were male. The majority of parents had completed high school 90% (N=27). Parents reported that 60% (N=18) of their youth were prescribed a stimulant medication.

The majority of parents, teenagers and physicians wanted information regarding etiology of ADHD, complications of ADHD, risk of substance abuse, drug interactions, and alternative treatments disclosed (Table 1). The majority wanted a general statement that specific rare side effects might occur included.

TABLE I PREFERENCES FOR INCLUDING THE FOLLOWING INFORMATION IN A DISCLOSURE

Item	Agree or Strongly Agree (%(N))		
	Teens	Parents	Physicians
Many teens with ADHD have learning problems	80.0(24)	86.7(26)	96.7(29)
Some teens with ADHD may start to feel sad	53.3(16)	66.7(23)	75.9(22)
Without treatment, teens with ADHD may have trouble finishing schoolwork	90.0(27)	100.0(30)	96.7(29)
Without treatment, teens with ADHD may develop behaviour problems	76.7(23)	93.3(28)	80.0(24)
Doctors don't know exactly what causes ADHD	60.0(18)	86.7 (26)	76.7(23)
Doctors think that ADHD is more common in some families than others	53.3(16)	80.0(24)	93.3(28)
Doctors think ADHD is related to changes in brain chemicals	53.3(16)	93.3(28)	86.7(26)
Brain areas that control attention may be less active in people with ADHD	70(21)	93.3(28)	70.0(21)
The medicine acts on chemicals in the brain	73.3(22)	96.7(29)	89.7(26)
Teens who have taken stimulants for years may feel better about themselves than those who haven't	73.3(22)	76.7(23)	80.0(24)
It is safe to stop taking medicine on weekends or holiday	90(27)	89.7(26)	79.3(23)
Stimulants can be abused	76.7(23)	90(27)	86.7(26)
Teens on stimulants don't usually abuse stimulants	70(21)	76.7(23)	6.7(20)
Stimulants should be used carefully when family members have abused drugs	86.7(26)	86.7(26)	75.9(22)
Drug allergies can occur	70(21)	87(26)	73.3(22)
Stimulants may interact with other medications	93.3(28)	96.7(29)	73.3(22)
Stimulants may interact with street drugs	73.3(22)	93.3(28)	83.3(25)
Behaviour therapy helps teens get along better	76.6(23)	93.3(28)	75.9(22)
Behaviour therapy doesn't help teens sit still, concentrate or pay attention	76.7(23)	86.2(25)	75.0(21)
Less than 1 kid or teen in 10,000 on stimulants gets a serious medical problem. When they happen doctors aren't sure that stimulants causes them. They report the problem to track them	63.3(19)	76.7(23)	75.0(21)

Note. 30 physicians, 30 parents, and 30 teenagers

When asked about specific rare side effects, for most of these, fewer than half of participants in each group endorsed including the side effect in a disclosure form (Table 2). However, a majority of parents and teenagers (73%) wanted the statement regarding the possibility of arrhythmias occurring when stimulant medication were prescribed included and approximately half of all parents and teenagers wanted the theoretical risk of seizures disclosed as well as the remote risk of strokes disclosed. . The mean number of items endorsed by teenagers, parents and physicians was 18.17 (SD =4.5), 21.8 (SD=3.6), and 18.7 (SD=4.7) respectively; these numbers are significantly different $F(2,87\text{ df})=6.4, p=0.003$. The differences were significant only between parents and doctors and between parents and teenagers. The mean number of rare items teenagers, parents and physicians endorsed was 2.9 (SD=1.8), 3.4 (SD=2.3) and 2.0 (SD=2.4), respectively; these numbers are significantly different. $F(2,87\text{ df})=3.5, p=0.035$. Post hoc analyses reveal, significant difference only between parents and physicians. Within each group of participants, the range of items endorsed went from no items to all items endorsed.

Discussion

This exploratory study of the preferences of teenagers, parents and physicians regarding information disclosure shows similarities and differences across the groups.

The majority of parents, teenagers and physicians wanted information on etiology of ADHD, possible complications of ADHD, risk of substance abuse, drug interactions, and alternative treatments provided as well as a general statement about rare risks disclosed. In general, parents wanted more items disclosed than teenagers or physicians.

Across the specific rare risks, there was a distribution of responses with the strongest endorsement related to potential drug interactions causing arrhythmias, seizures and strokes.

TABLE II PREFERENCES FOR INCLUDING THE FOLLOWING RARE SIDE EFFECTS IN INFORMATION DISCLOSURES

Item		^a Agree or ^b Disagree (%(N))		
		Teens	Parents	Physicians
Serious problems includes:				
a.	Inflamed blood vessels once caused a stroke. <ul style="list-style-type: none"> • Agree (%) • Disagree (%) 	50(15) 20(6)	53.3(16) 16.7(5)	23.3(7) 50.0(15)
b.	Decreased red or white blood cells <ul style="list-style-type: none"> • Agree (%) • Disagree (%) 	40(12) 10(3)	56.7(17) 16.7(5)	26.7(8) 46.7(14)
c.	Stiff muscles due to genetic disorder <ul style="list-style-type: none"> • Agree (%) • Disagree (%) 	46.7(14) 16.7 (5)	60(18) 16.7 (5)	30.0(9) 46.7(14)
d.	Illness in infant girl with brain problems <ul style="list-style-type: none"> • Agree (%) • Disagree (%) 	30(9) 30(9)	33.3(10) 43.3(13)	27. (8) 58.6(17)
e.	Arrhythmias when given along with other medications used to treat anxiety or depression <ul style="list-style-type: none"> • Agree (%) • Disagree (%) 	73.3 (22) 6.7(2)	73.3(22) 13.3(4)	46.7(14) 33.3(10)
f.	Stimulants can lower seizure threshold although they are not thought to cause seizures in those with or without seizures. There are only a few reported cases of seizure developing in teens with ADHD who have never experienced seizures <ul style="list-style-type: none"> • Agree (%) • Disagree (%) 	50(15) 20(6)	66.7(20) 26.7(8)	43.3(13) 36.7(11)
Note.,30 physicians, 30 parents, and 30 teenagers. ^a Agree or Strongly Agree ^b Disagree or Strongly Disagree				

This study has several limitations. First, the sample is small and therefore not necessarily representative. Second, the sample has primarily younger teenagers and may not reflect the views of older teenager and their parents. Third, many subjects had used stimulant medication, their attitudes might differ from medication naïve subjects. Fourth, we did not compare clients and their treating physicians. Clients may select physicians with similar attitudes and practices to their own. Finally, the subjects were recruited at 2 points; all physicians and about half the participants were interviewed in 2004 and the remaining participated in 2008 in order to increase the sample size. The 2 groups may have had different exposures to drug related information which may alter their views on disclosure of side effects.

In addition, during this study's enrolment period, the Food and Drug Administration (FDA) reviewed information regarding cardiovascular events potentially associated with stimulant medication and recommended including this information in patient inserts. (Food and Drug Administration 2007; Nissen 2006) We cannot comment specifically about participants' views regarding this since we did not specifically enquire about this. Prior to conducting this study, our literature review had not revealed cases of sudden cardiovascular events associated with stimulant medication. Furthermore, when physicians were asked whether additional information should be included on the consent form or even on the list of additional items to include, none spontaneously suggested including this risk in the disclosure suggesting that they either were not familiar with this outcome or did not endorse disclosing it. This association has been the subject of much controversy, (Anders and Sharfstein 2006; Nissen 2006) and the FDA recommended including a black box warning and preparing patient information leaflets in an effort to inform parents and patients. (Nissen 2006) Health Canada has informed physicians of the possible association, and added a warning for stimulant medication. (Health Canada 2007) In this study participants were asked about including one cardiovascular event, arrhythmias; one cerebrovascular event (stroke), items endorsed by at least half of parents and adolescents. Thus it is likely that they would want to be informed about other possible adverse cardiovascular effects as well, in keeping with the American and Canadian recommendations. Examination of the data without the later subjects, also reveals that clients want to be told about arrhythmias, suggesting that their views were not affected by the recommendations.

Although this study is small, the findings reveal that individuals differ in their information needs particularly in terms of the rarer risks that they want disclosed. Clinicians' personal views regarding the nature of information to disclose to patients may differ from patients, just as one patients' preferences may differ from another. Physicians need to assess patients' information needs on an individual basis when providing them with information related to treatment, particularly when practicing in jurisdictions using the reasonable patient standard of disclosure. Future work should replicate these findings on larger samples and extend these findings by examining people with other mental health difficulties, as well as exploring subgroup differences. For example, are more anxious parents and their youth more likely to want more information disclosed compared to those less anxious? Are there differences between the information preferences of smaller groups, such as new immigrants, those where English is not the mother tongue,

etc. Until further data is available clarifying which subgroups have particular information preferences, physicians need to remember that their adolescent patients' perspective as well as their adolescents' parents' perspective on information disclosure may differ from each other and from their personal preferences. Physicians cannot assume that their personal information preferences reflect those of their patients. In order to help patients make informed decisions, physicians should inform patients about the benefits and risks that clients value in medical decision making.

References:

- Anders T, Sharfstein S (2006). ADHD drugs and cardiovascular risk [letter]. *N Engl J Med* 354:2296-2298.
- Beauchamp TL, Childress JF (2006). *Principles of Biomedical Ethics*. 6th ed. New York, New York, Oxford University Press.
- Berry DC (2004) Interpreting information about medication side effects: Differences in risk perception and intention to comply when medicines are prescribed for adults or young children. *Psychol Health Med* 9:227-234.
- Berry DC, Gillie T, Banbury S (1995). What do patients want to know: An empirical approach to explanation generation and validation. *Expert Systems with Applications* 8:419-428.
- Berry D, Michas I, Bersellini E (2002). Communicating information about medication side effects: Effects on satisfaction, perceived risk to health, and intention to comply. *Psychology and Health* 17:247-267.
- Blishen BR, Carroll WR, Moore C (1987). The 1981 socioeconomic index for occupations in Canada. *Can Rev Sociol Anthropol* 24:465-488.
- Davis TC, Mayeaux EJ, Fredrickson D, Bocchini Jr JA, Jackson RH, Murphy PW (1994). Reading ability of parents compared with reading level of pediatric patient education materials. *Pediatrics* 93:460-468.
- Davis TC, Crouch MA, Wills G, Miller S, Abdehou DM (1990). The gap between patient reading comprehension and the readability of patient education materials [review] [26 refs]. *J Fam Pract* 31:533-538.
- Dickens BM (2002). Informed consent. In: *Canadian Health Law and Policy*. 2nd ed. Edited by Downie J, Caulfield T. Markham, Ontario, pp 129-156.
- Faden RR, Becker C, Lewis C, Freeman J, Faden AI (1981). Disclosure of information to patients in medical care. *Med Care* 19:718-733.
- Food and Drug Administration (2007). FDA directs ADHD drug manufacturers to notify patients about cardiovascular adverse events and psychiatric adverse events. Accessed at http://www.fda.gov/bbs/topics/NEWS/2007/NEW_01568.html, 2007.
- Grisso T, Appelbaum PS (1998). *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals*. Oxford University Press. Worcester, Massachusetts.
- Harris G (2004a). Antidepressants seen as effective for adolescents. *New York Times*, June 2.
- Harris G: F.D.A (2004b). links drugs to being suicidal. *New York Times*, September 14.
- Health Canada (2007). Attention deficit hyperactivity disorder (ADHD) drugs: Updated and standardized labelling regarding vary rare cardiac-related adverse events. Accessed at http://www.hc-sc.gc.ca/dhp-mps/medeff/advisories-avis/prof/2006/adhd-tdah_medic_hpc-cps_e.html, 2007.

- Health Care Consent Act (1996)*, S.O. 1996, C. 2, Sch. A.
- Kirkey S (2007). Young Canadian children are being prescribed anti-psychotic drugs. Accessed at <http://www.mindfreedom.org/kb/youth-mental-health/canada-neuroleptics/>, 2007.
- Kluger J (2003). Medicating young minds. *Time*, November 3.
- Marshall E (2000). Duke study faults overuse of stimulants for children. *Science* 289:721.
- Neame R, Hammond A, Deighton C (2005). Need for information and for involvement in decision making among patients with rheumatoid arthritis: A questionnaire survey. *Arthritis Rheum* 53:249-255.
- Nissen SE (2006). ADHD drugs and cardiovascular risk. *N Engl J Med* 354:1445-1448.
- Philip M (2007). Nearly half of children in crown care are medicated. *The Globe and Mail*, June 9.
- Reibl v Hughes*, [1980] 2 S.C.R. 880.
- Rozovsky LE, Rozovsky FA (1990). *The Canadian Law of Consent to Treatment*. Toronto, Butterworths.
- Schlozman S (2005). Psychiatric drugs: The new pharmacopoeia. *Newsweek*, April 25.
- Shaffer D, Fisher P, Lucas CP, Dulcan MK, Schwab-Stone M (2000). NIMH Diagnostic Interview Schedule for Children Version IV (NIMH DISC-IV): Description, differences from previous versions, and reliability of some common diagnoses. *J Am Acad Child Adolesc Psychiatry* 39:28-38.
- Shaffer D, Schwab-Stone M, Fisher P, Cohen P, Piacentini J, Davies M, Conners CK, Regier D (1993). Preparation, field testing, interrater reliability, and acceptability. (The Diagnostic Interview Schedule for Children-Revised Version, DISC-R)(part 1). *J Am Acad Child Adolesc Psychiatry* 32:643-650.
- Shaffer D, Fisher P, Dulcan MK, Davies M, Piacentini J, Schwab-Stone ME, Lahey BB, Bourdon K, Jensen PS, Bird HR, Canino G, Regier DA (1996). The NIMH Diagnostic Interview Schedule for Children Version 2.3 (DISC-2.3): Description, acceptability, prevalence rates, and performance in the MECA study. *J Am Acad Child Adolesc Psychiatry* 35:865-877.
- Ziegler DK, Mosier MC, Buenaver M, Okuyemi K (2001). How much information about adverse effects of medication do patients want from physicians?[see comment]. *Arch Intern Med* 161:706-713.

Acknowledgements: *The authors acknowledge the generous support of the Canadian Institute of Health Research Operating Grant, Number #64471.*

Competing Interests: *None identified. Both authors own mutual funds.*

Address for Correspondence:

Debbie Schachter
250 College Street
Toronto, Ontario, Canada
M5T 1R8

e-mail: *Debbie_Schachter@camh.net.*

Advance Directives and the Problem of Informed Consent

Marcia Sokolowski MA PhD

Ethicist, Baycrest Hospital, Toronto, Canada

ABSTRACT

Advance directives in Canada are instructions made by capable adults that pertain to future healthcare treatment choices at a time of incapacity. My experience as an ethicist working in an Ontario long-term care facility that provides medical treatment to patients with Alzheimer's Dementia portrays a range of important ethical concerns that arise out of the use of advance directives, at least in terms of their current use. In this article I present a particular case and identify and analyze one of the more prominent ethical challenges that exist. My conclusion is that advance directives in Ontario do not meet the criteria for autonomous decision-making in the sense of informed consent. They may have initially been conceptualized as cohering to the standard of informed consent (and thus to the traditional principle of autonomy), but in reality, generally they do not. This point is well evidenced in the forthcoming case of Mr. Black.

Key Words: advance directives; dementia.

Introduction:

I work as an ethicist in a long-term geriatric facility in Ontario where many patients with a diagnosis of progressive dementia reside. Generally speaking, Alzheimer's, the most common type, is often regarded as a fate worse than death and depicted as a disease that robs persons of their selves. Many fear that, as a result of technological advances, they will be kept alive much longer than they would like to be, suffering from the indignities of old age and dementia. They worry that the protective instincts of medical professionals or sheer bureaucratic inertia might result in prolonging their lives under conditions they consider hellish from their current perspectives. Or perhaps their loved ones or legal guardians would be not so well intentioned and would make decisions according to their own best interests and not according to those of their relatives with dementia.

This is where the idea of an *advance directive* can become very alluring.¹ It is often seen as the answer to one of our biggest worries - that we will have no control over our lives when we are old, sick, demented and suffering miserably. The biggest nightmare seems to be that we will have lost the right to say "no" to life-sustaining treatment. This grave concern, and sometimes an

associated one that we will become a burden to our children in our old age motivate people to complete an advance directive. There are a number of other potential benefits from creating an advance directive as well. Some people might feel gratified to think that they have relieved their loved ones from making difficult decisions on their behalf. Their loved ones may share this relief as well as experience a sense of comfort believing they have honoured their loved ones' end of life wishes. Having an advance directive might decrease disputes amongst family members, as well as between healthcare team members who have differing opinions amongst themselves and/or with family members regarding medical treatment decision-making.²

According to Canadian common law capable adults are allowed to provide instructions about their health care choices during a time of future incapacity. These directives might include preferences about treatment wishes regarding acceptance or refusal under certain situations.³ In Ontario, capable adults may also appoint an individual (or individuals) to speak on behalf of them at a time of future incapacity. These designated persons are called substitute decision-makers (SDMs), also known as *proxies*.⁴

Many people verbally express their wishes to their loved ones. A smaller number put them in writing. As a result of some recent landmark cases (where there was a great deal of conflict ensuing about whether to withdraw life-sustaining treatment from people in vegetative states), there has been a rapid increase in people completing their advance directives. Basically its future use is mainly for SDMs to help guide medical decision-making. When you write an advance directive you are (allegedly) projecting your medical treatment wishes into the future. This document will speak for you through the voices of your SDMs if you are unable to do so yourself.

The statements in directives regarding future treatment wishes are often framed in general terms. Occasionally more specific details are given regarding the conditions that should be in place in order for a specific treatment wish to be complied with.⁵ The documents are often downloaded from legal websites and there may not be a great deal of thought put into the writing of them. Wishes might be impulsively scribbled onto a cocktail napkin, or more thoroughly contemplated and formally documented. Sometimes lawyers are involved and offer additional input as far as benefits and consequences of writing a directive goes. Sometimes loved ones participate in the process. The directive may be updated, or forgotten about.

The Case of Mr. Black

Five years ago, at the age of seventy-five, Mr. Black, a retired defense lawyer, married and father of three adult children, began to experience short-term memory lapses explained by his physician as due to normal aging. As an attorney, he knew something about the merit of advance directives. Frightened by the future prospect of a potential full-blown dementia (he had witnessed his best friend's physical and mental demise due to dementia) he spent a few days considering what he should write in his own advance directive. He had been primed by his lawyer to think about his current values and interests and to ensure he took them into consideration when he wrote his living will. Mr. Black completed the advance directive form, stating that if he could no longer enjoy the kinds of activities he found pleasurable, such as traveling with his wife, playing golf, dining at fine restaurants or engaging in debates with his adult children, he would wish to receive no treatment except pain treatment, if diagnosed with an incurable disease. He stated that living under those conditions would be unbearable for him.

Currently, Mr. Black is an eighty year-old gentleman in a long-term nursing home in rural Ontario. He has moderate to severe stage Alzheimer's Dementia. He spends most of the day sleeping. Mr. Black does not speak, has trouble swallowing due to reflex impairment, and is fed pureed foods. His physician is concerned about his decreasing ability to swallow. Given Mr. Black's inability to provide informed consent, the physician turned to Mr. Black's wife who was his substitute decision-maker.⁶ He informed her that she will need to consider the option of having a feeding tube inserted, since Mr. Black is unable to intake enough nutrition to maintain his daily nutritional needs.

The doctor reviews the potential benefits, risks and consequences. In particular, he stresses the potential adverse consequences of having a feeding tube in great detail. These possible consequences include a stomach rupture, with resultant bleeding, recurrent aspirations, heart failure as well as infection at the insertion site. Mrs. Black reminds everyone that her husband has an advance directive and a copy of it is in his medical chart. It stipulates what his wishes would be at a later point in time, if not competent to express himself. The doctor reads the advance directive aloud. There is unanimous agreement that the situation Mr. Black described in his advance directive seems to match the current situation. Since he is not able to express competent wishes at this time, nor has he been able to do so for a long time, the advance directive is referred to as it represents his most recent capable wishes. In line with what he had written, everyone is in agreement that he should not receive any treatment for his pneumonia, with the understanding that his death will likely occur in a few days. He will be provided with comfort measures only, including continued pain medication. Mr. Black dies in his sleep four days later with his family at his bedside. Professional team members and family members feel that they have done the 'right thing' by allowing him to die, in accordance with his advance directive.

Ethical Issues and Discussion

Does the advance directive meet the minimum standard for informed consent?

The Ontario legal requirements for informed consent are a

minimum standard.⁷ The legal requirements include being able to understand the information that is provided, including risks and benefits; being able to appreciate the consequences of accepting or refusing the medical treatment; and being able to make choices voluntarily. Even a *prima facie* straightforward case like Mr. Black's shows us that these requirements are not equal to the subtleties and complexities of situations in which consent becomes an issue. I propose augmenting the requirements in the following way: a person writing an advance directive must also understand and appreciate the risks and benefits of having an advance directive versus not having one. This, in turn, would require being informed about other legal standards and procedures that come into play in the absence of an advance directive. We are not only talking about understanding the information regarding treatment wishes and appreciating their consequences. We also need to understand the information pertinent to an advance directive in general, including one's own specifically.⁸ Each of these elements, crucial to making an informed decision about an advance directive, is both practically and conceptually fraught with problems, yet I have never seen practical or conceptual clarification explained for people contemplating an advance directive. These conditions are particularly hard to meet, simply because so little information is available on the topic. As a professional working in the field, I think it seriously undermines the moral and possibly legal authority of advance directives if the consequences of having one are not understood.

Did Mr. Black meet the requirements of informed consent when he wrote his advance directive? Probably not; probably, nobody could. To have done so would mean that he understood he could become incapacitated to the point where he would be unable to experience the pleasures he enjoyed in interacting with his spouse and adult children. There is no definition provided in Ontario's *Consent to Treatment Act* of the term "understand", but generally it seems to mean having the rational ability to grasp the concepts involved.⁹ In theory, Mr. Black would need to be able to understand the various scenarios. He would also need to be able to "appreciate" the consequences of what he was requesting. Again, there is no definition of "appreciation" in the relevant legislation in Ontario. The usual understanding of "appreciation" is that one must be able to understand what it means for a specific scenario to be applied to oneself. Sometimes it is termed *emotional understanding*.

So, at the time he is writing his advance directive, Mr. Black needs to be able to imagine himself as incapacitated and quite "otherwise" to how he is currently. Furthermore, he needs to be able to predict how he will experience himself in the context of his life as someone incapacitated. The challenging, perhaps impossible, task he faces is to make an informed decision *now* - in the context of being competent and having the life he has now, the values, beliefs, wishes and dreams as applicable to him currently - about his *future* self in a very different context as a very ill dementia patient. Mr. Black has to be able to imagine what that future life would be like for him and what his subjective experience of it would be, including what it would "feel like" for him. And on the basis of this imagining, he also has to make predictions *now* about what kind of medical treatment he would *subsequently* want to refuse or accept.

An advance directive written with contemplation of a dementia diagnosis in the future requires vastly greater imaginative prowess than do most other kinds of decisions that we tend to make. I

doubt we are capable of the task. To complicate matters further, I have rarely (if ever) heard of any advance directive that was written with any input from a medical practitioner. In order to understand the information pertaining to refusal or acceptance of any medical treatment, let alone be able to appreciate the consequences, there would need to be relevant and sufficient medical information given to the person to ponder. *This is rarely done.*

However, if we assume for the moment that Mr. Black would in fact receive some relevant medical information about a future scenario, it is probable that he would be able to understand it, although the amount of information would always be incomplete because nobody could anticipate the fullness of every possible scenario. We cannot know now what advances in medical research and technology will be available in the future. Furthermore, I think that regardless of how imaginative Mr. Black's mind might be, being able to appreciate himself as being quite different than he is currently is a very tall order. Of course I cannot prove this. However, I think we have evidence in general to the contrary, mainly owing to the fact that our beliefs and values can indeed shift in unforeseen and surprising ways when we experience significant life changes. Research demonstrates that we are in fact poor predictors of what will matter to us and what wishes and values we will hold dear in such a situation.¹⁰ Reliably exercising this personal and moral imagination would require answering some clearly vexing questions. What if I am so different in the future that I no longer hold the same values or wishes? What if I change my mind and cannot competently express this change of mind? What if I am able to express myself, but others think I am incompetent so they do not place much value on what I am saying? Will I be a stranger to my past self?

The difficulty in answering these questions about the future is underscored by the reasonable suspicion that we do not always know ourselves so well even in the present. Currently, as long as we are considered to be competent, we are allowed to change our minds, about most things anyway. If we are considered incompetent in the future, we will no be allowed to do so, at least from a legal point of view. If these concerns, which constitute some of the relevant consequences of having an advance directive, are not considered by us, let alone *appreciated*, how could it be argued that there was informed consent? I doubt very much that most people in the midst of writing an advance directive are even alerted to the existence of these kinds of limitations.

Furthermore, we cannot know if the level of appreciation that Mr. Black experienced met suitable standards because we do not have any objective criteria of measurement (recall that the Ontario *Consent to Treatment Act* does not even provide a definition of "appreciation"). This leaves us to glean the extent of Mr. Black's grasp of his advance directive from fragmentary and indirect evidence. Mr. Black did witness the demise of a loved one in a similar condition. Perhaps he had some personal experience with competency issues in his own past. We can hardly guess with any confidence. These kinds of experiences might add some weight to an "appreciation score" so to speak, though perhaps only to the "understanding" part. In addition to the problem of not knowing how to measure these "abilities" of imagination and prediction, there is, as mentioned, the additional problem of now knowing what criteria the "assessor" is using, or if there even is such a person who is guiding the author of the directive. Perhaps the culture

of dementia will in the future itself have changed significantly as well, with people not fearing the disease as much. Who knows? Certainly we do not know this currently. Advance directives are fraught with such unknowns, rendering the question of informed consent a deeply problematic one.

When we are of sound enough mind to consider future decision-making scenarios, at a time when we are no longer able to express a competent treatment decision, we are deeply influenced not only by what we see when we observe people with dementia, but by how our society depicts the experience and meaning of such an illness. There already exist important differences in the way different socio-cultural groups view and respond to Alzheimer's disease.¹¹

Currently the most dominant North American understanding of the meaning of Alzheimer's disease is that it is a neurological illness entailing "loss of personhood" or self, largely due to memory impairment. This definition is intertwined with other notions such as diminished competence, questionable ability to consent to medical treatments and negative personality changes. If Mr. Black entertains thoughts about how his life might be were he to develop Alzheimer's Dementia, he will likely view that disease in the negative light in which it is usually depicted. Will he also entertain thoughts that the current stereotypes of this disease might change over time? Will Mr. Black consider that by the time he could be diagnosed, he might consider this diagnosis less or more ghastly than he does now?

When Mr. Black wrote his advance directive, who guided him? Aside from some minimal advice from his lawyer, who assumed that because of Mr. Black's legal background he was already somewhat informed about advance directives, Mr. Black received no professional advice or support to complete his advance directive. We might assume that the lawyer who signed off for Mr. Black was satisfied, but we do not know if he provided Mr. Black with even the minimum standard of information required (whatever that might be), or a thoughtful enough *process* to ensure that Mr. Black could satisfy the requirements of an autonomous and informed decision. And yet, astonishingly, Mr. Black's efforts went well beyond what is actually required for an advance directive to be official. An advance directive does not require that a lawyer support or inform the process. Mr. Black could have hurriedly scribbled a few lines on an airplane dinner napkin and that would have qualified as an advance directive. Or, he may have downloaded a directive from the internet and filled it out hurriedly, perhaps after downing a few too many beers, and nobody would have known the difference.

Mr. Black was a practicing attorney for many years, so chances are he was aware of the legal status and benefits and consequences/limitations of a living will in general, probably more so than the average person would be. Nonetheless, we do not know if Mr. Black seriously considered all the risks and benefits of having an advance directive and was really able to appreciate them. As well, being a lawyer likely has no bearing on how skilled he might be in the areas of imagination and prediction. In fact, it is possible that as a lawyer who appreciates intellectual debates, it might have been harder for him to imagine himself as cognitively incapacitated. As well, there was no known concern about his competence level at the time. Mr. Black's immediate family believed that his advance directive was well thought out and not an impulsive undertaking, which in their minds gave them greater confidence in believing

it represented “who he was” and “what he really wanted.” At no point did any team or family member ever raise any concerns or questions about the legitimacy of his advance directive. The integrity of his advance directive seemed to be beyond question for them. This is not in the least bit unusual. Rarely does anyone raise this kind of question. Having an advance directive is still a fairly rare event and often the knee-jerk response is to be grateful that one even exists. Usually, there is no event that would result in someone suggesting such a review of the advance directive’s legitimacy. The general attitude toward advance directives in the medical care professions is positive and little attention has been paid to any cautionary tales, so most people would not think to question their usefulness. The preparation process of an advance directive can be severely lacking and yet the directive is often assumed by those charged with applying it to be not only valid, but highly valued.

It should be obvious by now that there are reasons to doubt the soundness of the very notion of an advance directive. Let us say that Mr. Black knew enough to consider that sometimes people with dementia might have a change of heart, or might no longer perceive Alzheimer’s to be such a terrible thing. In fact, suppose that he himself had witnessed some people in this exact situation. Or, let us assume that he knew that his predictive ability was somewhat faulty. Would this knowledge add credibility to his advance directive? Potentially it could, particularly if he were to cite this concern and suggest how the substitute decision-maker might respond to any caution specifically noted in his directive.

Lurking in the background of these specific issues with Mr. Black is a crucial and more general question:

Are the decisions we make in the form of an advance directive (based on precedent autonomy) in the event of future “incapacity” significantly different from the more usual decisions we make?

The short answer is yes.

One difference has to do with the amount of time that elapses between when the decision is made and when it is to be carried out. The other has to do with the degenerative nature of dementia and the subsequent changes that occur in the person. The specific problems that arise are generally associated with one or both of these factors.

I think it is fair to assume that as more time goes by there may be more opportunities for unanticipated events to intrude. In the case of the advance directive, once an individual is incapacitated and can no longer change these instructions, it could become increasingly misrepresentative and misleading. For example, perhaps Mr. Black might even enjoy the kinds of experiences he could have when demented. Likely, he did not know or appreciate that social/emotional memories might linger into even the most advanced stages of dementia, and that he would reap great rewards from having his wife sit at his bedside daily. Perhaps, shortly after his last pneumonia, there would be a cure for dementia. In Mr. Black’s case, however, his advance directive was not written decades before, so chances are it was more relevant than if it had been written years before.¹²

In summary, then, there are two major problems with the responsible implementation of advance directives: irreversibility of decision and predictive difficulties.

Plausibly, it would be prudent to assume that irreversible decisions ought to be made with particular certainty. But how can we increase certainty given that, by definition, the kind of future circumstances relevant to informed advance directives remain largely unknown, unpredictable, and impossible to appreciate?

Of course, many types of decisions that we make also involve imagining ourselves to be in situations not easily imaginable, and are also made without a great deal of certainty. The decision to become parents is a prime example. It is not uncommon for new parents to claim that no amount of information or imagination sufficed as ample preparation. “You have to experience it to know it” is a sentiment expressed fairly regularly by new parents. As already stated, research supports the view that we are poor predictors of how we will experience ourselves in radically different situations. Perhaps our values might radically change and, so too, our ideas about what constitutes a good life. Many able-bodied persons imagine they would never want to live if paralyzed and wheel-chair bound. Yet, when faced with that situation, many do not wish to have their lives ended. Not all adjust well, but many report that their quality of life is at least satisfactory.

Indeed, there are similarities between advance directive decisions and the more common types of everyday decisions. However, a living will that addresses future dementia has additional limitations. Persons need to be able to imagine both physical and cognitive changes, including memory impairment. Some people worry that they will “no longer be the same person” and may not experience themselves to be “them”. Their transformation might be so drastic as to render previous considerations of the future life to be nothing more than chance guesses.

Let us remember that once someone is deemed incompetent, there can in practice be no effective changing of one’s mind. Through writing a living will, Mr. Black is binding himself in the future to what he presently decides about his future self. Paradoxically, what constitutes an act of freedom to make a choice now for oneself could later also be experienced as imprisonment. In practical terms, the original Mr. Black cannot change his mind after he is deemed incompetent, should he wish to reverse his earlier decision to refuse treatment. Perhaps post-dementia he does not really care that he can no longer energetically debate with his children. Maybe he has had enough of travelling and prefers to spend most days resting in bed. And perhaps he would want to receive medical treatment even if still he cared about debates and travel. Unfortunately, once judged incompetent, Mr. Black cannot confirm his earlier choices, nor can he refute them.¹³

Here we have the crucial distinction between advance directive decisions and the many other kinds of decisions we make that also cannot be “undone” or reversed. While we cannot travel backward in time and change the past, outside of our imagination, we can still decide to do something in reaction to a past decision we currently wish we had not made, if we are still deemed competent. We can alter the future to some extent, provided our autonomy is intact. For example, while we cannot reverse the decision to bear a child after the child is born, we can place the child for adoption or

surrender the child to a children's welfare agency. There are usually options we can take to continue to exert some control in our life. But with an advance directive aimed at refusal of life-sustaining treatment, there is no further action of self-determination after this one.

Concluding Thoughts

The case of Mr. Black did not raise any particular ethical issues for either the family members or the healthcare team in terms of applicability of his advance directive. It appeared to be quite straightforward. Nobody raised any questions or concerns about predictability, irreversibility of decision, or issues related to informed consent. There was consensus amongst all the stakeholders involved that the conditions stated in his advance directive matched his current circumstances, thus triggering the need to comply with the wishes stated in his directive.

Generally, as an ethicist I am called upon when there is lack of agreement amongst either the family or healthcare team members (or between both groups) about interpretation of the directive. Less often, concerns about predictability and issues related to informed consent are raised. Nonetheless, everyone involved in the case of Mr. Black felt that the "right" action was taken when the advance directive was followed. Perhaps they are correct. However, if they are, surely it cannot be based upon the principle of precedent autonomy or its practical application, informed consent, foundational to the conceptualization of the advance directive in the first place.

Endnotes

1. Advance directive is also known as a *living will* or *directive*.
2. Judith A. Wahl, *Options for Advance Care Planning* (Ontario: Advocacy Centre for the Elderly, updated February 2009).
3. Currently in Ontario directive requests to refuse or withdraw treatment carry more legal weight than do requests for treatment.
4. Many people designate an SDM to speak on their behalf, regardless of whether or not they have an advance directive. The legal term for such a person is *Power of Attorney*. If there is no legal power of attorney, then there is hierarchical ranking of persons from which one is selected, eligible to fulfill that role. The designation of SDM is used in these circumstances. However, for simplicity sake, I will use the term SDM to refer as well to the power of attorney.
5. The term *treatment wishes* is used both to denote treatments the author wishes to receive as well as treatments the author wishes to refuse in the future.
6. Even when asked simple questions requiring a 'yes' or 'no' response, there is no discernable indication that Mr. Black understands, nor is he able to respond in a meaningful way.
7. The attainment of "fully" informed consent is an ideal which cannot be achieved, but nonetheless should be strived for. As the late Benjamin Freedman said, "There is no end to 'fully informing' patients". See Benjamin Freeman, "Chapter 6: Informed Consent and the Competent Patient," in *Readings in Biomedical Ethics: a Canadian Focus*, 2nd ed., edited by Eike-Henner W. Kluge (Scarborough: Prentice Hall, 1999): 71. We should, I add, try to ensure *everyone* is "sufficiently informed" though there are of course differing opinions on what exactly that means.
8. For example, in some Canadian provinces, including Ontario, a substitute decision-maker is the person responsible for applying/interpreting the terms of the directive, not the physician.
9. However, there is a requirement that the treatment provider who is requesting consent describe the treatment in ways that a *reasonable* person would be able to understand (emphasis added). I am not sure at all I would be able to even begin to know how to define a "reasonable" person for this context.
10. Angus Dawson, "Advance Directives," *General Practice and Ethics*, ed. Christopher Dowrich and Lucy Frith (London: Rutledge, 1999) 130-171; Christopher James Ryan, "Betting your life: an argument against certain advance directives," *Journal of Medical Ethics* 22, no. 6 (1996): 96-99.
11. See M.B. Holstein, "Ethics and Alzheimer's disease: widening the lens," *Journal of Clinical Ethics* 9, no. 1 (1998): 13-22.
12. However, while the increasing passage of time does allow for more unanticipated events to occur, there could be examples where the passage of more time could work to one's benefit. For example, because we cannot predict how someone with dementia might respond, it is equally possible that someone might respond in a way that coheres with what was anticipated in the advance directive. So, in this context passage of time would not be the significant factor, given the randomness of chance. In general, however, people do not radically transform themselves within a very short time period. In this sense the passage of time would be more relevant. Also, it is probably more likely that significant medical advances will occur over the longer rather than shorter haul, rendering the advance directive less informed than it would be if written closer to the time of when it would be enacted, especially if news of upcoming advances was made public.
13. In fact, DeGrazia asks if one can neither confirm nor refute an earlier choice, to what extent is it actually an "earlier" choice rather than a "current" one? One could thus argue that there is no precedent autonomy on that basis. One needs a current decision to differentiate it from a former decision, or vice versa. See David DeGrazia, "Advance Directives, Dementia, and 'The Someone Else Problem,'" *Bioethics* 13, no. 5 (1999): 373-391.

References:

- Dawson, Angus. "Advance Directives." In *General Practice and Ethics*, edited by Christopher Dowrich and Lucy Fritch, 130-171. London: Rutledge, 1999.
- DeGrazia, David. "Advance Directives, Dementia, and 'The Someone Else Problem.'" *Bioethics* 13, no. 5 (1999): 373-391.
- Freedman, Benjamin. "Informed Consent and the Competent Patient." In *Readings in Biomedical Ethics: a Canadian Focus*. 2nd ed. Edited by Eike-Henner W. Kluge, 71. Scarborough: Prentice Hall, 1999.
- Holstein, M.B. "Ethics and Alzheimer's Disease: Widening the Lens." *Journal of Clinical Ethics* 9, no. 1 (1998): 13-22.
- Ryan, Christopher James. "Betting Your Life: an Argument Against Certain Advance Directives." *Journal of Medical Ethics* 22, no. 2 (1996): 95-99.
- Wahl, Judith A. *Options for Advance Care Planning*. Ontario: Advocacy Centre for the Elderly, Updated February 2009.

Acknowledgements: None.

Competing Interests: None.

Address for Correspondence:

e-mail: msokolowski@baycrest.org

Treatment-Resistant Major Depression and the Capacity to Terminate Care

Barbara R. Sommer, MD

Associate Professor in Psychiatry

Director, Outpatient Geriatric Psychiatry

Stanford University School of Medicine

Stanford, CA, USA

Donna J. Roybal, MD

Department of Psychiatry,

Stanford University School of Medicine, California, USA

ABSTRACT

Of patients suffering from major depression, only around 70-80% experience remission, with the rest having only a partial response or no response at all to treatment, resulting in severe emotional distress and hopelessness. For the older patient who becomes malnourished as a result, depression may become life threatening, even if the patient is not overtly suicidal. We present the case of such a patient, who after many courses of antidepressant trials and electroconvulsive therapy, requested that treatment be terminated, along with the nasogastric feeding that had been keeping him alive. The patient knew that this course would result in his death. We propose that in this case, major depression was similar to other end stage medical disorders for which there are no curative treatments, and that the patient had capacity to terminate his care. We propose that he suffered from "terminal depression", and we review the literature on this subject.

Key Words: depression; treatment-resistant; end-of-life; elderly; ethics.

Introduction:

As patients direct the amount and invasiveness of care at the end of life, the decisions made are accepted without question only if competence is assured. When a patient suffers from depression, these end-of-life issues generally are delayed until the depression has lifted, with the implicit assumption that passive suicidal feelings and hopelessness will abate or disappear. Moreover, patients are most often considered

temporarily incapable of making such important decisions when depressed, with studies showing that in general they have more optimism after antidepressant treatment, and that this optimism also may apply to decisions about advanced directives^(i,ii).

However, the literature on the longitudinal course of depression suggests that there are a significant number of patients that either only partially respond, or do not respond at all to antidepressant therapy, despite good adherence to adequate trials. While some studies estimate the incidence to be up to 30%⁽ⁱⁱⁱ⁾, the exact figures are difficult to estimate, with most studies evaluating patients after only one trial^(iv,v). Unremitting, severe depression may lead to a dramatic reduction in quality of life, often with inability to fully return to work^(vi). Older patients may experience a decline in physical health as they decrease their food consumption and ambulation. Frail older patients may be at risk for falls, and after staying in bed for protracted periods, also may run the risk of deep vein thrombosis. Complicating this picture is the risk posed when older patients are given multiple medications, increasing the risk for delirium^(vii).

While treating such patients with all available regimens is the standard of care, there are instances when patients do not improve, and remission becomes a frank impossibility. Research suggests that some late-onset depressions, associated with abnormalities in the limbic areas of the brain^(viii), diminish the possibility of a full response to medications or electroconvulsive therapy (ECT), which require such pathways. Furthermore, it has been found that patients not responding to antidepressant therapy may be at increased risk of cognitive decline, and this deleterious effect of antidepressants should make the clinician consider discontinuing medications in older patients that have not had a treatment response^(ix).

After a patient has undergone several courses of oral medications and ECT, without therapeutic effect, we propose that the

malnourished, frail, older, depressed individual may be seen as suffering from the psychiatric equivalent of a terminal medical illness. The question then arises as to whether such a severely depressed patient has the capacity to terminate care, knowing that the outcome will hasten death. While there is literature on the termination of care in the case of a patient with a medical illness and concomitant depression, there is little that discusses this question as it pertains to depression as the primary illness.

We discuss the case of a man who had had a robust pre-morbid baseline, but after the initial onset of depression in later life, experienced a several-year period of protracted, recurrent depressive symptoms. After many different medication trials and ECT, he asked that his treatment be discontinued, knowing that because of the severely malnourished state emanating from his primary depression, death would ensue. We postulate that this case may be considered “terminal depression.” The patient’s wife consented that his case be described.

CASE PRESENTATION

Without a past psychiatric history, Mr. A first experienced a profound depression at age 59. There were no confounding medical illnesses, medications, or family stresses, and he did not present with concurrent psychosis or dementia. His prominent difficulties with poor sleep and appetite, and lack of energy, treated with citalopram and psychotherapy, led to a remission for five years after a psychiatric hospitalization, and Mr. A was able to resume his job.

Five years after this initial depression, Mr. A’s wife found that he was becoming irritable and isolative, and then he asked that she arrange funeral preparations. He no longer was able to function as the professor he had been but when his outpatient psychiatrist prescribed an increase in citalopram, he did not agree with the plan, having lost confidence in the medication on which he again became symptomatic. He then began to ask his wife whether they could afford a funeral, feeling that his mental illness was a sign that he was to die at an early age. With this depression, he became severely slowed in his motor function, (anergy) and having become paranoid that others were poisoning his food, he stopped eating. He had intrusive thoughts and during this hospitalization, the staff felt he was experiencing auditory hallucinations. A CT scan of his brain was normal. Mr. A remained alert, oriented, and fluent in his speech. Neurological examinations were unrevealing.

Within three months, Mr. A stopped eating all together, and by this time had lost 45 pounds. With extreme poverty of thought and slowness of speech, delayed after a question was asked, he was voluntarily admitted for his third hospitalization, this time to a medical/psychiatric unit. At times he refused to get out of bed to perform activities of daily living, and despite his lack of the classic waxy flexibility on physical examination diagnostic of catatonia, the magnitude of his anergy made the staff nonetheless consider the diagnosis. He described a somatic delusion about esophageal and intestinal blockage, causing him to refuse to eat or drink. An MRI of the brain was consistent only with nonspecific chronic small vessel ischemic disease. Also noted was mild global prominence of the ventricles and sulci consistent with mild cerebral tissue loss, specifying that the loss was slightly greater than expected for an

individual his age. A Mini Mental State Exam (MMSE) at time of this third admission was 29/30, missing one point for “serial 7’s”. A diagnosis of dementia was ruled out.

Mr A received a course of 16 bilateral ECT treatments during this hospitalization, with scores on the Montgomery-Åsberg Depression Rating Scale (MADRS) decreasing only from 53 to 34, reflective of continuing very severe depression. Of some benefit, he became less paranoid and began oral intake again and gained 20 pounds. The ECT did not result in demonstrable cognitive impairment.

Five months after discharge, the patient relapsed, requiring another psychiatric hospitalization.

Another medication regimen was prescribed, and while the neurovegetative symptoms improved, he continued to complain of depressed mood at the time of discharge. Given the magnitude of his functional decline from his baseline, a course of 16 ECTs was again administered. Unfortunately, his MADRS score only decreased from 45 to 33. At the time of final discharge, he was able to participate in some ward groups and activities, and he was able to leave his room for short escorted walks with his wife or with staff. He continued to exhibit constricted affect, to appear dysphoric, and he stated he felt “frustrated” for lack of overall improvement in his mood. He did not appear psychotic.

Mr. A’s wife stated that about six months later, he became “tired of seeing the psychologist and taking medications”, telling her “Enough is enough.” His refusal to take medications was again followed by refusal to eat, and another psychiatric hospitalization. His primary care provider felt that Mr. A had capacity to make his own decisions and after consulting with an ethicist, informed Mr. A’s wife that it was “ok to let him go.” Medication adherence was an issue, as Mr. A was at this point refusing to abide by a daily regimen.

He was hospitalized a fifth time, after a total weight loss of 50 lbs over the previous six months. His mental status exam was significant at this time for severe psychomotor slowing, severely constricted emotional tone, and irritability. He showed no motivation, lying in bed throughout the day. He stated he was anxious, and had no interest in watching or reading about baseball, his previous avocation.

Mr. A’s MMSE was 19/28 at the beginning of this fifth admission with trouble with concentration, recall, remembering a 3-step command, and reading and obeying commands. He was unable to draw a pentagon or to write a sentence, stating he was too weak. He did complain of autobiographical memory loss from his previous ECT treatments. His ability to perform tasks with dexterity was intact but he was unable to interpret abstractions and was concrete in thinking. However, his ability to assess the advantages and disadvantages of ECT were intact. He remembered these risks and benefits based on recall from his prior ECT experience. An MRI of the brain revealed moderate prominence of ventricles and sulci suggesting global volume loss. Again, chronic small vessel ischemic changes in the frontal lobes were noted, without change from the previous study. Also noted were more severe changes in the basal ganglia (motor area) bilaterally. Given the presence of cortical and subcortical white matter lesions, cognitive deficits, gait disturbances, and history of tremor that accompanied his late

life depression and anxiety, diagnoses of vascular dementia and vascular depression were made. While neuropsychological testing was attempted, Mr. A could not tolerate it.

With the anxiety pharmacologically treated and now in good control, he was able to get out of bed, with aid from physical therapy once or twice a day.

It was at this point that that the patient finally decided that he was no longer interested in any treatment for depression. He was able to recall that he had had several psychiatric hospitalizations, ECT with little effect, and now, feeling a burden to his wife, he felt that there was nothing left to ameliorate his low level of functioning. He no longer wanted his wife to visit. At the same time, when she did see him, she often cried at his deterioration, and now was in counseling herself. He acknowledged to one of the authors that he felt he had lost his dignity. A palliative care consultation was called, but he refused to see the team.

While he appeared to have capacity to refuse treatment, given his concomitant severe depression with somatic delusions, an ethics consultation was sought to determine if the team could abide by his wish. It was determined that the patient did indeed have capacity, and he was transferred to a skilled nursing facility, nasogastric tube (NGT) in place. He continued to demonstrate paucity of speech, with long latency of response. After three weeks at the skilled nursing facility, the patient pulled the NGT, and said "Good-bye" to his wife. He died several days later.

A complete list of his medication regimens is listed in Figure 1.

Discussion

We propose that Mr. A may be thought of as having suffered from the psychiatric equivalent of a terminal illness. Like other patients suffering from medical disorders, who do not respond even to the most up to date strategies, and who are considered "non-responders", his prognosis became increasingly grave. As it became progressively more difficult for him to experience a sustained remission, he began to spend increasing amounts of time in hospitals. His treatments were aggressive, and while one may argue over the details of some combinations of treatments, there is no argument that he received adequate trials of several antidepressants in adequate doses, with evidence-based augmentation strategies. Furthermore, he was administered ECT twice. Nonetheless, no treatment, save citalopram at the onset of his symptoms, was helpful for a sustained period.

Mr. A was competent in his understanding that after having had many available psychiatric treatments, one viable option was to continue with enteral (tube) feeding and even more medications in an assisted living environment. Alternatively, he could have accepted ECT, which had not caused sustained remission in the past and which gave rise to autobiographical memory loss. In addition to his psychiatric diagnosis of major depression with psychosis, he may have also been suffering from the depression and demoralization often superimposed on patients in the terminal phases of medical illnesses, and which may increase the desire to die^(x,xi). Mr. A also likely suffered from mild vascular dementia,

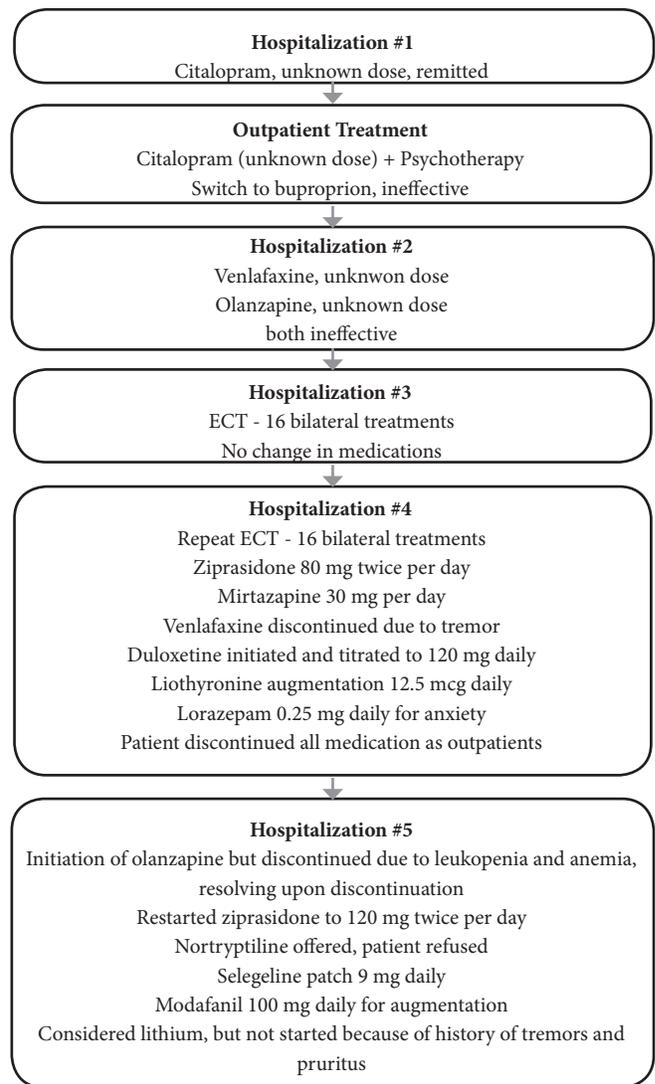


Figure 1: Treatment Course. Note all antidepressant trials lasted a minimum of 10 weeks with assured adherence by patient and his wife unless specified otherwise.

which was not thought to impact on his ability to rationally make decisions about his end-of-life care.

In the psychiatric setting, a patient who refuses treatment, or who expresses a right to die is most often considered *a priori* to suffer from a psychiatric disorder. However, studies have shown that patients with serious medical illnesses often exhibit depressed symptoms in the last month of life. It has been suggested that while such patients should be given rights to determine their care, they often are not^(xii). In the Netherlands, where physician assisted suicide has been practiced and studied for over a decade, it also has been found that patients with depression are not necessarily incompetent to make end of life decisions^(xiii). Psychiatrists have been found able to make such adjudications about competence in such circumstances on a first interview only 6% of the time^(xi).

Mr. A was a voluntarily admitted patient who, while depressed, was never suicidal during any of his admissions, and who clearly understood the ramifications of the different courses that could be taken on his behalf. He was seen as capable of making decisions

on his own behalf, despite his depression. This capability was in line with most research findings that even patients with very severe depression maintain their competence to make health care decisions ^(xiv).

This case is important because older individuals with white matter abnormalities on MRI, reflective of abnormalities in cortico-striato-limbic networks may be predisposed to chronic, refractory depression ^(viii). These networks may be seen as the “cables” required for antidepressant therapy action. Such patients are analogous to other medical patients with end-stage organ disease, refractory to known medical treatments, who wish to terminate their care. With a minority of psychiatric patients for whom there are no viable treatments left, whose oral intake, by virtue of depression, is not life sustaining, there may exist the ethical decision that no treatment is a humane option. In this case, the patient, with no history of suicidal feelings, was felt to be capable of making such an important end of life choice.

References:

- i. Leeman CP. (1999) Depression and the right to die. *General Hospital Psychiatry* 21:112-115
- ii. Bruce ML, Ten Have TR, Reynolds III CF, et al. (2004) Reducing suicidal ideation and depressive symptoms in depressed older primary care patients: A randomized controlled trial. *JAMA* 291(9): 1081-1091
- iii. Keller MB, Klerman GL, Lavori PW, et al. (1984) Long-term outcome of episodes of major depression: clinical and public health significance. *JAMA* 252: 788-792
- iv. Fava M, Davidson KG: Definition and epidemiology of treatment-resistant depression. *Psychiatric Clinics of North America* 1996; 19(2): 179-200
- v. Sargeant JK, Bruce ML, Florio LP, et al: Factors associated with 1-year outcome of major depression in the community. *Arch Gen Psychiatry* 1990; 47:519-526
- vi. Mintz J, Mintz LI, Arruda MJ, et al: Treatments of depression and the functional capacity to work. *Arch Gen Psychiatry* 1992; 49: 761-768
- vii. Tuma R, DeAngelis LM: Altered mental status in patients with cancer. *Arch Neurol* 2000; 57: 1727-1731
- viii. Alexopoulos GS, Murphy GF, Gunning-Dixon FM, et al: Microstructural white matter abnormalities and remission of geriatric depression. *Am J Psychiatry* 2008; 165: 238-244
- ix. Culang ME, Sneed JR, Keilp JG: Change in cognitive functioning following acute antidepressant treatment in late-life depression. *Am J Geriatr Psychiatry* 2009; 17(10): 881-888
- x. Breitbart W, Rosenfeld B, Pessin H, et al: Depression, hopelessness and desire for hastened death in terminally ill patients with cancer. *JAMA* 2000; 284(22): 2907-2911
- xi. Ganzini L, Goy ER, Dobscha SK: Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey. *BMJ* 2008; 337:a1682-1687.
- xii. Sullivan MD, Youngner SJ: Depression, competence, and the right to refuse lifesaving medical treatment. *Am J Psychiatry* 1994; 151:971-978
- xiii. Van der Lee ML: Depression and physician assisted dying. *BMJ* 2008; 337:a1558.
- xiv. Werth JL. (2004) The relationships among clinical depression, suicide, and other actions that may hasten death. *Behav Sci Law* 22: 627-649

Acknowledgements: The authors would like to gratefully acknowledge Dr. Armin von Gunten, who reviewed the manuscript.

Competing Interests: No disclosures to report. There has been no funding for research on which this article is based.

Address for Correspondence:

Barbara R. Sommer, MD
Director, Outpatient Geriatric Psychiatry
Stanford University School of Medicine
Stanford, CA, USA 94305-5723

email: brsommer@stanford.edu

Contemporary Issues of Ethical E-therapy

Sharon Lee MA

Doctoral Student in Counseling Psychology

University of Iowa

Iowa City, USA

ABSTRACT

E-therapy is fast becoming an inevitable addition to counseling due to the increased use and accessibility, the internet and advances in e-therapy technology in the U.S. With the growth of any method of treatment, awareness of ethical concerns regarding best practices is a necessity. E-therapy has unique ethical challenges that mental health professionals should be aware of when utilizing computer mediated counseling. Specifically, there are five common ethical concerns of on-line counseling that should be addressed during the informed consent process: appropriate concerns for e-therapy, the possibility of misunderstanding, maintenance of professional boundaries, issues of confidentiality, and interruption of services. This paper also calls for professional organizations to update their ethical guidelines to reflect the changing ethical concerns in e-therapy, as well as enact better enforcement of these guidelines.

Key Words: e-therapy; on-line counseling; telepsychology; ethics.

Introduction:

The internet has become a conduit for everyday communication and a tool to access both physical and mental health services. For the past 20 years, there has been a surge of on-line activity with approximately 128 million subscribed internet users in the U.S. (Fox, 2009). Of these on-line consumers, approximately 61% of American adults surveyed reported using the internet to obtain health information. Also 42% of all adults say they or someone they knew was helped by the medical advice or health information found on the internet (Fox, 2009). This finding is consistent with reports of steady increases in the utilization of on-line search engines for information regarding mental health issues, as well as the documented increase in use of telecommunication in providing psychological services within the current field (APA, 2010; Rainie, 2009). These statistics indicate that Americans are relying increasingly on the internet as a resource to improve their overall well-being.

The popularity of on-line mental health resource consumption is supported by the recent advancements in technology. Current

internet-accessible devices have eroded barriers that once stood in the way of consumers' access to information and/or mental health services (Pew Internet & American Life Project, 2009). The explosion in technological advances and cultural shift towards internet-based communication has also supported the acceptance of e-therapy. E-therapy is defined in this paper as an internet-based modality in delivering psychological support that can be synchronous (simultaneous) or asynchronous (time-delayed) communications. Beginning in the 1980's, e-therapy became an emerging delivery method within the practice of counseling psychology (Alleman, 2002; Oravec, 2000; Skinner & Zack, 2004). This modality of communication is mediated primarily through a computer-like device between a mental health professional and client (Alcaniz, Botella, Banos, Zaragoza, & Guixeres, 2009; Grohol, 1999).

E-therapy's use of computer mediated communications (CMC) also has several unique nuances that differ from face to face (FtF) transmissions of counseling, such as the lack of non-verbal communication. These nuances have critical implications in adhering to ethical practices in therapy. The ethical concerns of e-therapy addressed in this paper will use the ethical guidelines outlined by the American Psychological Association (APA) and the International Society of Mental Health Organization's (ISMHO). The use of both ethical guidelines will provide a comprehensive means of understanding the ethical needs within e-therapy. Though the APA ethical guidelines (2002) has modified the language in several of its codes and standards to be more inclusive of internet therapy, it has not specifically addressed all ethical concerns regarding e-therapy. Therefore ISMHO (2009) guidelines can be used as a complement to APA guidelines in order to enhance the understanding of the ethical nuances faced by e-therapists.

This paper will first give a brief overview of existing e-therapy modalities and then elaborate on five common ethical challenges for e-therapists that should be discussed within the informed consent process. Lastly, final thoughts will be provided about the future needs of e-therapy for practitioners.

Modalities of E-therapy

Today's advances in computer hardware and software allow for instantaneous interactions between human users that come in

various formats, such as: e-mail, support groups, live chats, video-conferencing, and informational websites. E-mail counseling was one of the first methods to be utilized in e-therapy. An asynchronous method, this modality allows the client and therapist to exchange short narratives through e-mail. Typically, most e-mail services limit responses to 200 words and clients are provided with a response from the therapist within 48 hours. On-line support groups are held in open forums that connect individuals all over the world surrounding a specific mental help topic (Oravec, 2000). This format generally has a rolling membership and allows anonymity for users who wish to participate (Oravec, 2000). Unlike e-mail and support groups, video conferencing and live chats are synchronous methods of communication which allow for instantaneous conversation between users. Finally, informational websites provide psychoeducational information about various mental health topics. These various modalities within e-therapy all have their unique strengths and challenges, and are not immune to common ethical dilemmas that therapists may face.

Common Ethical Concerns of E-therapy

With the new technological advances in conducting therapy, mental health professionals need to be continually vigilant about conducting therapeutic services in the most ethical manner possible. This ensures that trust and quality services are provided as e-therapy continues to become mainstreamed. Providing ethical services for clients is a difficult challenge for therapists. Despite the overlapping ethical considerations between e-therapy and FtF modality, there are additional challenges that are unique to on-line delivery. Five ethical challenges that will be elaborated in this paper are: appropriate concerns for e-therapy, the possibility of misunderstanding, maintenance of professional boundaries, electronic confidentiality and privacy issues, and interruption of therapy due to technological problems. All five concerns are important components to include within an informed consent process.

Appropriate concerns for e-therapy

One of the first risks of e-therapy to be discussed with the client during the informed consent process are the appropriate concerns that e-therapy can address. For instance, clients whose presenting concerns are due to an immediate crisis, eating disorder, or severe psychosis would not fit well within this modality due to the difficulty in ensuring the safety or accuracy of assessment without visual cues and the physical proximity of the client (Kanani & Regehr, 2003; Metanoia, 2009). Self-harm is especially a concern within this modality due to several limiting factors within e-therapy. For instance, those who offer e-therapy through e-mail communication will find that it is lacking in its immediacy of receiving and responding to communications by a suicidal client. Additionally, those who offer therapy over instant messaging are often only given a screen name and may not know the location of the client at the time of communication. Therefore provision of emergency care may be difficult if the client had not provided and/or is resistant in providing any additional contact information,

such as his or her current location. (Kanani & Regehr, 2003; Shaw & Shaw, 2006). Due to the safety challenges associated with e-therapy, the ISMHO (2009) guidelines recommend that therapists inform clients of possible emergency procedures, obtain proper contact information that can be used to inform emergency officials if the situation arises, and identify alternative therapists or another mental health professional that is local to the client and has agreed to be accessible to the client if needed.

Possibility of misunderstanding

Another risk that clients are likely to encounter while engaged in e-therapy is the potential misunderstanding between therapist and client due to the missing non-verbal cues (ACA, 2005; Alleman, 2002; Mallen, Vogel, & Rochlen, 2005; Recupero & Rainey, 2005). Within FtF therapy, both therapist and client have the benefit of non-verbal cues that enhance the understanding of what is being said in session. These non-verbal communications allow for more subtle communication of important feelings, such as empathy and understanding. However, within some modalities of e-therapy, such as e-mail or live chats, non-verbal cues are not accessible for either the therapist or client. In Haberworth, Parr, Bradley, Morgan-Fleming, & Gee's (2008) qualitative study of counselors-in-training experiences of communicating with a client via an instant message chat function, they found that the dearth of non-verbal communications could hinder conversations between the therapist and client. This was especially true for those who had little prior experiences with communicating on-line. This study highlights the importance of body language as well as prior experience with the communication medium within a therapeutic session. Without these two components, a potentially difficult environment for building the therapeutic alliance could be created. Thus it is important to consider building more time into fostering the alliance, as well as taking care in discussing the methods of conveying meaning within the sessions.

One method of building trust and alliance is to address these risks early on within the informed consent process. Not doing so could easily lead to feelings of frustration, lack of control, and hurt between the client and therapist. During the first few sessions, an exploration of alternative methods that both parties can implement to reduce the risk of misunderstanding can help to facilitate communication within the counseling sessions. Some alternative methods proposed are: emoticons, use of capital letters, fonts, and sizes as a means to provide text-based cues of typical non-verbal behavior (Alleman, 2002). Adjustments, such as these, can help to accommodate some limitations of service delivery over the internet. Another method of assisting in the facilitation of communication and trust is to encourage the use of teleconferencing technology. This technology allows for direct observation of non-verbal body language communication that is often lost in other modalities of e-therapy. Additionally, this method of communication has become a growing trend as more personal computers are equipped with webcams. Free programs such as Skype are becoming more popular as a method of communication on-line. For instance, in a recent survey video conferencing has quadrupled in direct mental health service use between 2000 and 2008 (APA, 2010). Though the percentage of mental health professionals utilizing this technology is still quite

small compared to use of e-mail, it has shown great potential in overcoming communication barriers often experienced within other modalities of on-line communication.

Maintenance of professional boundaries

A third challenge within e-therapy is maintaining the delicate balance between professional and personal boundaries. One important boundary concern is the ever growing accessibility of private information on the internet. Today's internet users utilize search engines and social network webpages, such as Wikipedia or Facebook, than in the past (Rainie, 2009). For instance, Lenhart (2009) found that in a survey of adults 18 and older, 46% use social networking websites such as Facebook, Myspace, and LinkedIn. Additionally, there is documented increase of clients utilizing these websites to gain additional information about health professionals and illness, as a means to connect to their health care providers, or to find medical or emotional support (Lehavot, 2009). Though the ethics codes were created to apply directly to professional activities, cyberspace constantly blurs the boundaries of professional and personal. Ethical guidelines that were developed to address multiple relationships are not specific to this type of on-line activity. However, APA ethical guidelines do state that any foreseeable multiple relationship that may be potentially harmful should be avoided. Therapists should be aware of the type of personal information about themselves that is accessible to the public on-line. This potential for harm is especially salient in therapist's use of blogs or social networking sites, such as Facebook (Lehavot, 2009). For instance, if a client requests to "friend" their therapist on Facebook, which allows them access to the therapist's profile, this puts the mental health professional in a difficult situation if the profile was not meant for public viewing. Potentially damaging information may be accessed by the client, and could be counterproductive to treatment. However, if the request to access and connect with the therapist through social networking is denied, this could also be damaging towards the established therapeutic alliance. Therefore, boundaries in cyberspace should also be discussed if necessary, and privacy options for social networking sites should be utilized as means in controlling the type of information are accessible to the public.

The second challenge to professional boundaries is the increased incidences of distraction when providing service and likelihood of confidentiality breaches when working from a distance. One of the greatest benefits of e-therapy is the convenience of providing services from home. However, this can also increase the risk of distractions while providing services as the professional and personal sphere becomes more blurred. This can increase the chances of distraction by family members or household duties, which may decrease the quality of the therapy session. Haberstroh et al. (2008) recommended that professional and personal life spheres be clearly delineated when therapists work from home. This could include set hours in a private and separate room or office so that professional business can take place without distraction. Additionally, extra precaution regarding the accessibility of the computer by others should be taken to ensure confidentiality. Such precautions could be to avoid using a family computer and enabling a password protection for the computer used for therapy

purposes. By adhering to these boundaries, therapists are able to maintain best practices and decrease the risk of harm to the client.

Electronic confidentiality and privacy issues

The fourth ethical risk that should be addressed within the informed consent process is that of maintaining confidentiality and privacy, of both the client and counselor. E-mails, on-line support groups, and instant messaging all leave a digital trail that can be compromised if not secured properly (Frame, 1997; Kanani & Regehr, 2003; Mallen et al, 2005). Therefore, a clear understanding of the risks to confidentiality must be discussed during the informed consent process, as confidentiality breaches could have potential serious consequences for the client.

The risk of confidentiality breaches can be twofold for the client. Breaches can occur due to unauthorized access of information and or an error in correspondence transmission (Kanani & Regehr, 2003). Examples of these breaches include: inadequate security of the website or simple human error when sending off an e-mail. The ISMHO (2009) and APA (2002) ethical guidelines state that proper security must be taken by the therapist in maintaining confidentiality. For the e-therapist, this means implementing proper security, such as the use of encryptions and firewalls that protect information from hackers or malware (Frame, 1997). Hackers, identity thieves, and malware are common threats within the cybersphere that can forcibly access confidential information; therefore knowledge of technology and best practices in securing correspondence is important for both client and therapist. These serious breaches of confidentiality can be avoided by both therapist and client through due diligence in implementing security practices, and a clear understanding of the limitations in confidentiality within cyberspace. Therefore one of the most important tasks of a cyber-therapist is to ensure that confidentiality disclosures are thoroughly discussed prior to entering a therapeutic relationship.

A necessary disclosure about maintaining confidentiality is a shared responsibility between both client and therapist. Typically, both have access to the digital transcripts generated from e-mail and chat correspondence and stored in their respective computers (Kanani & Regehr, 2003; Mallen et al, 2005). E-mails and chat histories can be potentially accessible to others not intended to have access to the information. For instance, significant others may have access to e-mail accounts and computers in their home, employers often monitor computer use at work, and strangers may have access to the browser history on the public computers at an internet café or library. These confidentiality breaches leave the client in both a psychologically and economically vulnerable position, as the sensitive information shared could potentially be utilized in a malicious manner. For instance, information regarding the mental health of an individual can be used as a means to stall employment advancement or could be fodder for office gossip. All of these possibilities of potential breaches that fall outside the therapist's control; therefore, it is important for the therapist to disclose this potential risk as well as educate the client how to keep their information secure and to remain mindful of their own confidentiality (Mallen et al, 2005).

Interruption of therapy due to technological problems

The last risk that should be included during the informed consent process is the potential of interrupting therapy due to technological problems. This is an inherent and unique problem of e-therapy, as it is foreseeable that servers may crash, equipment may malfunction, or there may be a loss of internet connection. APA (2002) code of ethics states that therapists should make a reasonable effort to plan with the client on emergency plans for alternative continued services if e-therapy services are interrupted. The ISMHO (2009) ethical guidelines address this concern more specifically by stating that clients should be informed of safeguards to service interruption, alternative contact information for the therapist, procedures in case of emergency, and local therapists who can act as back-up in case of interruption. Without these precautions, interruption of therapy may cause undue harm towards the client if he or she urgently needs to speak with the therapist.

Discussion

Therapists should become familiar with these unique risks of e-therapy and be prepared to discuss these concerns with the client during the informed consent process.

While this paper only presented five common ethical dilemmas faced by e-therapists, the number of ethical concerns is likely to expand as this method of service delivery becomes more popular and technology continues to evolve. Though FtF counseling may never be fully replaced by e-therapy, it is likely that most therapists will have the opportunity to incorporate e-therapy into their practice.

Because e-therapy is becoming more popular, it is important for ethical concerns to be consistently enforced to ensure the safety of clients. Shaw & Shaw (2006) found that less than half of the online counselor websites surveyed followed the accepted American Counseling Association's ethical guidelines. This information is disconcerting, as this puts both client and counselor at a higher risk of harm and is damaging to the reputation of the field as a whole. One contributor to this problem is the inconsistency between the various professional organizations that outline the necessary ethical guidelines for e-therapy, as well as how they enforce these ethical guidelines. For instance, APA guidelines only recently changed their wording to be more inclusive of electronic use. However, the organization's effort in addressing the ethical needs of this growing modality pales in comparison to the American Counseling Association's (ACA) changes and inclusion of e-therapy ethical guidelines. Though ACA has more specific guidelines that address e-therapy, it is still not comprehensive. As e-therapy is a continually emerging modality, therapists are encountering professional ethical guidelines which may not address all the concerns of providing counseling on-line. It is imperative that in-depth and updated guidelines be considered for inclusion on all the major psychological association's ethical guidelines. By raising consciousness about these issues within the professional field, this will allow e-therapy to grow into a stronger and safer method of service provision.

References:

- American Counseling Association (2005). *ACA code of ethics*. Retrieved from <http://www.counseling.org/Files/FD.ashx?guid=ab7c1272-71c4-46cf-848cf98489937dda>
- APA (2010). Telepsychology is on the rise. *Monitor on Psychology*, 41, 11.
- Alcaniz, M., Botella, C., Banos, R.M., Zaragoza, I., & Guixeres, J. (2009) The intelligent e-therapy system: A paradigm for telepsychology and cybertherapy. *British Journal of Guidance & Counselling*, 37, 287-296.
- Allenman, J.R., (2002) Online counseling: The internet and mental health treatment. *Psychotherapy: Theory/Research/Practice/Training*, 39, 199-209.
- American Psychological Association (2002). *Ethical principles of psychologists and code of conduct*. Washington, DC. : Author
- Fox, L. (2009, October 26) *The social life of health information*. Retrieved from <http://www.pewinternet.org/Presentations/2009/39--ePatientConnections.aspx>
- Frame, M.W. (1997) The ethics of counseling via the internet. *The Family Journal*, 5, 328-330.
- Grohol, J.M. (1999). Best practices in etherapy. Retrieved from <http://psychcentral.com/best/best3.htm>.
- Haberstroh, S., Parr, G., Bradly, L., Morgan-Fleming, B., & Gee, R. (2008). Facilitating online counseling: Perspectives from counselors in training. *Journal of Counseling & Development*, 86, 460-470.
- International Society of Mental Health Online(2009). *Suggested principles for the online provision of mental health services*. Retrieved on from
- Kanani, K.,& Regehr, C. (2003). Clinical, ethical, and legal issues in e-therapy. *Families in Society: The Journal of Contemporary Human Services*, 84, 155-162. <http://www.ismho.org/suggestions.asp>
- Lehavot, K. (2009). "MySpace" or yours? The ethical dilemma of graduate students' personal lives on the internet. *Ethics & Behavior*, 19, 129-141.
- Lenhart, A. (2009, October 8). *The democratization of online social networks*. Retrieved from <http://www.pewinternet.org/Presentations/2009/41--The-Democratization-of-Online-Social-Networks.aspx>
- Mallen, M.J. , Vogel, D.L., & Rochlen, A.B. (2005). The practical aspects of online counseling: Ethics, training, technology, and competency. *The Counseling Psychologist*, 33, 776-818.
- Metonia (2009). The ABC's of "Internet Therapy" Retrieved from <http://www.metanoia.org/imhs/isitforyou.htm>
- Oravec, J. (2000). Online counseling and the internet: Perspectives for mental health care supervision and education. *Journal of Mental Health*, 9, 2, 121-135.
- Pew Internet & American Life Project (2009, June 11). 61% of American adults look online for health information. [Press release]. Retrieved from <http://www.pewinternet.org/PressReleases/2009/The-Social-Life-of-Health-Information.aspx>
- Postel, M.G., Haan, H.A., & Jong, C.A.D (2008) E-therapy for mental health problems: A systematic review. *Telemedicine and e-health*, 14, 706-714.
- Shaw, H.E., & Shaw, S.F. (2006). Critical ethical issues in online counseling: Assessing current practices with an ethical intent checklist. *Journal of Counseling & Development*, 84, 41 53.
- Skinner, A., & Zack, J.S. (2004). Counseling and the internet. *American Behavioral Scientist*, 48, 434-446.

Rainie, L. (2009, October 7). *The rise of the e-patient*. Retrieved from <http://www.pewinternet.org/Presentations/2009/40-The-rise-of-the-e-patient.aspx>

Recuperio, P.R., & Rainery, S.E. (2005). Informed consent to e-therapy. *American Journal of Psychotherapy*, 59, 319-331.

Acknowledgements: None.

Competing Interests: None.

Address for Correspondence:

*Department of Psychological and Quantitative Foundations
University of Iowa
N361 Lindquist Center
Iowa City, IA, USA 52242-1529*

e-mail: Sharon-Lee@uiowa.edu

Watch Your Language: A Review of the Use of Stigmatizing Language by Canadian Judges

Michelle Black MSc LLB candidate,
Schulich School of Law, Dalhousie University

Jocelyn Downie MA MLitt. LLB LLM SJD
Canada Research Chair in Health Law and Policy, Professor of Law and Medicine,
Schulich School of Law, Dalhousie University
Halifax, Canada

ABSTRACT

Despite ongoing advances in understanding the causes and prevalence of mental health issues, stigmatizing language is still often directed at people who have mental illness. Such language is regularly used by parties, such as the media, who have great influence on public opinion and attitudes. Since the decisions from Canadian courtrooms can also have a strong impact on societal views, we asked whether judges use stigmatizing language in their decisions. To answer this question, we conducted a qualitative study by searching through modern Canadian case law using search terms that were indicative of stigmatizing language. We found that, although judges generally use respectful language, there are still many instances where judges unnecessarily choose words and terms that are stigmatizing towards people with mental illness. We conclude that, to help reduce the stigma associated with mental illness, judges should be more careful with their language.

Key words: stigma; mental illness; judges; language.

"The difference between the almost right word and the right word is really a large matter - it's the difference between the lightning bug and the lightning."⁽¹⁾

- Mark Twain

INTRODUCTION

It might be expected that with more knowledge about the causes and consequences of psychological disorders, we would see a reduction in stigmatizing behaviours towards those who have mental illness. However, according to a U.S. Surgeon General's Report and other, more recent research, there is actually even more stigma now than there was forty years ago.⁽²⁾ The history of mental illness can be captured by Kale's description of the history of epilepsy: "4000 years of ignorance, superstition, and stigma followed by 100 years of knowledge, superstition, and stigma."⁽³⁾ This is troubling because stigmatization may lead to a person being stereotyped and/or discriminated against, for example through loss of job or housing opportunities, denial of societal rights (e.g., to hold elective office in the United States⁽⁴⁾), and being made more reluctant to seek psychiatric care.⁽⁵⁾

A commonly identified culprit in the stigmatization of mental illness is the media.⁽⁶⁾ Television shows, movies, and news outlets regularly convey images of people with (often unnamed) mental illnesses as dangerous individuals to be feared. They also play regularly to any number of the other prevalent stereotypes of individuals with mental illness.⁽⁷⁾ Less well recognized is the role of the courts in the stigmatization of mental illness. However, it has been reported that U.S. judges have a history of using and/or allowing stigmatizing language in their courtrooms.⁽⁸⁾ We therefore decided to investigate the use of such language in Canadian cases.

Canadian courts are highly respected institutions and, given the powerful position of judges in our society, we wondered whether stigmatizing language was being used in and by them. To determine whether the language used by Canadian judges in their decisions was stigmatizing with respect to mental illness, we conducted a computer-based qualitative research review. We found that, although judges are generally respectful in their decisions, there were a number of instances in which judges used stigmatizing language.⁽⁹⁾ To explain how we came to this conclusion, we first define our terms and describe our methodology. We then describe

and discuss our results. We then offer some reflections on possible reasons for these results and, finally, call upon all Canadian judges to stop the use of stigmatizing language with respect to persons with mental illness.

TERMINOLOGY

It is important to first carefully define our terms – specifically, stigma and stigmatizing language. Stigma as a concept has evolved over time, with researchers taking the dictionary definition (“a mark of shame or discredit”⁽¹⁰⁾) and transforming it into a much more complex concept. The early work of Goffman is seen as a critical foundation from which much of the expansion of the concept of stigma has been built.⁽¹¹⁾ Goffman defined stigma as an attribute with particular results; stigma is “an attribute that is deeply discrediting” within a particular social interaction which results in the stigmatized person being reduced from “a whole and usual person to a tainted, discounted one.”⁽¹²⁾ Since Goffman’s early work, a substantial literature on stigma has been produced; Link and Phelan attribute the ever-growing supply of definitions and information arising in this context to the variety of circumstances in which stigma research has been conducted and to the multidisciplinary nature of such research.⁽¹³⁾

A survey of the increasingly complex definitions of “stigma” can be somewhat bewildering. Sartorius, for example, describes stigma as “the negative attitude (based on prejudice and misinformation) that is triggered by a marker of illness - e.g., odd behaviour or mention of psychiatric treatment ...”⁽¹⁴⁾ Corrigan carries the concept a step further to assert that “[s]tigma is the cue that signals a specific attitude-behavior link.”⁽¹⁵⁾ On this view, the attitude is the driving force behind the behaviours. According to Link and colleagues, “stigma exists when elements of labeling, stereotyping, separation, status loss, discrimination, and emotional reactions occur together in a power situation that allows them.”⁽¹⁶⁾ Thus, stigma is seen as a mark, an attitude, a behavior, an attitude-behaviour link, or a result. It is seen to rest in the subject or the object of the stigmatization. We are not in a position to resolve the definitional debates of this specialized field. We therefore acknowledge the complexity but take as our working definitions the following:

- *Stigma* means “a mark of shame or discredit”
- *Stigmatizing* means “causing or bestowing stigma”
- *Stigmatizing language* is language that marks mental illness as something for which one should feel shame, conveys negative judgments about persons by virtue of their mental illness, and relies upon or reinforces negative stereotypes of persons with mental illness.

METHODS

Following the Supreme Court of Canada’s decision in *R v Swain*,⁽¹⁷⁾ Parliament amended sections of the *Criminal Code of Canada* (*Criminal Code*) dealing with mental disorders.⁽¹⁸⁾ For example, and of particular relevance for this paper, in s. 16 of the *Criminal Code*, the word “insanity” was replaced with the term “mental disorder.”⁽¹⁹⁾ Thus, an accused could be found “not criminally responsible on account of mental disorder” instead of “not guilty by reason of insanity”. The substance of s. 16 remained essentially

the same; the wording was the biggest change. The changes to the wording of s.16 were made after conducting consultations with, among others, “health officials” and NGOs including the Canadian Mental Health Association, who felt that a change in the wording would “bring it in line with current psychiatric views”⁽²⁰⁾

We hypothesized that, despite deliberate changes in the wording of the legislation and despite increased knowledge about the etiology of mental illness and the importance of choosing words carefully, stigmatizing language would continue to be found in the text of judges’ decisions. To test our hypothesis, we first established a list of words and phrases that can be stigmatizing in the context of talking about persons with mental illness. We then searched for these terms in the decisions of judges in Canadian courts available through LexisNexis Quicklaw. We searched all Canadian cases reported after the enactment of Bill C-30 on February 4, 1992.

The specific terms for which we searched were: “admit”, “confess”, “arrest”, “imprison” (with “mental health”, “mental illness”, or “mental issue” in the same paragraph); a selection of archaic terms, including “insane” (truncated so deviations such as “insanity” would also be picked up), “lunatic”, “imbecile”, “idiot”, “nutter”, “shrink”, “headshrinker”, and “moron” (with “mental health”, “mental illness”, or “mental issue” in the same sentence); and “schizophrenic”⁽²¹⁾. Generally, these terms were chosen because, in the context of decisions involving persons with mental illness, they can be (whether indirectly or directly, whether intentionally or not) stigmatizing towards those with mental illness. More detailed explanations of the problems with the use of such language can be found in the Results/Discussion section.

RESULTS/DISCUSSION

We should first note and indeed emphasize that the judges’ decisions dealing with persons with mental illness are generally crafted to show a high level of respect for those with mental illness. Many cases do not use any stigmatizing language and some of the terms for which we searched were not found.⁽²²⁾ However, there remain disturbing uses of stigmatizing language in judicial decisions. The following results and discussion include examples of the use of stigmatizing language and explain more fully why we and others consider such use to be stigmatizing and, therefore, to be avoided.⁽²³⁾

Inaccurate Terminology

Admit

“Admit” is a term that is sometimes used by judges when speaking of people acknowledging their mental illness.

“I would add that a decision to consent to treatment on P.C.’s⁽²⁴⁾ behalf would not violate P.C.’s determined refusal to admit that he suffers from mental illness, since such a decision would not be made by P.C.”⁽²⁵⁾

“K.J.D.’s refusal to admit that she is “sick” or suffering from a mental illness may arguably support the conclusion that she does not have insight into her illness.”⁽²⁶⁾

“Mrs. S. tried very hard to avoid the issue of her mental condition at the time. At one point she said that it would only be raised if it

was necessary. The irresistible conclusion is that at the time she was suffering from a serious mental illness which she did not care to admit.⁽²⁷⁾

"I do not believe that counselling while on a conditional sentence order would cause Mr. S. to accept that he has a mental problem of some sort. I am forced to conclude that a jail sentence is more likely to achieve that necessary end. I think this is an aspect of specific deterrence, a perhaps somewhat unusual aspect, but it is necessary before rehabilitation can take place for Mr. S. to admit a problem and be willing to actively attempt to deal with it."⁽²⁸⁾

"Dr. W. pointed to a further inconsistency in Mr. M.'s behaviour. Most paranoid schizophrenics are reluctant to admit they are ill once they are in treatment, and will resist taking medication and try to hide their illness. However, Mr. M. tended to call out to anybody who would listen that he was ill."⁽²⁹⁾

"In Dr. D.'s opinion, Mr. W.'s behaviour presents certain risks to himself and to others, and requires treatment, which should be administered by force if he refuses it. Dr. D. assesses these risks on the basis of Mr. W.'s past behaviour, his refusal to admit that he has any mental illness, his inability to understand how medical treatment can improve his mental state, and his innate mistrust of the Institute's staff."⁽³⁰⁾

Since the stigma surrounding mental illness is still so strong, people who have received a diagnosis of mental illness might feel that it is something to which they might have to "admit". However, judicial use of this term perpetuates the notion that mental illness is something of which to be ashamed, or to keep as a secret. This cannot be due to a lack of acceptable alternatives - there are many words or phrases, such as "acknowledge", "show appreciation (for)", and "recognize" that convey the appropriate meaning without the connotation of shamefulness.

Arrest

"Arrest" is a term that is sometimes used by judges when describing the apprehension of persons with mental illness not on suspicion of having committed criminal offences but, rather, for the purpose of having them taken into the mental health system for purposes of psychological assessment.

"Subsequently, police attended at the accused's location and arrested him under the authority of the Mental Health Act and transported him to hospital."⁽³¹⁾

"There were indications from D.K. that her husband was upset and depressed. As a result, the respondent was arrested under the Mental Health Act, R.S.N. 1990 c. M-9 and brought to the police lockup in St. John's for assessment by a doctor."⁽³²⁾

"It was at this point, some 30 minutes after awakening the Accused, that Constable K. stated that he had 'reasonable and probable grounds to believe' that she was a danger to herself, and he therefore arrested her under the Mental Health Act."⁽³³⁾

However, the term "arrest" is inappropriate when describing the process of detaining a person under mental health legislation for psychological assessment.⁽³⁴⁾ The word "arrest" is, of course, an appropriate term to use when describing police actions in relation

to, for example, a theft. However, none of the provincial/territorial mental health acts actually contain the word "arrest".⁽³⁵⁾ Despite this, as illustrated above, the word "arrest" continues to be used by judges when describing the apprehension of someone for the purposes of having them submit to a psychiatric evaluation under mental health legislation.

Surprisingly, judges persist in using the word "arrest" even when they are aware that it is not present in the statute. For example, one judge used the sub-heading: "Arrest under the Mental Health Act" and then proceeded to outline the provisions of that part of the act: "The Mental Health Act ... provides that a person suffering from a mental disorder, defined in s. 1(g) of the Act, may be apprehended under s. 10 or s. 12 of the Act."⁽³⁶⁾ Despite having just given a word-for-word recitation of the relevant part of the statute, and despite the fact that the word "arrest" does not appear in the section, the judge still referred to the process as an "arrest".

Similarly, another judge discussed at some length the purpose behind the *Mental Health Act*, but still referred to the action taken as being an "arrest" rather than detention or apprehension:

"I presume that on each occasion the complainant was arrested pursuant to s. 17 of the Mental Health Act. A purposive analysis of the arrest power under s. 17 of the Mental Health Act reveals that it is meant to be employed as the initial stage in a course of treatment for an individual in certain circumstance[s] including whether the police officer is of the opinion that 'the person is apparently suffering from mental disorder of a nature or quality' that will likely result in serious bodily harm or serious physical impairment to that person or another person."⁽³⁷⁾

Another judge acknowledged that there is some value to distinguishing between arresting a person and taking a person into custody, but maintained that being "arrested" per the Criminal Code and being taken into custody per the *Mental Health Act* are essentially the same thing:

"I recognize the social value of distinguishing between people who have been taken into custody for health reasons and those who have been arrested because they allegedly committed a criminal offence. However, the reality remains that generally police officers are authorized to act in the same manner under the Act as they would under the Criminal Code, R.S.C. 1985, c. C-46, when performing an arrest. There is really no substantive distinction between the act of forcibly taking someone into custody, and the act of arresting someone. Both generate risks to the individual, the police and the public. Specifically, as compared to a criminal offence, taking a person into custody who has mental health problems potentially generates similar or sometimes greater risks to officer and public safety. Such a risk is clearly present when the officers are responding to a threat by a person to cause bodily harm to himself or to another person."⁽³⁸⁾

The judge here failed to appreciate the seriously stigmatizing impact on individuals with mental illness of suggesting that there is no meaningful substantive difference between being suspected of having committed a crime and being thought to be mentally ill. With the focus on the effects on police officers and the public, the judge lost sight of the effect on the persons with mental illness.

Certainly, there are times when a person who happens to have

a mental illness will be arrested because they are alleged to have committed a crime. But when the judge explicitly indicates that the person was “arrested” per mental health legislation, it is an inaccurate and stigmatizing statement.

Imprison

Just as it is stigmatizing and inaccurate to say that a person has been arrested under mental health legislation, so too is it objectionable to indicate that a person is being “imprisoned” at a psychiatric institution, even when they are there involuntarily. Nonetheless, such language can be found in the case law:

“Considering that the defendant Hospital is not empowered to imprison its patients or force treatment upon them, absent Certification under the Mental Health Act which is the province of physicians, I query the seriousness of this argument.”⁽³⁹⁾

If a person is being detained at a hospital for a psychiatric evaluation or treatment, they are not being imprisoned. It is important to distinguish between the two concepts, as speaking of imprisonment and arresting people under mental health legislation perpetuates the notion that people with mental health problems are, or are like, criminals and have done something blameworthy.

Archaic Language

Insane

Just as it is no longer acceptable to refer to someone as “crazy”, it is also unacceptable to use such terms as “lunatic”, “imbecile”, “idiot”, and “insane”.⁽⁴⁰⁾ While it might be argued that some of these words do continue to appear in legislation, it is unnecessary to use these words unless quoting directly from the statute. As mentioned in the Introduction, deliberate steps have been taken to remove the word insanity from the mental disorder provisions of the *Criminal Code*, so one would (and reasonably could) expect a concurrent shift in the language of the courts. However, it is still possible to find objectionable archaic language in the case law:

“It is obvious that it is fundamental to Mr. C.’s case in the present action that he is not insane and was not insane when he was judicially found to be insane.”⁽⁴¹⁾

“Either she [the accused] is insane or she is evil, one or the other, which one is it?”⁽⁴²⁾

“In this case, the Crown argues that while the foregoing comments were specific to an insanity defence, they apply equally to this case where the defence lies in a lack of intent.”⁽⁴³⁾

“First of all, we must point out that, after rejecting the defence of insanity, the jury could still have considered the appellant’s mental condition in deciding whether the Crown had proven beyond a reasonable doubt that she had the specific intent to commit murder when she killed her son.”⁽⁴⁴⁾

“The Alberta Court of Appeal set aside the conviction and ordered a new trial on the ground that the trial judge had erred in his interpretation of the insanity provision of s. 16(1) of the Criminal Code, R.S.C., 1985, c. C-46. The Crown appeals to this Court against that order, seeking reinstatement of the conviction for murder.”⁽⁴⁵⁾

“Before dealing with those two submissions I want to say that, in my opinion, the Judge was correct in not putting either insanity or self-defence to the jury. There was no evidence that Mr. H. met the test of insanity set out in s. 16 of the Criminal Code of Canada or that he was acting in self-defence.”⁽⁴⁶⁾

“(Nor is it likely that someone can really intend to get so intoxicated that they would reach a state of insanity or automatism.)”⁽⁴⁷⁾

In what might appear to be a step in the right direction, a judge in one case put the word “insane” in quotes, thus appearing to recognize its problematic nature. However, the footnote accompanying the word belies even a moderately positive interpretation of the step: “I use the word ‘insane’ when speaking at a general level to refer to anyone who is exempt from criminal liability under s. 16 of the *Criminal Code*.”⁽⁴⁸⁾ As of the decision date, “insane” was no longer a term used in s.16.

One response to our criticism of the continued use of the term “insane” might be that the new terminology (i.e., mental disorder) is ungainly. This is in fact a criticism that some have levied against “people first language” (discussed below under the subheading “Non-People First Language”) - that people first language “is unwieldy and repetitive, and any ear tuned to appreciate vigorous, precise prose must be offended by its impact on a good sentence.”⁽⁴⁹⁾ Similar criticisms, under the guise of economy of language, have been implied in terms of the s.16 provisions:

“However, in order to more accurately reflect the provisions of section 16 of the Criminal Code [Justice Bastarache] stated that the terms ‘mental disorder’ automatism and ‘non-mental disorder’ automatism should be used instead of insane and non-insane automatism. Professor Paciocco refers to non-mental disorder automatism more economically as ‘sane automatism’ which is a term that I prefer.”⁽⁵⁰⁾

But we are not just talking about the quality of prose or the elegance of a sentence. More importantly, we are also talking about the dignity of people who should not be identified by words that are insulting and harmful. Despite what the judge said in the previous example, there is no necessity to be economical in the judgment. Respectful, yes. Accurate, yes. Economical, no.

Unlike the judges quoted above, other judges acknowledge the change in the *Criminal Code* (“The current wording of s. 16 which references ‘mental disorder’ recently replaced earlier language defining insanity”⁽⁵¹⁾) and they make use of the new terminology (“it is the defence’s primary position that Mr. S.A.T.C. is not criminally responsible for his actions in the sense that the defence of mental disorder which is set forth in section 16 of the Criminal Code of Canada applies.”)⁽⁵²⁾ Clearly, it is possible to phase out the use of this antiquated term.

Lunatic

Archaic words such as idiot and lunatic were once acceptable terms.⁽⁵³⁾ Now, they are rarely to be found, although some (particularly lunatic) are still lurking in various statutes⁽⁵⁴⁾ and some judges seem comfortable with continuing to use the term “lunatic”. “As long ago as 1955, our Court of Appeal observed in *Hardman v. Falk*, [1955] 3 D.L.R. 129 at p. 133:

The contract of a lunatic is voidable not void: see York Glass

Co. v. Jubb (1925), 134 L.T. 36. Courts of equity will not interfere if a contract with a lunatic is made in good faith without any knowledge of the incapacity of the lunatic and no advantage is taken. If the contract is fair and the respondent had no knowledge that the appellant was a lunatic, the appellant is without a remedy: see Wilson v. The King, [1938] 3 D.L.R. 433 at p. 436, S.C.R. 317 at p. 322. [Robertson J.A.]

So, too, I suggest would the party contracting with the lunatic in circumstances such as those here be without a remedy.⁽⁵⁵⁾

Even though the word “lunatic” is still found in some current federal and provincial legislation, judges have the opportunity to substitute more acceptable words or to use quotation marks (and cite the statute) as an acknowledgement that the use of such words as acceptable labels has expired. In the above example, the judge was not even citing a statute and therefore should have chosen a different word.

Non-People First Language

Schizophrenic

Unfortunately, judges often describe people in terms of their illness:

“Mr. P. is a disadvantaged individual. He has been diagnosed as a paranoid schizophrenic.”⁽⁵⁶⁾

“Mr. C. also suffers from a major mental illness. He is a paranoid schizophrenic.”⁽⁵⁷⁾

“M.M. (who is now deceased) was a developmentally delayed, schizophrenic woman who spent time at the Kingston Centre mall.”⁽⁵⁸⁾

“He, Mr. S., certainly understands the importance of him being labeled a schizophrenic as opposed to one being labeled as suffering from antisocial personality disorder.”⁽⁵⁹⁾

“S.M. is 38 years old. She is single and is a chronic schizophrenic.”⁽⁶⁰⁾

“A patient in a mental hospital asked to make a will ... The testator, a paranoid schizophrenic, exhibited bizarre behaviour on the evening of his psychiatric examination and before and after executing the will.”⁽⁶¹⁾

“He is a schizophrenic and has been schizophrenic since his young - late teen years, early twenties.”⁽⁶²⁾

“He also accepted that schizophrenics have an impairment of the executive functions of the brain which can manifest itself in difficulty spontaneously processing information as they encounter it, resulting in a slowed down thought process. He stressed, however, that it is highly variable as to how impaired a schizophrenic might be. Some are highly functional and others show significant deficits manifested by episodic memory deficits and a compromise of executive control processes.”⁽⁶³⁾

“It is very common for schizophrenics to resist taking anti-psychotic medications because the illness compromises insight into the illness, its presence and the need for treatment.”⁽⁶⁴⁾

The problem with identifying people with mental illnesses by the diagnosis which they happen to have (as, for example, “a

schizophrenic”) is that it is the first (and sometimes only) way in which they are identified, which can lead to the dehumanizing of those persons. The dehumanization of people with mental illness is common and makes it too easy for anyone outside of the illness to think of the person as “a schizophrenic” rather than a person who has schizophrenia; the person is the disease, rather than the person has the disease. Yet, as Otto Wahl points out, we don’t do this with so-called physical illnesses - we don’t call people “cancerous” or “heart diseased”.⁽⁶⁵⁾ To avoid labeling people as their illness, many sources suggest using “people first language”, which recognizes that anyone, regardless of their physical or mental condition, is a person first and foremost. Rather than calling a person “a schizophrenic”, they should be referred to as a person with schizophrenia. This could, of course, be generalized to other psychiatric disorders (e.g., refraining from calling someone “a psychotic”).

REFLECTIONS ON REASONS FOR RESULTS

While we start from the assumption that judges are not *trying* to stigmatize, a search through the case law suggests that inappropriate words and phrases are still being used. Certainly judges have been known, at times, to fail to recognize the extent of other kinds of social development happening around them. Take, for example, Justice McClung’s deplorable words in the *Ewanchuk* case. There, McClung JA said (amongst other things) that the sexual assault committed by the offender was “less criminal than hormonal.” He also said that the woman “did not present herself to Ewanchuk . . . in a bonnet or crinolines.”⁽⁶⁶⁾ Madame Justice L’Heureux-Dube criticized McClung’s language for perpetuating the myths and stereotypes about sexual assault against women:

The Code was amended in 1983 and in 1992 to eradicate reliance on those assumptions; they should not be permitted to resurface through the stereotypes reflected in the reasons of the majority of the Court of Appeal. It is part of the role of this Court to denounce this kind of language, unfortunately still used today, which ... perpetuates archaic myths and stereotypes about the nature of sexual assaults ...⁽⁶⁷⁾

Similarly, we would argue that the language some judges use today continues to perpetuate the myths and stereotypes about mental illness, despite the change in language that was deliberately made in the *Criminal Code* following the 1991 *Swain* decision.

So why are some judges still using such language? It may be a combination of factors. There is some evidence to suggest that judges can be influenced by the media as well as by certain internal biases.⁽⁶⁸⁾ Further, judges hear such language coming from the expert witnesses - the psychologists and psychiatrists who treat the accused. Consider each of these possible influences in turn.

A great number of studies have examined the extent to which the media stereotypes people with mental illness, with the predominant stereotype being that of the dangerous “mental” patient.⁽⁶⁹⁾ In books, television, news programs, movies, newspaper articles, and even children’s programming, the media inundates society with misrepresentations of mental illness. The media has played a powerful and negative role in perpetuating the myths and stereotypes of mental illness and judges, like the rest of us,

are not immune to the influences of biasing information.⁽⁷⁰⁾ Thus, since our society (if the media can be taken as a measure of what our society will pay for and condone) still appears to feel quite comfortable with negative images of people with mental illness, it is possible that judges, too, are susceptible to such images.

Judges have also been shown to be just as prone to certain biases as other decision makers. Guthrie and colleagues conducted a series of experiments through which they found that judges show comparable amounts of hindsight bias (tending to think that someone should have “known better”) and egocentric bias (believing that they are less capable than others of making mistakes) than did decision makers in other studies.⁽⁷¹⁾ While Guthrie et al caution that their experiment does not necessarily translate directly into the courtroom, they suggest that there are indeed existing examples of occasions when a judge’s biases influenced certain decisions made in court. These biases to which the judge may be susceptible could result in the judge having a particular, pre-determined view of the people in his or her court and this may lead to the incorporation (or the lack of filtering) of stigmatizing language.

Finally, it is conceivable that judges hear stigmatizing language within the courtroom coming from the people who certainly ought to know better - those who work in the mental health field itself. Research studies have demonstrated that caregivers and those in the mental health field can be extremely stigmatizing.⁽⁷²⁾ Indeed, the Mental Health Commission of Canada is launching a 10 year anti-stigma campaign, and its first two focus groups are children and those employed in the mental health field.⁽⁷³⁾ But just as it is of course not acceptable for judges to blindly accept testimony, they need not also unthinkingly repeat testimony. A judge could use alternate words or terms or at least put quotes around language that is stigmatizing and distance the court from it. Similarly, a judge should feel entitled and responsible for challenging the language of the witness when it is derogatory towards those with mental illness.

CONCLUSION

In closing, it is important to stress that we do not believe that judges are actively trying to be stigmatizing. On the whole, in fact, judges appear to use appropriate and respectful language. Still, we trust judges to use respectful language since, as leaders of our community, they are unquestionably in a position to influence the way society thinks about mental illness.⁽⁷⁴⁾ That is why we look to them to set the linguistic tone, and why we suggest that some of them must be more careful with the words they choose. In his book “Telling is Risky Business”, Otto Wahl offers a list of things that we all can do to help reduce stigma and one of the items on his list is to “Watch our language”.⁽⁷⁵⁾ This is precisely what we would ask of all Canadian judges.

References:

1. Letter to George Bainton, 10/15/1888; online from: <http://www.twainquotes.com/index.html>.
2. US Surgeon General’s Report; US Department of Health and Human Services, 1999: 8; Rüsich, N., Angermeyer, M.C., Corrigan, P.W. (2005). Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *European Psychiatry*, 20, 529-539 [Rüsich].
3. Kale, R. (1997). Bringing epilepsy out of the shadows: Wide treatment gap needs to be reduced. *British Medical Journal*, 315, 2-3.
4. Hemmens, C., Miller, M., Burton, V.S. Jr., Milner, S. (2002). The Consequences of Official Labels: An Examination of the Rights Lost by the Mentally Ill and Mentally Incompetent Ten Years Later. *Community Mental Health Journal*, 38, 129-140, Corrigan P.W., Watson, A.C., Heyrman, M.L., Warpinski, A., Gracia, G., Slopen N., Hall, L.L. (2005). Structural stigma in state legislation. *Psychiatric Services*, 56, 557-563 [Corrigan].
5. Corrigan, supra, note 3; Rusch, supra, note 2; Overton, S.L. & Medina, S.L. (2008). The stigma of mental illness. *Journal of Counseling & Development*, 86,143-151 [Overton]; Corrigan, P. (2004). How stigma interferes with mental health care. *American Psychologist*, 59, 614-625.
6. For an interesting discussion of the media’s portrayal of mental illness, see Wahl, O.F. (1995). *Media Madness: Public images of mental illness*. New Jersey: Rutgers University Press. [Wahl]
7. e.g., lazy, incurable, malingering, lacking intelligence, unpredictable, weak, etc. See Kate McLaughlin online at: <http://www.katemclaughlin.net/dispel-the-myths-overcome-the-stigma/>.
8. Perlin, M. (1999). Half-wracked prejudice leaped forth: Sanism, pretextuality, and why and how mental disability law developed as it did. *The Journal of Contemporary Legal Studies*, 10, 3-35.
9. We also looked broadly at decisions referencing “mental illness” as a background context for the study and based this conclusion on that review.
10. *Merriam-Webster’s Collegiate Dictionary* (10th ed.). (1993). Springfield, MA: Merriam-Webster.
11. Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.
12. *Ibid.*, p.3.
13. Link, B.G. & Phelan, J.C. (2001). Conceptualizing Stigma. *Annual Review of Sociology*, 27, 363-385 [Link].
14. Sartorius, N. (2007) Stigma and mental health. *Lancet*, 370, 810-811.
15. Corrigan, P.W. Beat the stigma and discrimination! Four lessons for mental health advocates. Online at: <http://www.dmh.ca.gov/PEIStatewideProjects/docs/CorriganBeattheStigmaandDiscrimination.pdf>.
16. Link, B.G., Yang, L.H., Phelan, J.C., & Collins P.Y. (2004). Measuring Mental Illness Stigma. *Schizophrenia Bulletin* 30, 511-541.
17. R. v. Swain, 1 S.C.R. 933 (1991), S.C.C.
18. Bill C-30, *An Act to Amend the Criminal Code*; enacted February 4, 1992.
19. Other changes included, for example, the elimination of the lieutenant governor’s warrants; *Ibid.*
20. *House of Commons Debates*, Volume III (14 October 1991) at 3296 (Hon. Kim Campbell).
21. This last term was used as an example of non-people first language. See below for a discussion on this issue.
22. For example, confess (as in “confessing” to having a mental illness), imbecile, idiot, nutter, shrink, headshrinker, and moron.
23. It must be emphasized here that we conducted a qualitative not a quantitative study. Our research question was whether

this kind of language was still being used rather than to what extent it was still being used. We restricted our approach in this way to make the project feasible (there would simply be an unmanageable number of cases to review if one wanted to draw conclusions about prevalence) and because we felt that the ongoing existence of use was a problem worth discussing independent of the prevalence of use.

24. In an effort to avoid further exposure of the individuals involved, we use only their initials.
25. C. v. J., 59 O.R. (3d) 737 (2002), ON.C.A.
26. K.J.D. v. C., O.J. 2462 (2006), ON.Sup.Ct.Jus.
27. S. v. L., O.J. 3957 (2001), ON.Sup.Ct.Jus.
28. R. v. S., B.C.J. 2988 (2004), B.C.Prov.Ct.
29. R. v. M., A.J. 1640 (2002), AB.Q.B.
30. Institut Philippe Pinel de Montréal v. W., Q.J. 1041 (1997), Q.C.C.S.
31. R. v. A., O.J.1591 (2006), ON.Ct.Jus.
32. R. v. K., 355 (1993), N.L.S.C.
33. R. v. M., B.C.J. 2400 (2008), B.C.Prov.Ct.
34. See, e.g., the Psychiatric Patient Advocate Office, online at: <http://www.ppao.gov.on.ca/sys-arr.html>.
35. Although, in the French version of the Yukon Mental Health Act, the word "arrêtée" is used; in English the word used is "apprehend" *Mental Health Act*, R.S.Y. 2002, c. 150 s. 41(1).
36. R. v. C., A.J. 292 (2005), AB.Prov.C.
37. R. v. R.L., O.J. 4095 (2007), ON.Sup.Ct.
38. R. v. T., M.J. 252 (2007), MB.Q.B.
39. W.V.W. v. Misericordia Hospital, A.J. 875 (1999), AB.Q.B.
40. National Alliance on Mental Illness, online at: <http://www.naminh.org/action-fight-stigma.php>.
41. C. v. D., O.J. 1942 (1995), ON.Ct.
42. R v. B., (2009), unreported, ON.Ct.Jus.
43. R. v. A., B.C.J. 570 (2008), B.C.S.C.
44. R. v. D., N.B.J. 55 (2002), N.B.C.A.
45. R. v. O., 2 S.C.R. 507 (1994), S.C.C.
46. R. v. H., N.B.J. 37 (1996), N.B.C.A.
47. R. v. D., 3 S.C.R. 63 (1994), S.C.C.
48. R. v. L. O.J. 4016 (1997), ON.C.A.
49. Vaughan, C.E. (2009) People-first language: An unholy crusade. *Braille Monitor*, online at: <http://www.nfb.org/images/nfb/Publications/bm/bm09/bm0903/bm0903tc.htm>.
50. R v. B., M.J. 172 (2004), MB.Prov.Ct.
51. R. v. S.A.T.C., S.J. 492 (1996), SK.Q.B.
52. *Ibid.*
53. Matloff, J. (2008). Idiocy, lunacy, and matrimony: Exploring constitutional challenges to state restrictions on marriages of persons with mental disabilities. *American University Journal of Gender, Social Policy & Law*, 17, 497-520.
54. e.g., *Provincial Subsidies Act*, R.S.C. 1985, c.P-26, *Devolution of Estates Act*, R.S.N.B. 1973, c.D-9, *Watershed Associations Act*, R.S.S. 1978, c.W-11, *Registry Act*, R.S.N.B. 1973, c. R-6.
55. R. v. R., B.C.J. 9 (1998), BC.S.C.
56. R. v. P., Nu.J. 17 (2007), Nu.Ct.Jus.
57. R. v. C., O.J. 5857 (1998) ON.Ct.Jus.
58. R. v. C., O.J. 3609 (2007), ON.Sup.Ct.Jus.
59. R. v. S., O.J. 2765 (2009), ON.Ct.Jus.
60. Nova Scotia (Minister of Community Services) v. M.N.S.J. 367 (1995), NS.Fam.Ct.
61. P. v. S., N.J. 217 (1999), N.L.S.C.T.D.
62. R. v. B., A.J. 245 (2006), AB.Prov.Ct.
63. R. v. I., O.J. 312 (2008), ON.Sup.Ct.Jus.
64. R v. W., O.J. 744 (2007), ON.Sup.Ct.Jus.
65. Wahl, O.F. (1999) *Telling is Risky Business*. New Jersey: Rutgers University Press, p 220.
66. R. v. Ewanchuk, A.J. 150 (1998), AB.C.A.
67. R. v. Ewanchuk, 1 S.C.R. 330 (1999), S.C.C.
68. Guthrie, C., Rachlinski, J.J., & Wistrich, A.J. (2001). Inside the Judicial Mind. *Cornell Law Review*, 86, 777-830 [Guthrie]; Robbenolt, J.K. & Studebaker, C.A. (2003). News Media Reporting on Civil Litigation and Its Influence on Civil Justice Decision Making. *Law and Human Behavior*, 27, 5-27 [the authors note that this phenomenon in judges particularly requires more study].
69. Corrigan, P.W., Watson, A.C., Gracia, G., Slopen, N., Rasinski, K., Hall, L.L. (2005). Newspaper stories as measures of structural stigma. *Psychiatric Services* 56, 551-555; Clement, S. & Foster, N. (2008). Newspaper reporting on schizophrenia: A content analysis of five national newspapers at two time points. *Schizophrenia Research*, 98, 178-183; Day, D.M. & Page, S. (1986). Portrayal of mental illness in Canadian newspapers. *Canadian Journal of Psychiatry*, 31, 813-817; Klin, A. & Lemish, D. (2008). Mental Disorders Stigma in the Media: Review of Studies on Production, Content, and Influences. *Journal of Health Communication* 13, 434-449; Wahl, *supra* note 6.
70. Landsman, S. & Rakos, R.F. (1994). A preliminary inquiry into the effect of potentially biasing information on judges and jurors in civil litigation. *Behavioral Sciences and the Law*, 12, 113-126; Wistrich, A.J., Guthrie, C., & Rachlinski, J.J. (2005). Can judges ignore inadmissible information? The difficulty of deliberately disregarding. *University of Pennsylvania Law Review*, 153, 1251-1345.
71. Guthrie, *supra* note 68.
72. The Standing Senate Committee on Social Affairs, Science and Technology. (2006). *Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada*. Online at: <http://www.parl.gc.ca/39/1/parlbus/commbus/senate/Com-e/SOCI-E/rep-e/rep02may06-e.htm>; Overton, *supra* note 4; Barney, L.J., Griffiths, K.M., Christensen, H., & Jorm, A.F. (2009). Exploring the nature of stigmatising beliefs about depression and help-seeking: Implications for reducing stigma. *BMC Public Health*, 9, 61; Thornicroft, G., Rose, D., Kassam, A. (2007). Discrimination in health care against people with mental illness. *International Review of Psychiatry*, 19,113-122.
73. See Mental Health Commission of Canada online at: <http://www.mentalhealthcommission.ca/English/Pages/AntiStigmaCampaign.aspx>
74. The case in footnote 39 received much attention from local press, with newspapers running such subheadlines as: "‘Either she’s insane or she’s evil,’ judge says in handing commuter 12 months [sic] probation plus fines for burning victim in morning rush". *Globe and Mail* online at: http://v1.theglobeandmail.com/servlet/story/RTGAM.20090601.escenic_1163315/BNStory/. National Coverage from other sources inevitably included the line cited in note 39.
75. Wahl, *supra* note 65, p. 178.

Funding and Support: *The authors are grateful to the Institute of Neurosciences, Mental Health and Addiction (INMHA) of the Canadian Institutes of Health Research (CIHR) for their generous financial support through the Neuroethics New Emerging Team (NET) grant.*

Acknowledgements: *The authors would like to thank the members of the neuroethics NET (www.neuroethics.ca) and NovelTechEthics (www.noveltechethics.ca) for their thoughtful comments on earlier versions of this paper.*

Competing Interests: *None.*

Address for Correspondence:

*Jocelyn Downie
6061 University Avenue
Halifax, Nova Scotia, Canada B3H 4H9
e-mail: jocelyn.downie@dal.ca.*

Addressing Treatment Futility and Assisted Suicide in Psychiatry

Justine S. Dembo, MD, PGY-3

Department of Psychiatry

University of Toronto

Toronto, Canada

In psychiatric residency training, as well as in practice, we work under the assumption that all mental illness is treatable, and that treatment never becomes futile. Meanwhile, in somatic medicine, there is a subspecialty, palliative care, devoted to improving the quality of life for those who are dying of an incurable illness. In somatic medicine, increasingly, physicians and the public are discussing the questions of legalizing terminal sedation, assisted suicide, and euthanasia for suffering related to refractory, incurable illness. As a resident in psychiatry, I struggle to understand the discrepancies in this regard between psychiatry and other medical specialties. After discussion with several advisors and bioethicists, I have come to believe that several questions should be open for discussion: what are the ethical issues we must address in psychiatry when considering how to help patients with unbearable, prolonged treatment-refractory suffering? Why is it that we are more comfortable with the notions of “refractoriness” and “terminality” in physical illness than in mental illness? What would “palliative psychiatry” look like, and when – if ever – might assisted suicide be a reasonable course of action in mental health care? In addressing these issues here, I intend to open a critical discussion, but not to argue an opinion. Given the tragedies that have historically ensued in the field of medicine as a result of refusal to discuss ethically contentious issues, and given the increasing publicity regarding assisted suicide in the western world, it seems pertinent to address this as it may apply to psychiatry.

In the Netherlands and Oregon, and most recently Washington and Montana, assisted suicide for terminal somatic illness is legal, or has been decriminalized, under very specific conditions. Only in the Netherlands, thus far, have these conditions been extended to include patients suffering from refractory mental illness in the absence of somatic disease, and within this category the conditions are more stringent. This development in the Netherlands began in 1991 following a case in which a psychiatrist, Dr. B. Chabot, assisted in the suicide of a 50-year-old woman with chronic depression.^{1,2,3,4} Dr. Chabot was charged by the Dutch Supreme Court and suffered a minor penalty because he had not provided the patient with an “independent expert consultation.” That said, this case set a precedent in which the courts stated that physician assisted suicide “may be justifiable for a patient with severe psychic suffering due to a depressive illness and in the absence of a physical disorder or terminal condition.”¹

Following this case, the Royal Dutch Medical Association adapted its guidelines for assisted suicide from somatic to psychiatric illness.¹ The next publicized case occurred in 1997 and involved a 48-year-old woman with chronic, severe, and treatment-refractory major depression and anorexia nervosa. Due to her psychiatrist’s compliance with the new guidelines, no charges were pressed. In 1995, it was estimated that two to five patients per year receive assisted suicide in the Netherlands for exclusively psychiatric illness.¹ This same research indicated that 37% of Dutch psychiatrists had at least once received an explicit request for physician assisted suicide for psychiatric reasons, the most common of which was depression. These findings beg the question of whether North American physicians receive similar requests; they also indicate that this is a highly relevant discussion in psychiatry.

Multiple ethical, legal, and philosophical principles must be considered in order to acquire a balanced perspective on what ethicist Eric Matthews describes as “an abstract idea that has non-abstract consequences.”⁵ I will attempt to address the most pertinent of these here.

Suffering and Personhood

How, as physicians, are we to diagnose suffering? The diagnosis is murky at best in somatic medicine, but in psychiatry is at times completely bewildering. Ethicist Eric Cassell reminds us that suffering is an affliction in which the intactness of not only the body, but also the *self* or person, is threatened.⁶ Suffering is therefore suffering, whether it is physical or psychological. Where terminal sedation or physician assisted suicide are legal and are in consideration for a particular patient, physicians consider both physical suffering and the existential pain related to that suffering in their decision-making process. Is it, then, inconceivable that severe existential pain in the absence of physical illness could ever be a rational reason to consider ending one’s life? What if we relate the notion of “existential pain” to that of personhood, and loss of personhood through mental illness? Cassell lists multiple components of “personhood,”⁷ including one’s valued social roles and relationships, the uniqueness of emotional expression, the experience of gender and sexuality, the joy of having a rich spiritual and fantasy life, and the perception of having a meaningful future. Serious mental

illness interferes with – and I might argue detracts from – multiple aspects of personhood, the loss of which in turn leads to suffering. I would ask of the reader to consider the following: how many, and which, aspects of your own personhood would you be willing to lose, before you would no longer want to live?

Rational Suicide and Capacity

The above questions lend themselves to a discussion of rationality and capacity in decision-making about suicide. In psychiatry, we often assess capacity for treatment decisions, place of residence, and financial decisions; an individual is considered capable if she understands the nature of the issue at hand, as well as the likely consequences, and potential risks, harms, and benefits, of pursuing one decision over another. Interestingly, we do not assess capacity in this way for a decision to suicide. Furthermore, in somatic medicine, when a patient is deemed capable with respect to treatment decisions, she is allowed to refuse life-saving treatment; in psychiatry, however, we can certify a suicidal individual without formally assessing that person's capacity to decide upon suicide.

There is actually a significant body of literature devoted to addressing the question of whether suicide can be a rational decision. Many argue that suicide is rational if the despair prompting the suicidal wish is rational: that surely despair can be justified if there is, realistically, very little hope for a better future.^{1,3,8,9,10} Who has the right to determine what constitutes a “better future” is in itself sometimes debatable. In the context of mental illness, this debate is extraordinarily complex. Some mental health professionals believe that suicidality alone is an indicator of mental illness, whether or not other DSM-IV criteria are met for a mental disorder. There are also those who believe that in the presence of a mental illness – no matter which illness – suicidality is automatically irrational. Furthermore, some professionals question whether rationality can be maintained in psychotic versus nonpsychotic illnesses.^{2,11} It seems that the boundaries between a realistic appraisal of a difficult and deteriorating life course, a cognitive distortion, and further, of a delusion, are frighteningly ill-defined. One philosopher, Jeannette Hewitt, reminds us that human beings are frequently irrational, but their irrationality “rarely interferes with their rights or freedom unless accompanied by a diagnosis of mental illness.”⁸ She asks whether hopelessness is ever a realistic appraisal of life circumstances and illness course in schizophrenia and other mental illnesses, rather than just a “symptom of psychopathology.”⁸

Treatment Futility

It would be wrongful to assume that all suicidal individuals, psychotic or not, can realistically appraise their likelihood of having a better future. Having entered the profession of psychiatry for the purpose of helping people to achieve improved futures, I find it dreadful, as do many of my colleagues, to contemplate the possibility that there are some people I cannot help. We do, however, live in a universe of likely infinite possibilities, and therefore it is plausible that in some cases mental illness and its resultant unbearable psychic pain can indeed be refractory to treatment. Surely this is the case in psychiatry, as it is in the rest of medicine. Ethically speaking, how do we manage these situations? At what level of probability of no improvement or no cure, can we deem treatment “futile?” Whose role is it to determine what constitutes “futility” for any specific patient? How many treatments should we attempt,

and what should the duration of each treatment be? How many side effects should we expect our patients to tolerate in the name of treatment? And, at what point do we allow our patients to give up on treatment, and on life itself? At what point are we, as physicians, entitled to “give up?” Once we have given up, what kinds of palliation can we then provide?

This discussion highlights not only the importance of the patient's autonomy, but also of the physician's: there is, after all, in medical and ethical literature, a consensus that there are limitations to a physician's obligation to provide care that she believes has no benefit.¹² I would ask also whether acknowledging futility could ever be helpful for the patient, for the physician, and for the therapeutic alliance, and whether refusing to acknowledge futility could ever be harmful. According to the Hippocratic Oath, I have sworn both to “do no harm or injustice to my patients” and “not to give a lethal drug to anyone if I am asked.”¹³ I wonder if it is possible that by refusing at all costs to provide a lethal drug, I would ever be doing the “harm” of prolonging intractable suffering? I understand that current best psychiatric practice in North America eschews even non-intervention in suicide, and so the idea of assisted suicide is further afield. However, I wonder how this might apply to situations in which a failed suicide attempt has left an individual with permanent debilitation or chronic pain that has worsened what was already intolerable suffering. Furthermore, I cringe to imagine that after a lifetime of suffering, an individual with refractory mental illness would have to die in solitude and fear, and that if the attempt fails this may result in worsened suffering. Some practitioners argue that many individuals who survive a suicide attempt later express gratitude that they are alive and that therefore suicide should be prevented in all cases; there is, however, a significant response bias here as we cannot inquire as to the feelings of those who have succeeded in ending their lives. Could assisted suicide ever, therefore, be considered a “harm reduction” approach in refractory mental illness?

The Slippery Slope

There are many valid counterarguments to the notion of legalizing treatment cessation, palliative sedation, assisted suicide, and euthanasia in somatic medicine, let alone in psychiatry. One of the prominent writers in this area, Herbert Hendin, argues passionately that if we legalize physician assisted suicide in any field of medicine, there is a risk that patients will lose autonomy through coercion, for example related to caregiver burnout, family attitudes toward the given illness, or financial stress.^{2,14} Other slippery-slope advocates warn that legalization of physician assisted suicide would prevent us from working harder to improve the standard of care, including social supports and medical resources (including palliative care providers and facilities), that would enhance a patient's quality of life and thereby prevent the distress leading to suicidality.^{11,12} What if the perpetuating factors for an individual's suicidality are isolation, stigma, and the structure of society itself, as opposed to her mental illness? Until we can improve social supports, ameliorate isolation, and decrease stigma, are we simply avoiding addressing the greater social factors at hand, by allowing for or assisting in suicide?^{11,14} Multitudes of other questions abound: what if the suicidal patient's psychiatrist is over-invested or suffers from her own biases related to suicide? How does one avoid solely protecting the psychiatrist's need to see an end to a patient's suffering, in lieu of protecting the patient's right to continued treatment? And, how would society

perceive psychiatry – and the field of medicine itself – if some or all of the above concepts were legalized?

Given the new, and often murky, legal status of assisted suicide in somatic medicine, let alone psychiatry, there is thus far little data that addresses the above questions. However, due to the high documentation and reporting standards in Oregon following the Death With Dignity Act, some outcome data are available.¹⁶ Contrary to the “slippery slope” concerns, the data indicate that between 1998-2003, those who died under the Act had the following characteristics: 80% were enrolled in hospice care, which is the gold standard of palliative care; 98% had health insurance, and over 60% had private health insurance; 97% were white, middle-class, and had a college degree; physicians’ unanimous response to the initial request for assisted suicide was to put more supports in place to enhance quality of life; only 50% of patients who received a lethal prescription chose to use the given medication to end their lives; and finally, the deaths under the Act in Oregon accounted for less than 0.5% of total deaths in the state during this time period. These data indicate that contrary to our fears, those who request and undergo physician-assisted suicide for terminal somatic illness neither lack an appropriate standard of medical care, nor belong to marginalized groups. It goes without saying, however, that further research is required in order to generalize these conclusions to individuals suffering from refractory psychic pain due to mental illness.

Conclusions

Although exceedingly complex and painful, this discussion is necessary, and possibly increasingly so as the debates about palliative sedation, assisted suicide, and euthanasia become more heated in North American medical circles. Psychiatry, as medical profession, has an important role to play. I would like to address fairly, and from all possible angles, the original question: how can I help my patients with prolonged, treatment-refractory illness, in the most ethical ways? How do I most effectively reduce my patients’ suffering while preserving their autonomy and personhood? Is the prolongation of life in psychiatric illness, with or without a somatic illness, always the best choice? Is it possible, or ethical, to assess capacity for a decision to commit suicide? What would be the psychiatric equivalent of palliative care? Given the above countless questions, debates, and unresolved ethical quandaries, it has become increasingly clear to me that this must be a subject open to discussion. Avoiding it is not only detrimental to the well-being of our patients, but also to that of our profession and its place within medicine.

References:

1. Groenwald JH, Van der Maas PJ, van der Wal G. Physician-assisted death in psychiatric practice in the Netherlands. *NEJM* 1995; 336: 1795-1801.
2. Ogilvie AD, Potts SG. Assisted suicide for depression: the slippery slope in action? *BMJ* 1994; 309:492.
3. Hawton K, Burgess S. Suicide, euthanasia, and the psychiatrist. *Philosophy, Psychiatry, & Psychology* 1998; 5.2: 113-26.
4. Berghmans R. Physician-assisted suicide and mental illness. *Philosophy, Psychiatry, & Psychology* 1998; 5.2: 131-5.
5. Matthews E. Choosing death: Philosophical observations on suicide and euthanasia. *Philosophy, Psychiatry, & Psychology* 1998; 5.2: 107-11.

6. Cassell E. Diagnosing suffering: A perspective. *Annals of Internal Medicine* 1999; 131: 531-4.
7. Cassell E. The nature of suffering and the goals of medicine. *New England Journal of Medicine* 1982; 306 (11): 639-45.
8. Hewitt J. Rational suicide: philosophical perspectives on schizophrenia. *Med Health Care and Philosophy* 2009; 13: 25-31.
9. Ganzini L et al. Attitudes of Oregon psychiatrists toward physician-assisted suicide. *American Journal of Psychiatry* 1996; 1469-73.
10. Matthews E. Choosing death: Philosophical observations on suicide and euthanasia. *Philosophy, Psychiatry, & Psychology* 1998; 5.2: 107-11.
11. Sakinofsky I, Swart GT. Suicidal patients and the ethics of medicine. *Canadian Journal of Psychiatry* 1986; 31: 91-6.
12. Hendin H, Foley K. Physician-assisted suicide in Oregon: A medical perspective. *Michigan Law Review* 2008;106: 1613-39.
13. From NIH internet site: http://www.nlm.nih.gov/hmd/greek/greek_oath.html
14. Sakinofsky I. Rational suicide and the older adult: A humane experiment gone adrift. *Crosscurrents (CAMH publication)* 2008; summer: 18.
15. Helft PR, Siegler M, Lantos J. The Rise and Fall of the Futility Movement. *NEJM*, 2000; 343: 293-296.
16. Werth JL, Wineberg H. A critical analysis of criticisms of the Oregon Death With Dignity Act. *Death Studies* 2005; 29(1):1-27.

Acknowledgements: *The author would like to acknowledge the following individuals: Dr. Barbara Russell, Dr. Samuel Packer, Dr. Jan Malat, Dr. Isaac Sakinofsky, Dr. Blair Henry.*

Competing Interests: *None*

Address for Correspondence: *justine.dembo@utoronto.ca*

FILM REVIEW

Intimate relationships and dementia – an extended commentary on *Away from Her*

Reviewed by:

L. Syd M Johnson PhD, Postdoctoral Fellow

Timothy M Krahn BA (Hons), Research Associate

Novel Tech Ethics, Dalhousie University

Halifax, Canada

Key Words: aging; dementia; Alzheimer disease; identity crisis; interpersonal relations; grief; sexuality; object attachment; emotional bonds; psychological adaptation; residential facilities; institutionalization.

Introduction: Dementia, identity and relationships

We tend to think of our lives progressing in a linear fashion, from start to finish, infancy to old age, birth to death. Within a lifetime, there is the progressive accumulation of experience, understanding, knowledge, memory, and relationships, all shaping our identities, our understanding of who we are, our place in the world, and giving meaning to our lives. Dementia interrupts that linear progress.ⁱ When memories are lost, or when the capacity to form new memories disappears, an important link to the contents of our own identity can be lost too (Addis & Tippett, 2004; Jetten et al., 2010). Close relationships may be disrupted by dementia (Blieszner & Shifflett, 1990; Hellström et al., 2007)ⁱⁱ— persons with dementia may forget their loved ones, losing access to decades of shared experience. While death severs a relationship, leaving a survivor to continue on alone, dementia is different. A relationship may be severed, but both persons continue.ⁱⁱⁱ Perhaps the “survivor,” the caregiver or loved one of the demented person, continues on their life trajectory, following the same path, but without the company of the other (see Beeson, 2003; Pearlin et al., 1990). But their former partner, parent, friend now diverges, traveling with dementia, taking a different path for the remainder of his or her life.

The literature on caregivers of persons with dementia is filled with research on the burdens and psychological stresses that the disease places on caregivers^{iv} (Gonzalez-Salvador et al., 1999; Volicer, 2007). The vast literature on dementia includes much discussion of the loss of identity and personhood suffered by the demented individual (Degrazia, 1999; Dworkin, 1986; Hughes, 2001; Lindemann, 2009; Naue & Kroll, 2009), but—with a few notable exceptions (e.g. Graham & Bassett, 2006)—little on how dementia alters those identity-constituting interpersonal

relationships such that the loved ones of the person with dementia experience a loss or change of identity as well (Baldwin, 2009:31).^v They are the collateral damage of dementia.

As Françoise Baylis explains: “Persons are interdependent beings and so it is that a person’s identity – including her traits, desires, beliefs, values, emotions, intentions, memories, actions and experiences – is informed by her personal relationships, these relationships being characterized by varying degrees and kinds of intimacy and dependence” (Baylis, 2010; see Lindemann, 2007:353-354). Much of what makes us “who we are” belongs “not to self reflection but to the mutual recognition between two people” (Oppenheimer, 2006:199-200; see Taylor et al., 1994). For both parties in a dyad, recognition, the lack of it or the perceived lack of it, has profound effects on the way behaviour is viewed and controlled (Graham & Bassett, 2006:337). And as Janice Graham and Raewyn Basset further add:

While many studies focus on maintaining a past self, some researchers examine the construction of a flexible, changing self in the present. Further, the self in the present may be co-constructed in relation to a shared past between carer and cared-for (Forbat, 2005). Where interactions with others are based on a past self, in the present the person still reflects on past roles (Cohen-Mansfield et al., 2000). (Graham & Bassett, 2006:337)

The film *Away from Her* addresses this poignant and neglected aspect of dementing illnesses like Alzheimer’s disease, exploring the ways in which we are anchored by love and relationships, and how the unmooring that accompanies dementia—for example, the loss of shared memory (Bateman, 2007:23)—affects not just those whose memories are lost, but also those whose memories remain intact or, at the very least, much more secure and stable.^{vi} As persons partially constituted by their relationships with their forgetful loved ones, those who (can) remember become lost too, as they navigate with now varying degrees of loneliness (Graham & Bassett, 2006), the path along which they once walked with another.

Prevalence, symptoms, sequelae and the needs of persons with dementia

A 2006 Canadian census has observed that those aged 55-64 are the fastest-growing age group in the country (an increase of 28.1% from 2001), followed next by those over 80 years old (Statistics Canada, 2007). The “baby boomers”, those born between 1946-1965, are turning 60 and reportedly entering the age of greatest risk for dementia (Forbes & Neufeld, 2008). The Canadian Studies on Health and Aging reported in 1994 that 252,600 (8%) of all Canadians aged 65 years and over, and 35% aged 85 and older, suffer from dementia. The same study estimated that if these prevalence rates remain constant, by 2021 the number of Canadians with dementia will rise to 592,000 (CSHA, 1994). At the time of this study, about half of those Canadians living with dementia were cared for within institutional settings and half lived in the community (CSHA, 1994; Graham & Bassett, 2006; Mcdowell et al., 1994). And of those living in the community, almost two-thirds had never been formally diagnosed (Sternberg et al., 2000). The reality is that many persons with dementia are left to cope with their illness (and all the risks attached to it) either on their own, or within the context of their family or set of close relations (Mcdowell et al., 1994; Sternberg et al., 2000).

The behavioural and psychological symptoms of dementia include hallucinations and delusions, depression, sleeplessness, anxiety, physical aggression, wandering, restlessness, pacing, screaming, crying, repetitive questioning, agitation, and other symptoms and behaviours which “are responsible for increased caregiver burden and decreased quality of life for caregivers and patients” (Finkel, 2003:800). Additionally, the social isolation and sense of loss experienced by persons with dementia result in a vicious cycle: people with dementia have the same cluster of psychological needs as everyone else — comfort, attachment, inclusion, occupation, and identity — yet the “dialectical interplay between neurological impairment and social psychology” results in a dwindling of their opportunities for meeting those needs (Kitwood, 1997:83; see Baldwin, 2009). As Tom Kitwood further explains:

The needs are more obvious in people with dementia, who are far more vulnerable and usually less able to take the initiatives that would lead to their needs being met. The pattern of need will vary according to personality and life history, and often the intensity of manifest need increases with the advance of cognitive impairment. (Kitwood, 1997:81).

The result is that just as those psychological needs increase, they become increasingly poorly met, both because of the neurological impairments of the demented person, and because of those needs going unrecognized and sometimes even neglected (see Graham & Bassett, 2006).

Studies show that mental health comorbidities, including mood and anxiety disorders, are more common with Alzheimer’s disease and other forms of dementia than matched controls without the disease (mood disorders: 19.5% vs. 5.3% and anxiety disorders: 16.3% vs. 4.0%) (Nabalamba & Patten, 2010). It is estimated that depression afflicts up to 60% of patients with dementia, although some studies show rates as high as 85% (Finkel, 2003:807; Volicer, 2001:387). Depression has significant negative effects on patients and caregivers:^{vii} it can decrease the ability to engage in meaningful

activities; increase dependence in activities of daily living; and lead to several peripheral symptoms, such as agitation, repetitive vocalization, apathy, insomnia, food refusal, anger, irritability, and resistance to care (Volicer, 2001:387).

The benefits of close, personal relationships

Depression in the elderly (including individuals in the community and residential care) is strongly linked with factors indicating increased dependency marked by decline in functional and cognitive capacity (Anstey et al., 2007). In a study by Thomas and colleagues on the reasons given by informal caregivers for institutionalizing dementia patients previously living at home, it was noted that: i) “the most frequent caregiver complaint at the time of institutionalisation was incontinence, followed by withdrawal”; and ii) “[t]he caregiver’s main problem resulting in institutionalisation was dependence, with behavioural disorders in second place” (Thomas et al., 2004:127; cf. Vernooij-Dassen et al., 1997). Another study by Kales and colleagues has shown that patients with coexisting dementia and depression are high utilisers of inpatient and nursing home care. For patients with coexisting dementia and depression, “nursing home placement correlated significantly with baseline severity of functional impairment and mood measures, but not with other factors, including dementia stage and medical burden”(Kales et al., 2005:441).

Research shows that persons living in residential care facilities, including persons with dementia, benefit from forming companionship relationships with their new neighbours (Kitwood, 1997:82-83; Kutner et al., 2000:201). Friendships and close personal relationships, including those that develop into romances and sexual relationships, can help ease the transition into a strange new environment for dementia patients, who can become easily disoriented in an unfamiliar place. As Kitwood writes, “people with dementia are continually finding themselves in situations that they experience as ‘strange’^{viii}, and that this powerfully activates the attachment need” (Kitwood, 1997:82). Bonding and attachment create a kind of safety net when the world is full of uncertainty, and “there is every reason to suppose that the need for attachment remains when a person has dementia; indeed it may be as strong as in early childhood” (Kitwood, 1997:82; cf. Miesen, 2006).

Institutionalization or transition into a residential care facility can result in the loss of important and secure attachments for persons with dementia — cutting them off from friends, loved ones and spouses — undermining the sense of security for persons already vulnerable, insecure, and anxious. The effect can be devastating (see Kitwood, 1997:82; Kovach, 1998). Agitation and behavioural and psychological symptoms of dementia decrease in dementia residents who are involved in ongoing friendship relationships (Kutner et al., 2000:200). Increased frequency of agitated behaviour is observed when friendship interactions end, suggesting a “protective” effect of friendship for people with dementia (Kutner et al., 2000:201). When friendship relationships break up or change significantly, “dementia residents — like the general population — may be at increased risk of feelings of emotional distress” (Kutner et al., 2000:202). A scenario that is familiar to the staff of residential care facilities for people with

dementia is that personal relationships improve quality of life for the residents,^{ix} while residents who are socially isolated fare worse.^x “Without the reassurance that attachments provide it is difficult for any person, of whatever age, to function well,” Kitwood notes (1997:82).

The anecdotal stories abound of relationships that bring renewed happiness into the lives of residents in dementia care facilities: Supreme Court Justice Sandra Day O’Connor was reportedly thrilled when her husband found companionship with another woman after moving into a care facility:

[Justice] O’Connor spoke about the demands of caring for someone with Alzheimer’s, including unexpected, sometimes bittersweet, developments as her husband began to lose his ability to recognize his family. He formed romantic attachments with other patients at an assisted-care center in Arizona, and this transformed him, the former justice said, from someone who had been depressed and introverted into a much happier person.

She told the *New York Times*: “He was in a cottage, and there was a woman who kind of attached herself to him. It was nice for him to have someone there who was sometimes holding his hand and to keep him company. And then he was moved to a different cottage, because his condition deteriorated. And in the new cottage, there’s another woman who has been very sweet to him. And I’m totally glad.”

Ehrenfeld et al. describe several romantic and sexual relationships among institutionalized persons with dementia:

A married man and an infirm widow formed a romantic attachment that included love and caring, which was accepted with joy and understanding by the man’s wife. Each time she came to visit she made sure to bring a tasty treat for the elderly woman who cared for her husband.” (Ehrenfeld et al., 1999:148)

Z, a woman aged 80, showed special concern for D, a 76-year-old man who was not her husband or a relative. She assisted him with dressing and eating, and even checked if he was in bed. The two sat together at meals, conversed, and played cards and dominoes. When D’s wife came to visit, Z quickly left the room, returning only after the wife had left.” (Ehrenfeld et al., 1999:146)

The nature of relationships varies, from nurturing relationships and friendships, to romantic and sexual relationships which are “a reality in long term care” (Lichtenberg, 1997:6). Such associations (especially the latter) are not always accepted, however. Objections to relationships can come from families, spouses, staff, and even other residents of dementia care facilities, particularly when residents develop sexual relationships (Ehrenfeld et al., 1999:148; Lichtenberg, 1997). Ehrenfeld et al. report that “many professionals working in psychogeriatric wards report experiencing difficulties, distress and confusion regarding sexual display between institutionalized patients. Similar uneasiness is also expressed by family members and residents of psychogeriatric institutions” (Ehrenfeld et al., 1999:144). Most frequently, families object when female residents are sexually active, and demand that they be protected^{xi} (Ehrenfeld et al., 1999:148; see Nay, 1992). Melinda Henneberger tells of a thwarted romance between two

persons with dementia living in an assisted living facility:

Bob’s family was horrified at the idea that his relationship with Dorothy might have become sexual. At his age, they wouldn’t have thought it possible. But when Bob’s son walked in and saw his 95-year-old father in bed with his 82-year-old girlfriend last December, incredulity turned into full-blown panic... Because both Bob and Dorothy suffer from dementia, the son assumed that his father didn’t fully understand what was going on... Bob’s son became determined to keep the two apart and asked the facility’s staff to ensure that they were never left alone together. After that, Dorothy stopped eating. She lost 21 pounds, was treated for depression, and was hospitalized for dehydration. When Bob was finally moved out of the facility in January, she sat in the window for weeks waiting for him. She doesn’t do that anymore, though: “Her Alzheimer’s is protecting her at this point,” says her doctor, who thinks the loss might have killed her if its memory hadn’t faded so mercifully fast. (Henneberger, 2008)

Away from Her – from diagnosis to placement with residential care

Away from Her, which is based on Alice Munro’s short story “The Bear Came Over the Mountain” (1999), addresses the subject of love, not from the perspective of a person with dementia, but rather from the perspective of the one left behind. Among the most poignant aspects of the story is what happens when the character of Fiona Anderson (Julie Christie), who has Alzheimer’s disease, forgets her husband Grant (Gordon Pinsent) and forms a close relationship with another male companion.

Early in the film, Fiona receives a diagnosis of her condition. She accepts the news with calmness and peace. In a way, she already knew, as she told her friends, that she was “beginning to disappear.” Fiona’s reaction is consistent with the responses of some patients receiving a diagnosis of Alzheimer’s disease, who experience “a sense of relief and validation from knowing their diagnosis” (Aminzadeh et al., 2007:285). Such patients are aware, as Fiona was, that there had been changes to their memory and functioning, and a diagnosis provides them with an explanation, and an opportunity for intervention (Aminzadeh et al., 2007:285). Grant, on the other hand, denies the diagnosis,^{xii} and clings to the thin thread of hope that his wife of forty-four years will not get worse. “I’m not all gone...” Fiona tells Grant, “...just going.” Grant experiences Fiona’s going, her disappearing, as a leaving, a going away from him. When Fiona’s “going” gets worse, and she becomes lost and disoriented, she decides to enter a dementia care facility called Meadowlake. Grant has trouble letting go^{xiii} (cf. Paun, 2003). It’s just a “rest cure,” he tells her, “experimental” and not “permanent.”^{xiv}

The facility’s policies state that new residents cannot receive any visitors or phone calls until thirty days after they are admitted,^{xv} a rule designed to (purportedly) promote successful integration, reduce confusion, and ease the transition to the new environment. Grant is told by Meadowlake’s supervisor, Madeleine Montpellier (Wendy Crewson). As such, the rationale for this policy runs contrary to research concerning emotional attachment and dealing

with the effects of loss (Browne & Shlosberg, 2006; Cheston & Bender, 1999; Ingebretsen & Solem, 2004; MacDonald, 2001; Miesen, 1992). De Vries and McChrystal found that insecure attachment behaviour (e.g. rocking and howling) was observed for people with dementia—in this case, as caused by Creutzfeldt Jakob disease—when members from the study group were placed in unfamiliar surroundings with strangers and on departure of family members. “Grieving behavior in individuals, young or old, confronted with the (threatened) loss of an emotional link with people who are important to them, was fundamental to the experiences of these people...” (de Vries & McChrystal, 2010:287).

Notwithstanding the practical challenges involved, research indicates, and most care institutions and programs now recognize, the therapeutic benefits and ethical importance (Hughes & Baldwin, 2006; Martin & Younger, 2000) of:

- i. involving residents and/or their representatives—if not partnering with, informal carers/relatives—in the assessment, planning, provision and evaluation of any plan of care (Kapp, 1996; Ministry of Health and Long-Term Care, 2006: A1.1-5; Pritchard, 1999; Woods et al., 2008b; Woods et al., 2008a);^{xvi}
- ii. maintaining continuity of care as much as possible (Carpentier et al., 2008; Forbes & Neufeld, 2008; cf. Kovach, 1998; Ontario Ministry of Health and Long-Term Care, 2006; Vernooij-Dassen et al., 1997); and
- iii. designing environments that establish and maintain links to the familiar for persons with dementia (Cohen & Weisman, 1991; Miesen, 2004).

Several studies have examined the association between selected outcomes and the character of the relationship between caregiver and care recipient with dementia. Norton observes that:

“Closer perceived relationships are associated with better adjustment to nursing home placement in persons with dementia (Whitlatch et al., 2001) [and] improved psychological well-being and problem-solving abilities (Burgener & Twigg, 2002). Conversely, avoidance by caregivers or insecure attachment styles in their [close relations] have been associated with more behavioral problems in the latter (Perren et al., 2007)”. (Norton et al., 2009:561)

What is more, the evidence also points towards the importance of *continued* attachments for general well-being in later life (Magai & Passman, 1997). For adult populations, the primary attachment figure is most commonly a partner or friend (Hazan & Shaver, 1987). Returning to the movie, then, it would appear that Meadowlake’s policy prohibiting Grant—the primary caregiver and close partner of Fiona—from either telephoning or visiting his wife for thirty days upon initial placement, is unreasonable, not to mention disrespectful. In fact, to make this sort of consent to “treatment”—in a very loose sense of the term, for there is no evidence in the movie that it is medically indicated—as a condition of admission, especially given the fact that most persons upon admission to a long-term care facility are quite vulnerable with few options (Kapp, 1996; Ontario Human Rights Commission, 2010), makes this a matter of injustice. Following such a policy could hardly be seen as motivated by serving Fiona’s best interests as

the patient.^{xvii} In fact, the policy flies in the face of evidence which points towards more successful provision of care by harnessing the protective function of attachment bonds, and it is noteworthy that this is especially true for serving persons in later life with dementia (Browne & Shlosberg, 2006; Cheston & Bender, 1999; Jones & Miesen, 2006).^{xviii} As such, Grant is more inclined to believe Fiona’s main nurse Kristy (Kristen Thomson) who confides to him that rule is probably designed to make life easier for the facility staff.

***Away from Her* – relational identity, resistance and adaptation**

Grant eagerly awaits his first visit with Fiona, but when he returns to Meadowlake after the prolonged separation, he finds her sitting and playing cards with another man, Aubrey (Michael Murphy), who is chronically mute and wheelchair-bound. Fiona approaches Grant, but in the course of their conversation, it becomes evident that she does not recognize her husband, and thinks he is a new resident at the facility. This pattern persists in subsequent visits — Fiona believes Grant to be an especially persistent suitor, but she is politely uninterested, having clearly and firmly bonded with Aubrey, who needs her with childlike dependence and intensity. Grant comes to accept his wife’s need for this new companion — after all, Aubrey is someone she can nurture and care for (Cicero & Detweiler, 2009),^{xix} someone present for her in the ongoing immediacy of profound forgetfulness. “He doesn’t confuse me,” Fiona explains.^{xx} Even so, Grant persists with visiting Fiona, in spite of being (for the most part) ignored by her. He may not provide day-to-day regular care for her directly anymore, but this has not stopped him from caring very deeply about her (cf. Graham & Bassett, 2006).

David Cockburn aptly notes that: “my conception of the present is, when I care for another, strongly conditioned by my understanding of the past” (Cockburn, 1997:69). The giving and receiving of care that happens between partners where one suffers from dementia, usually takes place in the context of a relationship (not uncommonly a longstanding one) that precedes the onset of the Alzheimer’s disease—a relationship that continues to evolve with the progress of the illness (Ablitt et al., 2009; Davies & Gregory, 2007:485; Forbat, 2005; Graham & Bassett, 2006). Just as aspects of the prior relationship impact how couples negotiate the dynamics and the roles assumed in the exchange of care (Davies & Gregory, 2007; Steadman et al., 2007; Williamson & Schulz, 1990), so also the process of living with dementia impacts on the relationship, “often causing change or loss which is difficult to accept or adjust to (Blieszner & Shifflett, 1990; Hellström et al., 2007)” (Ablitt et al., 2009:498).

As the story of Grant and Fiona’s life together is revealed in his memories, it becomes evident that theirs was a complicated relationship — one in which he, in the past, had been unfaithful. That difficult past — and all the emotional baggage — may be lost to Fiona, something that has drifted away along with her memory of her husband. And so part of what makes Aubrey an ideal companion is that there is no past there to forget, no baggage, no confusion — not for Fiona or Aubrey. They exist solely in the present, and have only a very short past and not much in the way of plans or hopes for the future. Comparatively, Grant, with his

memory intact, exists in a state of compounded loss: he misses his wife now, he grieves Fiona's loss of her past (in a way that she does not grieve for it), he mourns the future they will not have together, and he suffers yet another loss when he loses his wife to another man. Understandably, this pains and confuses Grant as he both resists the changes to the relationship while still trying to make sense of the situation and its implications for his own—personal, social, and moral—expectations for relating to Fiona. At one point Grant speculates in conversation with Kristy whether Fiona may be acting a part through her illness and the cultivation of her new attachment to Aubrey as a way to punish him for his past infidelity to her (cf. Askham, 1995). Grant is hereby struggling to cope with and understand how roles are changing for both him and Fiona (cf. Baldwin, 2009; Lebovitz, 1979; Quinn et al., 2010), and how the past trajectory of his relating to her will or will not continue (cf. Baldwin, 2009:32). His experience of this seems a demonstration of Margaret Urban Walker's claim in "Picking Up Pieces – Lives, Stories, and Integrity" that: "It is not only for moral purposes but also for purposes of intelligibility over time that we read and reread actions and other events backward and forward, weaving them into lives that are anything more than one damned thing after another" (1997:67).

A consistent association between loneliness and the experience of depression has been well documented (Beeson, 2003:137). When Aubrey is removed from the facility by his own wife Marian (Olympia Dukakis), it is Fiona who falls apart, exhibiting the symptomology, including depression, frequently observed among care residents—and, among the elderly more generally (Brodaty & Anstey, 1994; Fielden, 1992:294-295; Godfrey, 2005)—when cut off from close relationships (see Erber, 1994; Kutner et al., 2000). She suffers, suddenly, just as Grant had. Fiona's nurse warns Grant that she is in physical and mental decline, her vulnerability and despair allowing the Alzheimer's to advance more rapidly. Indeed, depression in Alzheimer's patients can aggravate dysfunction, compound memory impairment, "make the affected individual do worse than would be expected from the dementia alone—causing clinical conditions referred to as 'excess disability' states" (Strock, 1994).^{xxi}

Although *Away from Her* is primarily about the losses experienced by the spouse left to cope with a loved one's dementia, the movie accurately and touchingly depicts the emotional needs of persons with dementia as well. Whereas popular culture depictions of love in old age and cognitive decline are frequently comedic and dismissive (an expression of cultural discomfort with the subject, and a turning away from it through neglect or mockery) (Zernike, 2007), the film is open to the psychological complexity and emotional importance of Fiona's relationship with Aubrey, and the way that he, in his state of mute dependence, helps anchor and secure her amidst the unfamiliarity that her illness brings. As these events unfold for Grant to observe, he at first desperately seeks to hold onto Fiona as his wife, even becoming insistent in one scene that she remember (and by implication better observe) obligations to him as her husband. In this same scene he also makes a point to her that she is wearing someone else's sweater, not her own. His meaning to her is unmistakable: the person she once was would have never worn such a "tacky piece of clothing", and Grant is adamant she return to and remain that person. However, in time he too comes to see that she now has changed, and he accepts her as a somewhat different person with a new set of needs.

Grant is in a position to help Fiona, to demonstrate his love for his wife by facilitating the companionship she needs now. In this unexpected love triangle, the movie reflects on the meaning of love, and especially the richness, complexity and poignancy of what might be called "old love," to contrast with the intensity and, if you will, hysteria of young love as it is depicted in popular culture (Zernike, 2007; see Cicero & Detweiler, 2009). The kind of self-sacrificial caring Grant shows for Fiona is a kind of holding of her in her identity (cf. Radden & Fordyce, 2006:81) when she can no longer do it herself, a kind of holding that Hilde Lindemann calls "part of the work of preserving, maintaining, and nurturing people" (Lindemann, 2009:422). This holding of a person in her identity is "particularly needed by people with progressive dementias" (Lindemann, 2009:416; see Ablitt et al., 2009; Baldwin, 2009; Surr, 2006). In holding up his end of the marital contract (see McGill, 2008:101), Grant helps to hold Fiona in her identity. That is, just as being Fiona's husband is identity-constituting for Grant, being Grant's wife is identity-constituting for Fiona. If, as Lindemann says, identity is a representation of the self, "a tissue of stories, constructed not only first-person but also [of] many third-person perspectives, depicting the more important acts, experiences, relationships, and commitments that characterize a person and so allows that person and those around [her] to make sense of who [she] is" (Lindemann, 2009:417), then Grant, in ways he gradually comes to understand, must be a kind of identity-keeper for Fiona by dint of his memory-keeping powers (cf. Radden & Fordyce, 2006:82-83). Fiona has it right when she says, early in the film, that she is "beginning to disappear," for she is losing her grip on something essential to her self and identity. Since only Grant can maintain certain relational aspects of Fiona's identity (cf. Lindemann, 2007), he can, essentially, hold it in trust for her, by acknowledging that Fiona is still his beloved wife.

When Grant returned to Meadowlake after the thirty-day separation, he never found the Fiona he once knew. What if Grant had refused to let go of Fiona—which he managed to do—and instead of adapting himself, just abandoned her? After all, much of her apparent behaviour seemed to communicate a preference for him to stay away from her with all the confusion his presence brought to her. Grant chose to step aside, rather than step away, to adapt to Fiona, and for Fiona. Taking this unselfish approach in the face of all that seemed so confusing, Grant recovers something both he and Fiona had lost to dementia (cf. Graham & Bassett, 2006; Quinn et al., 2010; Radden & Fordyce, 2006).

End Notes:

- i. Hilde Lindemann explains: "Serious injury or illness can, and frequently does, play havoc with one's identity. To be critically ill for more than a few days is to lose control over one's physical and mental processes. It puts a stop to one's professional and social activities and interferes with one's memories, hopes, plans for the future and ongoing projects. It usually involves hospitalization, which means that one is uprooted from one's customary surroundings; denied access to cherished people, pets and objects; and thrust into a milieu governed by insider understandings to which one is not privy. All of this contributes to a disintegration of one's sense of self. Eric Cassell (1982) conceptualizes this disintegration as *suffering*;

to suffer is to feel oneself being undone. Suffering persists, writes Cassell, until the threat to the identity has passed or until the integrity of the identity can be re-established in some manner” (Lindemann, 2007:355-356).

- ii. See generally Ablitt et al. (2009) for a review of the influence of relationships factors in living with dementia.
- iii. “Existing research suggests that dementia can result in changes to marital intimacy and marital satisfaction (Baikie, 2002), joint negotiation and adjustment in acknowledging losses, as well as recognizing resilience and coping strategies (Robinson et al., 2005). More to the point, limited research in this area highlights the need to better understand how couples make sense of and adjust to a diagnosis of dementia and the impact that has on their marriage relationship. In addition, it is important to understand how the marriage relationship influences how dementia enters into the lives of couples, and its place within their marriage biographies” (Davies & Gregory, 2007:484-485).
- iv. At the same time, the emphasis on caregiver burden can be, and historically has been, overdrawn. Quinn notes that: “[w]hilst traditionally caregiving for a person with dementia has been viewed as a negative experience, more recent research indicates that caregiving can have positive outcomes such as feelings of gain or gratification (Kramer, 1997)” (Quinn et al., 2009:143). Nolan further explains that: “More than a decade ago Kahana and Young (1990) argued that one of the most significant challenges for the future of caregiving research was to move beyond the then-dominant unidirectional and asymmetrical models of care (for example, that promoted the belief that the needs of the cared-for person for support inevitably produced a sense of burden in the caregiver) towards relational and dynamic approaches which reflected the potentially negative and positive outcomes of care for both caregiver and care-receiver. They argued that there was a need to be more ambitious and to ‘glimpse beyond dyadic perspectives’(Kahana & Young, 1990) to include not only the wider family system but also the roles and relationship forged between dyads, families and the formal caring system” (Nolan et al., 2002:203).
- v. “‘Loss of self’ is a risk for spouses and children who provide care to partners/family members” (Beeson, 2003:137). Beeson further notes that: “AD [Alzheimer’s Disease] caregiving spouses experiencing ‘couple identity’ in a previously intimate marital relationship often find the transformed relationship with their AD spouse contributory to a loss of identity” (Skaff & Pearlin, 1992)” (Beeson, 2003:137). See also M. Rosenkoetter (1996) on fundamental changes to life patterns of couples when one of them enters an extended care facility.
- vi. Oppenheimer explains well the pain that accompanies the loss of recognition, saying: “When dementia brings loss of language, coordination, and memory, as with a fragmented image, the knowledge preserved in the relationship can allow the gaps to be partly filled in. It is part of loving, to know another so well that their turns of phrase, their responses, their humour can be predicted. It is part of the joy of being loved, to be so predicted. So it jars the relationship badly when you find the person you love (perhaps your wife or your mother) acting in an unfamiliar and unpredictable way and when for their part they see in your response the sudden revelation that you no longer understand them. The poignancy of such moments is all the greater precisely because it is the families and friends of people with dementia who are the most important safekeepers of their identities, insofar as they hold their histories, understand what was important to them in their former lives, and remember their preferences and habits of thought” (Oppenheimer, 2006:199-200).
- vii. Harrison and colleagues have even suggested that care for elderly persons involve “[r]ecognition of the importance of depression and investigation of the possibility that its appropriate management may improve quality of life and sometimes prevent institutionalization”(Harrison et al., 1990:102). Ablitt and colleagues’ review of the literature demonstrated that: “lower current relationship quality relates to increased depression in carers and people with dementia, and to increased strain in the carers. It also relates to reduced perceived self-efficacy in carers and reduced functional ability in people with dementia” (Ablitt et al., 2009:501).
- viii. “In research with dementia patients in different stages of the process, a strong correlation was found between phenomenon of parent fixation, the level of cognitive functioning and attachment behavior. This was explained by postulating that remaining aware of one’s cognitive dysfunctioning in dementia is like going into a ‘strange situation’ in which the person experiences feeling unsafe for long periods of time, powerless and with no structures to hold on to. Therefore the demented elderly have to cope with the same feelings that arise in situations which resemble separation, homelessness or displacement. The ‘awareness context’ brings the sufferer in a chronic trauma. To understand a dementia patient’s behavior correctly one needs to consider his AC [awareness-context]” (Miesen, 2004:68).
- ix. In a study by Bullard-Poe and colleagues it is reported that intimacy is directly related to life satisfaction (Bullard-Poe et al., 1994).
- x. Beeson reports that: “Research has found that the loss of companionship, loss of the reciprocal exchange of affection between spouses, and the loss of a confidant, especially in the marital dyad, can affect the quality of life for both the caregiver and the care recipient, as well as the continuity and quality of care for the AD [Alzheimer’s disease] spouse (Hays et al., 1998; Kramer & Lambert, 1999; Siriopoulos et al., 1999; Yates et al., 1999)” (Beeson, 2003:136).
- xi. See Lichtenberg for a competency tool that can be implemented to protect the patient from exploitation. Lichtenberg also discusses how family involvement, in negotiating these risks “is a necessary and sometimes difficult process” (Lichtenberg, 1997:7).
- xii. See Connell et al. (2004) for a discussion of family and caregiver attitudes to diagnosis of dementia in loved ones. See Pratt et al. for a discussion of “the psychosocial model of experience of receiving a diagnosis of dementia, where social

aspects such as interaction with professionals, services and carer relationships were shown to directly interact with the individual psychological experience of people with dementia and therefore impact on the overall experience of receiving a dementia diagnosis” (Pratt et al., 2006:56). See also Pratt & Wilkinson (2003).

- xiii. “Paun (2003) found a relentless commitment to provide dementia care at home in spite of difficult past relationships, which she attributed to the meaning attached to the marital bond” (Paun, 2003 cited in Davies & Gregroy, 2007:484). See Gaugler et al. (2001) on relinquishing in-home dementia care and the difficulties faced by family caregivers in transitioning their dependents to nursing homes.
- xiv. Grant and Fiona appear to have a close relationship. According to Ablitt and colleagues, lower pre-morbid relationship quality “has been shown to relate to depression, burden and emotional reactivity in carers. Although higher relationship quality appears to be a protective factor, there is some evidence that high levels of past closeness can increase distress in carers” (Ablitt et al., 2009:502).
- xv. The policy serves as a plot device, but to the best of our knowledge, it is very unlikely that such a policy would ever have been in effect for the time featured in the film. Though the type of institution and therefore jurisdiction of the Meadowlake care facility is not made clear in the film, the policy featured could be interpreted as in violation of the Residents’ Bill of Rights which on our reading would appear to guarantee a right to visitation as upheld in the Government of Ontario *Charitable Institutions Act* (Government of Ontario, 2009a), the *Homes for the Aged and Rest Homes Act* (governing municipal institutions) (Government of Ontario, 2009b), the *Nursing Homes Act* (governing for profit institutions) (Government of Ontario, 2009c), as well as Bill 21, *Retirement Homes Act* (2010) currently in its third reading (Government of Ontario, 2010). See also *Tab 09 standards: Residential Care* (Ministry of Health and Long-Term Care, 2006) which contains: i) direction for mechanisms to be in place to promote and support residents’ rights, autonomy, and decision-making at A1; ii) a reiteration of Residents’ rights at A1.11; and iii) long-term care home admission agreement requirements at A2.
- xvi. See J.W. Crane Memorial Library (2009) for a listing of “Current perspectives in the literature on family involvement in long term care”.
- xvii. See Community Legal Education Ontario (2008) for a discussion of the bill of rights for people who live in Ontario long-term care homes. See T. Daniel Frith’s (2007) article on “Nursing home visitation rights” for a discussion of relevant legislation in the United States.
- xviii. See Peak & Cheston (Peak & Cheston, 2002) as well as Woods & Ashley (Woods & Ashley, 1995) for a discussion of the clinical use of simulated presence therapy which mimics the presence of close attachments (to persons or objects) in order to reduce agitation and create calm for people with dementia.
- xix. Cf. Browne & Schlossberg who note that: “The recent advent of ‘doll therapy’ in dementia care is also somewhat based on the principles of attachment theory. Dolls are being introduced into a number of inpatient and residential care settings in attempts to improve communication between staff and residents and meet residents’ needs for attachment and a sense of purpose (Bryant & Foster, 2002; Moore, 2001). It has been observed that dolls can play a number of roles for the person with dementia, with the doll being referred to as a baby, husband, wife or teacher (Moore, 2001). Some residents have reported that dolls are ‘a great comfort’ to them (Moore, 2001) and observations suggest that dolls may rekindle positive emotions of the parental-child bond (Bryant & Foster, 2002). A growing body of case study material is offering support for the use of dolls in dementia care, particularly for clients who are exhibiting problem or challenging behaviours (see Bryant & Foster, 2002)” (Browne & Shlosberg, 2006:140).
- xx. Oppenheimer notes that: “In general, professional carers (whether the staff of nursing homes or home carers visiting intermittently) will take a person entering their care ‘as they are’: the relationship between them is built mainly on the present behavior, communication, and emotional responses, with little regard to their past identities. Over time, relatives who hold the history of the patient may try to educate the carers about them. Sometimes there are advantages in this difference in perspective. The person entering the nursing home can leave their dysfunctional relationship behind, can lose the unpleasant identity they carried, and can make a fresh start with people who have no presuppositions about their character or moral qualities, but will relate to them simply as a person needing care” (Oppenheimer, 2006:201-202).
- xxi. Ablitt et al. also note that: “The findings of Burgener and Twigg (2002) suggest that lower emotional well-being in the person with dementia and poorer relationship quality may lead to further loss of functional ability, and exacerbate the presentation of the dementia itself” (Ablitt et al., 2009:506).

References:

- Ablitt, A., Jones, G. V., & Muers, J. (2009). Living With Dementia: a Systematic Review of the Influence of Relationship Factors. *Aging Ment.Health*, 13, 497-511.
- Addis, D. R. & Tippet, L. J. (2004). Memory of Myself: Autobiographical Memory and Identity in Alzheimer’s Disease. *Memory*, 12, 56-74.
- Aminzadeh, F., Byszewski, A., Molnar, F. J., & Eisner, M. (2007). Emotional Impact of Dementia Diagnosis: Exploring Persons With Dementia and Caregivers’ Perspectives. *Aging Ment.Health*, 11, 281-290.
- Anstey, K. J., von, S. C., Sargent-Cox, K., & Luszcz, M. A. (2007). Prevalence and Risk Factors for Depression in a Longitudinal, Population-Based Study Including Individuals in the Community and Residential Care. *Am.J Geriatr.Psychiatry*, 15, 497-505.
- Askham, J. (1995). Making Sense of Dementia - Carers’ Perceptions. *Ageing and Society*, 15, 103-114.
- Baikie, E. (2002). The Impact of Dementia on Marital Relationships. *Sexual and Relationship Therapy*, 17, 289-299.

- Baldwin, C. (2009). Narrative and Decision-Making. In D. O'Connor & B. Purves (Eds.), *Decision Making, Personhood, and Dementia: Exploring the Interface* (pp. 25-36). Philadelphia, PA: Jessica Kingsley Publishers.
- Bateman, S. (2007). *Away From Her: An Alzheimer's Love Story. Preserving Your Memory - The Magazine of Health and Hope, Summer*, 22-24.
- Baylis, F. (2010). *The Self in Situ: A Relational Account of Personal Identity*. In J. Downie & J. Llewelyn (Eds.), *Relational Theory and Health Law Policy* (pp. forthcoming). Vancouver: UBC Press.
- Beeson, R. A. (2003). Loneliness and Depression in Spousal Caregivers of Those With Alzheimer's Disease Versus Non-Caregiving Spouses. *Archives of Psychiatric Nursing*, 17, 135-143.
- Blieszner, R. & Shifflett, P. A. (1990). The Effects of Alzheimers-Disease on Close Relationships Between Patients and Caregivers. *Family Relations*, 39, 57-62.
- Brodsky, H. & Anstey, K. (1994). Treatment of Depression in the Elderly. In E. Chiu & D. Ames (Eds.), *Functional Psychiatric Disorders of the Elderly* (pp. 177-211). Cambridge: Cambridge University Press.
- Browne, C. J. & Shlosberg, E. (2006). Attachment Theory, Ageing and Dementia: A Review of the Literature. *Ageing & Mental Health*, 10, 134-142.
- Bryant, J. & Foster, S. (2002). Can the Use of Dolls and Soft Toys Really Make a Difference in Dementia? Research and Planning of a Pilot Study for People With Dementia in a Long-Stay Care Setting (Residential Home). *Psychologists' Special Interest Group for the Elderly Newsletter*, 81, 44-46.
- Bullard-Poe, L., Powell, C., & Mulligan, T. (1994). The Importance of Intimacy to Men Living in a Nursing Home. *Arch.Sex Behav.*, 23, 231-236.
- Burgener, S. & Twigg, P. (2002). Relationships Among Caregiver Factors and Quality of Life in Care Recipients With Irreversible Dementia. *Alzheimer Dis.Assoc.Disord.*, 16, 88-102.
- Carpentier, N., Pomey, M. P., Contreras, R., & Olazabal, I. (2008). Social Care Interface in Early-Stage Dementia: Practitioners' Perspectives on the Links Between Formal and Informal Networks. *Journal of Aging and Health*, 20, 710-738.
- Cassell, E. J. (1982). The Nature of Suffering and the Goals of Medicine. *New England Journal of Medicine*, 306, 639-645.
- Cheston, R. & Bender, M. (1999). *Understanding Dementia: the Man With the Worried Eyes*. London: J. Kingsley Publishers.
- Cicero, C. & Detweiler, C. (2009). Solidarity and Ambivalence in *Away From Her*. *Journal of Aging, Humanities, and the Arts*, 3, 76-80.
- Cockburn, D. (1997). Simone Weil on Death. *Mortality: Promoting the interdisciplinary study of death and dying*, 2, 63-72.
- Cohen, U. & Weisman, G. D. (1991). *Holding on to Home: Designing Environments for People With Dementia*. Baltimore: Johns Hopkins University Press.
- Cohen-Mansfield, J., Golander, H., & Arnhem, G. (2000). Self-Identity in Older Persons Suffering From Dementia. Preliminary Results. *Social Science & Medicine*, 51, 381-394.
- Community Legal Education Ontario (2008). Every Resident: Bill of Rights for People Who Live in Ontario Long-Term Care Homes. Advocacy Centre for the Elderly and Community Legal Education Ontario. Retrieved May 29, 2010.
- Connell, C. M., Boise, L., Stuckey, J. C., Holmes, S. B., & Hudson, M. L. (2004). Attitudes Toward the Diagnosis and Disclosure of Dementia Among Family Caregivers and Primary Care Physicians. *Gerontologist*, 44, 500-507.
- Crane Memorial Library, J. W. (2009). Current Perspectives in the Literature on Family Involvement in Long Term Care. University of Manitoba. from: <http://myuminfo.umanitoba.ca/Documents/722/family.pdf>
- CSHA (1994). Canadian Study of Health and Aging: Study Methods and Prevalence of Dementia. *CMAJ.*, 150, 899-913.
- Davies, J. & Gregory, D. (2007). Entering the Dialogue: Marriage Biographies and Dementia Care. *Dementia*, 6, 481-488.
- de Vries, K. & McChrystal, J. (2010). Using Attachment Theory to Improve the Care of People With Dementia. *International Journal of Work Organisation and Emotion*, 3, 287-301.
- Degrazia, D. (1999). Advance Directives, Dementia, and 'the Someone Else Problem'. *Bioethics*, 13, 373-391.
- Dworkin, R. (1986). Autonomy and the Demented Self. *Milbank Quarterly*, 64, 4-16.
- Ehrenfeld, M., Bronner, G., Tabak, N., Alpert, R., & Bergman, R. (1999). Sexuality Among Institutionalized Elderly Patients With Dementia. *Nursing Ethics*, 6, 144-149.
- Erber, N. P. (1994). Conversation As Therapy for Older Adults in Residential Care: the Case for Intervention. *Eur.J.Disord. Commun.*, 29, 269-278.
- Fielden, M. A. (1992). Depression in Older Adults - Psychological and Psychosocial Approaches. *British Journal of Social Work*, 22, 291-307.
- Finkel, S. I. (2003). Behavioral and Psychologic Symptoms of Dementia. *Clinics in Geriatric Medicine*, 19, 799-824.
- Forbat, L. (2005). *Talking About Care: Two Sides to the Story*. Bristol, UK: Policy Press.
- Forbes, D. A. & Neufeld, A. (2008). Looming Dementia Care Crisis: Canada Needs an Integrated Model of Continuing Care Now! *Can.J Nurs.Res.*, 40, 9-16.
- Frith III, T. D. (2007). Nursing Home Visitation Rights. Articlesbase. Retrieved May 29, 2010, from: <http://www.articlesbase.com/health-articles/nursing-home-visitation-rights-163530.html>
- Gaugler, J. E., Pearlin, L. I., Leitsch, S. A., & Davey, A. (2001). Relinquishing in-Home Dementia Care: Difficulties and Perceived Helpfulness During the Nursing Home Transition. *Am.J.Alzheimers Dis.Other Demen.*, 16, 32-42.
- Godfrey, M. (2005). Risk and Resources for Depression in Later Life. *Journal of Public Mental Health*, 4, 32-42.
- Gonzalez-Salvador, M. T., Arango, C., Lyketsos, C. G., & Barba, A. C. (1999). The Stress and Psychological Morbidity of the Alzheimer Patient Caregiver. *Int.J.Geriatr.Psychiatry*, 14, 701-710.
- Government of Ontario (2009a). Charitable Institutions Act. R.S.O. 1990, C.9. CanLII. Retrieved June 1, 2010, from: <http://www.canlii.org/en/on/laws/stat/rso-1990-c-c9/latest/rso-1990-c-c9.html>
- Government of Ontario (2009b). Homes for the Aged and Rest Homes Act. R.S.O. 1990, Chapter H.13. CanLII. Retrieved June 1, 2010, from: <http://www.canlii.org/en/on/laws/stat/rso-1990-c-h13/latest/rso-1990-c-h13.html>
- Government of Ontario (2009c). Nursing Homes Act. R.S.O. 1990, Chapter N.7. Services Ontario e-Laws. Retrieved June 1, 2010, from: http://www.e-laws.gov.on.ca/html/repaledstatutes/english/elaws_rep_statutes_90n07_e.htm
- Government of Ontario (2010). Bill 21, Retirement Homes Act, 2010. Legislative Assembly of Ontario website, www.ontla.on.ca. Retrieved June 1, 2010, from: http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&Intranet=&BillID=2298

- Graham, J. E. & Bassett, R. (2006). Reciprocal Relations: The Recognition and Co-Construction of Caring With Alzheimer's Disease. *Journal of Aging Studies*, 20, 335-349.
- Harrison, R., Savla, N., & Kafetz, K. (1990). Dementia, Depression and Physical-Disability in A London Borough - A Survey of Elderly People in and Out of Residential Care and Implications for Future-Developments. *Age and Ageing*, 19, 97-103.
- Hays, J. C., Landerman, L. R., George, L. K., Flint, E. P., Koenig, H. G., Land, K. C. et al. (1998). Social Correlates of the Dimensions of Depression in the Elderly. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences*, 53, 31-39.
- Hazan, C. & Shaver, P. (1987). Romantic Love Conceptualized As An Attachment Process. *Journal of Personality and Social Psychology*, 52, 511-524.
- Hellström, I., Nolan, M., & Lundh, U. (2007). Sustaining 'Couple Hood': Spouses' Strategies for Living Positively With Dementia. *Dementia*, 6, 383-409.
- Henneberger, M. (2008). An Affair to Remember. Slate. Retrieved August 4, 2010, from: <http://www.slate.com/id/2192178>
- Hughes, J. C. (2001). Views of the Person With Dementia. *Journal of Medical Ethics*, 27, 86-91.
- Hughes, J. C. & Baldwin, C. (2006). *Ethical Issues in Dementia Care Making Difficult Decisions*. London: Jessica Kingsley Publishers.
- Ingebretsen, R. & Solem, P. E. (2004). Attachment, Loss and Coping in Caring for a Dementing Spouse. In B. M. L. Miesen (Ed.), *Care-Giving in Dementia: Research and Applications* (pp. 191-20982). London: Tavistock/Routledge.
- Jetten, J., Haslam, C., Pugliese, C., Tonks, J., & Haslam, S. A. (2010). Declining Autobiographical Memory and the Loss of Identity: Effects on Well-Being. *Journal of Clinical and Experimental Neuropsychology*, 32, 408-416.
- Jones, G. M. M. & Miesen, B. M. L. (2006). *Care-Giving in Dementia: Research and Applications*. London: Routledge.
- Kahana, E. & Young, R. (1990). Clarifying the Caregiving Paradigm: Challenges for the Future. In D. E. Biegel & A. Blum (Eds.), *Ageing and Caregiving: Theory, Research and Policy* (pp. 76-97). Thousand Oaks, CA: Sage.
- Kales, H. C., Chen, P., Blow, F. C., Welsh, D. E., & Mellow, A. M. (2005). Rates of Clinical Depression Diagnosis, Functional Impairment, and Nursing Home Placement in Coexisting Dementia and Depression. *Am.J Geriatr.Psychiatry*, 13, 441-449.
- Kapp, M. B. (1996). Enhancing Autonomy and Choice in Selecting and Directing Long-Term Care Services. *Elder Law Journal*, 4, 55-97.
- Kitwood, T. M. (1997). *Dementia Reconsidered: the Person Comes First*. Buckingham England: Open University Press.
- Kovach, C. R. (1998). Nursing Home Dementia Care Units: Providing a Continuum of Care Rather Than Aging in Place. *Journal of Gerontological Nursing*, 24, 30-36.
- Kramer, B. J. (1997). Gain in the Caregiving Experience: Where Are We? What Next? *Gerontologist*, 37, 218-232.
- Kramer, B. J. & Lambert, J. D. (1999). Caregiving As a Life Course Transition Among Older Husbands: A Prospective Study. *Gerontologist*, 39, 658-667.
- Kutner, N. G., Brown, P. J., Stavisky, R. C., Clark, W. S., & Green, R. C. (2000). "Friendship" Interactions and Expression of Agitation Among Residents of a Dementia Care Unit - Six-Month Observational Data. *Research on Aging*, 22, 188-205.
- Lebovitz, R. H. (1979). Loss, Role Change and Values. *Clinical Social Work Journal*, 7, 285-295.
- Lichtenberg, P. A. (1997). Clinical Perspectives on Sexual Issues in Nursing Homes. *Topics in Geriatric Rehabilitation*, 12, 1-10.
- Lindemann, H. (2009). Holding One Another (Well, Wrongly, Clumsily) in A Time of Dementia. *Metaphilosophy*, 40, 416-424.
- Lindemann, H. (2007). Care in Families. In R. E. Ashcroft, A. Dawson, H. Draper, & J. R. McMillan (Eds.), *Principles of Health Care Ethics* (2nd ed ed., pp. 351-356). Chichester: John Wiley & Sons.
- MacDonald, B. (2001). The Application of Attachment Theory to Clinical Work With Older Adults. *Psychologists' Special Interest Group for the Elderly Newsletter*, 76, 21-26.
- Magai, C. & Passman, V. (1997). The Interpersonal Basis of Emotional Behaviour and Emotion Regulation in Adulthood. In M. P. Lawton & K. W. Schaie (Eds.), *Annual Review of Gerontology and Geriatrics* (pp. Vol.17, 104-137). New York: Springer.
- Martin, G. W. & Younger, D. (2000). Anti Oppressive Practice: a Route to the Empowerment of People With Dementia Through Communication and Choice. *J Psychiatr.Ment.Health Nurs.*, 7, 59-67.
- Mcdowell, I., Hill, G., Lindsay, J., Helliwell, B., Costa, L., Beattie, L. et al. (1994). Patterns of Caring for People With Dementia in Canada. *Canadian Journal on Aging-Revue Canadienne du Vieillessement*, 13, 470-487.
- McGill, R. (2008). No Nation but Adaptation "The Bear Came Over the Mountain," Away From Her, and What It Means to Be Faithful. *Canadian Literature*, 98-111.
- Miesen, B. (1992). Attachment Theory and Dementia. In G. M. M. Jones & B. M. L. Miesen (Eds.), *Care-Giving in Dementia: Research and Applications* (pp. Vol.1, 38-56). London: Tavistock/Routledge.
- Miesen, B. M. L. (2004). Awareness in Dementia Patients and Family Grieving: a Practical Perspective. In B. M. L. Miesen (Ed.), *Care-Giving in Dementia: Research and Applications* (pp. 67-82). London: Tavistock/Routledge.
- Miesen, B. M. L. (2006). Attachment in Dementia: Bound From Birth? In B. Miesen & G. M. M. Jones (Eds.), *Care-Giving in Dementia: Research and Applications*, Volume 4 (pp. 103-132). London: Brunner-Routledge.
- Ministry of Health and Long-Term Care (2006). Tab 09 Standards: Resident Care. Government of Ontario. Retrieved June 1, 2010, from: http://www.health.gov.on.ca/english/providers/pub/manuals/ltc_homes/ltc_09.pdf
- Moore, D. (2001). It's Like a Gold Medal and It's Mine--Dolls in Dementia Care. *Journal of Dementia Care*, Nov/Dec, 20-22.
- Munro, A. (1999). The Bear Came Over the Mountain. The New Yorker. Retrieved December 4, 2010, from: http://www.newyorker.com/archive/1999/12/27/1999_12_27_110_TNY_LIBRY_000019900?currentPage=all
- Nabalamba, A. & Patten, S. B. (2010). Prevalence of Mental Disorders in a Canadian Household Population With Dementia. *Can.J Neurol.Sci.*, 37, 186-194.
- Naue, U. & Kroll, T. (2009). 'The Demented Other': Identity and Difference in Dementia. *Nursing Philosophy*, 10, 26-33.
- Nay, R. (1992). Sexuality and Aged Women in Nursing Homes. In the Face of Overwhelming Evidence That Sexuality Is Essential to Health and Identity, Society Continues to Make the Aged Sexually Invisible. *Geriatr.Nurs.*, 13, 312-314.
- Nolan, M., Ryan, T., Enderby, P., & Reid, D. (2002). Towards a More Inclusive Vision of Dementia Care Practice and Research. *Dementia*, 1, 193-211.
- Norton, M. C., Piercy, K. W., Rabins, P. V., Green, R. C., Breitner, J. C., Ostbye, T. et al. (2009). Caregiver-Recipient Closeness and Symptom Progression in Alzheimer Disease. The Cache County Dementia Progression Study. *J.Gerontol.B Psychol.Sci.Soc.Sci.*, 64, 560-568.

- Ontario Human Rights Commission (2010). Time for Action: Advancing Human Rights for Older Ontarians. www.ohrc.on.ca. Retrieved June 3, 2010, from: http://www.ohrc.on.ca/en/resources/discussion_consultation/TimeForActionsENGL?page=TimeForActionsENGL-Health.html
- Ontario Ministry of Health and Long-Term Care (2006). Long-Term Care Homes Program Manual. Government of Ontario. Retrieved June 1, 2010, from: http://www.health.gov.on.ca/english/providers/pub/manuals/ltc_homes/ltc_homes_mn.html
- Oppenheimer, C. (2006). I Am, Thou Art: Personal Identity in Dementia. In S. R. Sabat, S. J. Louw, & J. C. Hughes (Eds.), *Dementia: Mind, Meaning, and the Person* (pp. 193-203). Oxford: Oxford University Press.
- Paun, O. (2003). Older Women Caring for Spouses With Alzheimer's Disease at Home: Making Sense of the Situation. *Health Care for Women International*, 24, 292-312.
- Peak, J. S. & Cheston, R. I. L. (2002). Using Simulated Presence Therapy With People With Dementia. *Aging & Mental Health*, 6, 77-81.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the Stress Process: an Overview of Concepts and Their Measures. *Gerontologist*, 30, 583-594.
- Perren, S., Schmid, R., Herrmann, S., & Wettstein, A. (2007). The Impact of Attachment on Dementia-Related Problem Behavior and Spousal Caregivers' Well-Being. *Attach.Hum.Dev.*, 9, 163-178.
- Pratt, R. & Wilkinson, H. (2003). The Psychosocial Model of Understanding the Experience of Receiving a Diagnosis of Dementia. *Dementia: The International Journal of Social Research and Practice*, 2, 181-199.
- Pratt, R., Clare, L., & Kirchner, V. (2006). 'It's Like a Revolving Door Syndrome': Professional Perspectives on Models of Access to Services for People With Early-Stage Dementia. *Aging Ment. Health*, 10, 55-62.
- Pritchard, E. (1999). Dementia. Part 2: Person-Centred Assessment. *Prof.Nurse*, 14, 655-660.
- Quinn, C., Clare, L., & Woods, B. (2009). The Impact of the Quality of Relationship on the Experiences and Wellbeing of Caregivers of People With Dementia: a Systematic Review. *Aging Ment. Health*, 13, 143-154.
- Quinn, C., Clare, L., & Woods, R. T. (2010). The Impact of Motivations and Meanings on the Wellbeing of Caregivers of People With Dementia: a Systematic Review. *Int.Psychogeriatr.*, 22, 43-55.
- Radden, J. & Fordyce, J. M. (2006). Into the Darkness: Losing Identity With Dementia. In S. R. Sabat, S. J. Louw, & J. C. Hughes (Eds.), *Dementia: Mind, Meaning, and the Person* (pp. 71-88). Oxford: Oxford University Press.
- Robinson, L., Clare, L., & Evans, K. (2005). Making Sense of Dementia and Adjusting to Loss: Psychological Reactions to a Diagnosis of Dementia in Couples. *Aging & Mental Health*, 9, 337-347.
- Rosenkoetter, M. M. (1996). Changing Life Patterns of the Resident in Long-Term Care and the Community-Residing Spouse. *Geriatr. Nurs.*, 17, 267-272.
- Siriopoulos, G., Brown, Y., & Wright, K. (1999). Caregivers of Wives Diagnosed With Alzheimer's Disease: Husbands' Perspectives. *American Journal of Alzheimer's Disease*, 14, 87.
- Skaff, M. M. & Pearlin, L. I. (1992). Caregiving: Role Engulfment and the Loss of Self. *Gerontologist*, 32, 656-664.
- Statistics Canada (2007). 2006 Census: Age and Sex. Statistics Canada, www.statcan.gc.ca. Retrieved June 1, 2010, from: <http://www.statcan.gc.ca/daily-quotidien/070717/dq070717a-eng.htm>
- Steadman, P. L., Tremont, G., & Davis, J. D. (2007). Premorbid Relationship Satisfaction and Caregiver Burden in Dementia Caregivers. *J.Geriatr.Psychiatry Neurol.*, 20, 115-119.
- Sternberg, S. A., Wolfson, C., & Baumgarten, M. (2000). Undetected Dementia in Community-Dwelling Older People: the Canadian Study of Health and Aging. *J Am.Geriatr.Soc.*, 48, 1430-1434.
- Strock, M. (1994). Alzheimer's Disease - Decade of the Brain. National Institutes of Health and National Institutes of Mental Health. from: <http://www.hoptechno.com/alzheim.htm>
- Surr, C. A. (2006). Preservation of Self in People With Dementia Living in Residential Care: a Socio-Biographical Approach. *Soc. Sci.Med.*, 62, 1720-1730.
- Taylor, C., Gutmann, A., & Taylor, C. (1994). *Multiculturalism: Examining the Politics of Recognition*. Princeton, NJ: Princeton University Press.
- Thomas, P., Ingrand, P., Lalloue, F., Hazif-Thomas, C., Billon, R., Vieban, F. et al. (2004). Reasons of Informal Caregivers for Institutionalizing Dementia Patients Previously Living at Home: the Pixel Study. *Int.J Geriatr.Psychiatry*, 19, 127-135.
- Urban Walker, M. (1997). Picking Up Pieces -- Lives, Stories, and Integrity. In D. T. Meyers (Ed.), *Feminists Rethink the Self* (pp. 62-84). Boulder: Westview Press.
- Vernooij-Dassen, M., Felling, A., & Persoon, J. (1997). Predictors of Change and Continuity in Home Care for Dementia Patients. *Int.J Geriatr.Psychiatry*, 12, 671-677.
- Volicer, L. (2001). Management of Severe Alzheimer's Disease and End-of-Life Issues. *Clinics in Geriatric Medicine*, 17, 377-+.
- Volicer, L. (2007). Caregiver Burden in Dementia Care: Prevalence and Health Effects. *Current Psychosis and Therapeutics Reports*, 3, 20-25.
- Whitlatch, C. J., Schur, D., Noelker, L. S., Ejaz, F. K., & Looman, W. J. (2001). The Stress Process of Family Caregiving in Institutional Settings. *Gerontologist*, 41, 462-473.
- Williamson, G. M. & Schulz, R. (1990). Relationship Orientation, Quality of Prior Relationship, and Distress Among Caregivers of Alzheimers Patients. *Psychology and Aging*, 5, 502-509.
- Woods, P. & Ashley, J. (1995). Simulated Presence Therapy - Using Selected Memories to Manage Problem Behaviors in Alzheimers-Disease Patients. *Geriatric Nursing*, 16, 9-14.
- Woods, R. T., Keady, J., Ross, H., & Wenger, C. (2008a). *Partners in Care: a Training Package for Involving Families in Dementia Care Homes*. London: Jessica Kingsley Publishers.
- Woods, R. T., Keady, J., & Seddon, D. (2008b). *Involving Families in Care Homes: a Relationship-Centred Approach to Dementia Care*. London: Jessica Kingsley.
- Yates, M. E., Tennstedt, S., & Chang, B. H. (1999). Contributors to and Mediators of Psychological Well-Being for Informal Caregivers. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences*, 54, 12-22.
- Zernike, K. (2007). Still Many-Splendored; Love in the Time of Dementia. The New York Times. Retrieved December 4, 2010, from: <http://query.nytimes.com/gst/fullpage.html?res=9D01E2D91030F93BA25752C1A9619C8B63>

Acknowledgements: Research funded by Canadian Institutes of Health Research, MOP 77670, Therapeutic Hopes and ethical concerns: Clinical research in the neurosciences and by Canadian Institutes of Health Research, NNF 80045, States of Mind: Emerging Issues in Neuroethics

Competing Interests: None.

Address for Correspondence:

Timothy Krahn, Research Associate
Novel Tech Ethics, Faculty of Medicine
Dalhousie University
1234 LeMarchant Street
Halifax, NS, Canada B3H 3P7

e-mail: tim.krahn@dal.ca

BOOK REVIEW

The Virtuous Psychiatrist: Character Ethics in Psychiatric Practice.

By: Jennifer Radden and John Z. Sadler
Oxford University Press, 2010

Three Reviews...Three Perspectives

Review I:

Reviewed by: Jeffrey Kirby, MD, MA(Phil)

Psychotherapist, Student Health Services ;

Associate Professor & Ethics Consultant, Department of Bioethics;

Dalhousie University, Halifax, Canada

In *The Virtuous Psychiatrist*, Jennifer Radden and John Sadler argue that “only virtue ethics will allow us to formulate an adequate ethics for psychiatric practice.” In their view, the cultivation and habituation of a set of “role-constituted virtues” that include compassion (with empathy as a precondition), personal warmth and trustworthiness are necessary for the psychiatric practitioner to be effective in her/his work. The authors believe that it is crucial for psychiatrists and psychiatry trainees to possess these virtues because of the particular ethical challenges that they face, including the need to balance the competing obligations that arise from their dual roles of: 1) providing confidential, beneficial care to vulnerable patients, and 2) acting, necessarily at times, as ‘an agent of the state’ in the involuntary commitment of patients who are judged to be a significant risk to themselves or others.

The Virtuous Psychiatrist is an interesting read. It does an excellent job in advancing the existing conversation and debate about such topics as: the fundamentally interpersonal nature of psychiatric practice and training, the social-cultural construction of mental illnesses and their diagnoses, the benefits and burdens of the consumer and biomedical models of psychiatry, and the affective/emotional components of virtues.

The authors introduce and/or constructively reframe a number of useful concepts. One of these is what they call the “unselfing attitude” of the ethical psychiatrist, i.e., “the personally effaced yet acutely attentive and affectively attuned attitude toward the patient, the [therapeutic] relationship and its boundaries.” For psychiatrists and trainees, the ‘making small’ of their personal/self-regard interests while being present for, and attentive to, the therapeutic interests and safety of their patients is a laudable goal

even though, as the ‘inner talk’ histories in chapter seven make clear, this is likely to be only partially achieved. This notion resonates nicely with other emerging conceptions of the therapeutic relationship which question the utility of the established ‘professional boundary’ metaphor. One of these encourages psychiatrists to meaningfully engage with their patients within a zone of helpfulness and safety while carefully avoiding the two ‘harm’ end-zones of under-engagement and over-engagement. Radden’s and Sadler’s book contributes to an acknowledgement and appreciation of the importance of the ‘right’ kind of healing interactions between psychiatrists and their patients.

The authors call attention to how important it is for the psychiatric practitioner to possess self knowledge about his/her own personality traits, attitudes and (inevitable) biases. This is particularly so because most psychiatry residents come from ‘privilege’ and have no direct experience of the significant disadvantage that is the grinding reality of many persons living with severe and persistent mental illness. In addition, many medical students and physicians have obsessive-compulsive personality traits which may, without the development of relevant insight, contribute to a certain rigidity of thought and preference for control. In addition to possessing the virtue of self knowledge, Radden and Sadler argue convincingly that psychiatry trainees should be encouraged to develop Aristotelian phronesis, i.e., an ability to discern through lived experience ‘what matters’ and ‘what needs to be done’ in the patient’s particular circumstances.

Despite its strengths, *The Virtuous Psychiatrist* disappointed me in a few respects. While the authors’ acknowledge that “virtue language is confusingly ambiguous”, their claims fall prey, at times,

to some ambiguity and lack of conceptual clarity. For example, they describe virtues as being comprised of sets of enduring dispositions and capabilities without providing a theoretical grounding for why the having of such virtues is any better than the possessing of these subcomponent dispositions and capacities to respond and act in certain 'good' ways.

In the final chapter, Radden and Sadler, conclude that role-constituted virtues should and can be taught to psychiatry trainees. Throughout the book, they provide comprehensive support for their claim that patients should/will benefit if their psychiatrist possesses such virtues. However, the verdict is still out as to whether these virtues can be taught. There is little evidence to support the assertion that virtues can be engendered in adult learners, whose dispositions and capacities to act in morally good and bad ways are primarily established during their childhood. With regard to the 'how to' of virtue cultivation and habituation, the book provides only the thinnest of descriptions of others' work in this topic area.

My strongest reservation about *The Virtuous Psychiatrist* relates to the authors' strident advocacy for the primacy of a virtue ethics framework for psychiatric training and practice. In my regular engagement with psychiatric residents as an ethics educator, there is a lot of stimulating talk and enlightening debate about motives, actions and consequences, and often an affirmation of the need for some rules, which is more the operational language of Kantian ethics and consequentialism than that of virtue theory. In addition, a variety of justice-based approaches, including distributive, formal and social-relational accounts, have much to offer the normative analysis of 'what *should* be' in psychiatric training and practice. As such, rather than focusing on what virtue ethics has to offer as the authors recommend, a richly pluralistic approach to psychiatric ethics and good psychiatric doctoring seems to be warranted, in my view.

Competing Interests: None.

Acknowledgements: None.

Address for Correspondence:

e-mail: Jeffrey.kirby@dal.ca

BOOK REVIEW

The Virtuous Psychiatrist: Character Ethics in Psychiatric Practice.

By: Jennifer Radden and John Z. Sadler
Oxford University Press, 2010

Three Reviews...Three Perspectives

Review II:

Reviewed by: Ari Zaretsky MD FRCPC

**Director, Postgraduate Education and Associate Professor Department of Psychiatry,
University of Toronto.**

**Head, Mood Disorders Clinic and Director, Medical Education, CAMH,
Toronto, Canada**

Many books on biomedical ethics in general and psychiatric ethics in particular focus on basic ethical principles: non-maleficence, autonomy and justice. In psychiatry there is also an extensive focus on rules related to maintaining boundaries, confidentiality and the duty to warn. *The Virtuous Psychiatrist: Character Ethics in Psychiatric Practice* written by both a philosopher and a clinician provides a fresh perspective on psychiatric bioethics by focusing on character rather than on principles or rules. The authors argue that the psychiatric care provided to patients with severe mental disorders is an emotionally exacting practice-it makes distinctive moral demands on the character of the professional psychiatric practitioner. Care for the severely mentally ill, the most vulnerable population within our society, calls for special character traits and greater virtue than other medical practice settings. The authors draw heavily on Aristotle's *Nicomachean Ethics*, which construes professional ethics in moral terms, and argue that virtues or character must be the cornerstone of psychiatric bioethics, from which rules and principles are ultimately derived.

Although many readers of books on psychiatric ethics expect pragmatic clinical applications informing them of what they should or should not do in a specific clinical case, this book offers guidance on what character traits should be cultivated and provides insights into the character of the "good psychiatrist". The authors share with Aristotle a belief that virtues can be deliberately cultivated, deepened and augmented through learning (habituation). The philosopher Hume noted that important virtues involving social and affective traits such as empathy can be inculcated and instilled through good parenting and moral education. This observation

has great relevance to psychiatric educators when we reflect on the informal or silent curriculum of residency training.

The first chapter provides a context for locating psychiatric ethics distinctly within professional and biomedical ethics and adopts a methodology employed by the APA's *Annotations With Particular Application to Psychiatry* (2001), in which special features of biomedical ethics are discussed in relation to the field of psychiatry. Chapter 2 and Chapter 3 provide a cogent argument for why psychiatry is different and unique from other medical specialties. Unique features of psychiatry include: patient vulnerability, pervasive stigma and attitudes towards psychiatric symptoms, ongoing controversies over mental disorders in our society, the advent of the consumer movement and recent mental health care cost-containment initiatives by government and private industry. The authors argue for the application of virtue ethics to psychiatric clinical practice and emphasize an ethical framework based on moral leadership.

Chapter 4 focuses on the complex role of gender in psychiatry as it impacts on ethical concerns and argue for a gender-sensitive psychiatric practice. The authors touch on a number of important issues: the association of male heterosexuality with mental health, the gender biases inherent in a number of diagnostic categories and negative attitudes towards homosexuality and transgendered identity. Chapter 5 describes in more depth some of the character traits required by the psychiatrist in order to not only to possess virtue but also to convey this virtue to the public: trustworthiness, moral integrity, propriety, gender-sensitivity, moral leadership, fortitude, empathy, patience, self-knowledge and authenticity. In

the next chapter, the authors explore the ways in which adopting a virtue-based ethics framework can also pose specific challenges. Examples include the tension between the psychiatrist as healer and the psychiatrist who is expected to uphold criminal justice. Chapter 7 integrates the concepts discussed in previous chapters and tries to illustrate these concepts through the analysis of a number of vignettes related to real clinical practice and psychiatric supervision. The authors could have greatly enhanced the quality of this chapter by choosing more interesting clinical vignettes and making the dialogue more realistic. Dialogue from complex and ecologically valid vignettes in which a psychiatrist is successfully able to maintain boundaries with a sexually seductive patient, refuse a gift without hurting the feelings of a disadvantaged patient, sensitively refuses to commit fraud on behalf of poor patient who seeks to manipulate their insurance company would have been highly appreciated by the reader. A Vignettes that illustrate how a psychiatrist trainee addresses his or her own feelings when treating a patient that they genuinely dislike or that illustrates the emotional conflict experienced when behaving without full integrity or authenticity in one's private life would also be very powerful.

Overall, this is an excellent book and it is highly recommended to anyone interested in psychiatric bioethics including philosophers and clinicians but especially psychiatric educators. The book makes a compelling argument that by creating an ethics based on virtue rather than rules, psychiatric educators can and must inculcate these emotional and moral responses in the character of their own trainees.

References:

1. Aristotle. 1985. *Nicomachean ethics*, translated by T. Irwin. Indianapolis: Hackett.
2. American Psychiatric Association (APA). 2001. *The principles of medical ethics: With annotations especially applicable to psychiatry*. Washington, DC: American Psychiatric Association.

Competing Interests: None.

Acknowledgements: None.

Address for Correspondence:

e-mail: ari_zaretsky@camh.net

BOOK REVIEW

The Virtuous Psychiatrist: Character Ethics in Psychiatric Practice.

By: Jennifer Radden and John Z. Sadler
Oxford University Press, 2010

Three Reviews...Three Perspectives

Review III:

Reviewed by: Sam Izenberg MD FRCPC

Assistant Professor, Department of Psychiatry, University of Toronto.

Chair of the Ethics Committee of the Toronto Institute/Society for Contemporary Psychoanalysis, Toronto, Canada

This book seeks to reposition psychiatric ethics in terms of virtues as opposed to rules. While not rejecting the need for rules, the authors argue that this common deontological approach is too limited to be of use as the basis of psychiatric ethics. Their argument is that psychiatric practice is distinctive enough so as to warrant special “ethical” attention, beyond that of professions in general and that this uniqueness is best addressed by looking at the virtues required to address it. While the definition of virtues remains somewhat unclear, virtues seem to be understood as “moral qualities” (p. 200) so the discussion is really about the character of the psychiatrist, one of “moral psychology”. The goal is “to go beyond platitudes about virtue and... (show)...why the particular “practice setting” of psychiatry requires particular attributes in psychiatrists”.

I read this book both as a Canadian community psychiatrist (protected from the strictures of “managed care”) practicing psychotherapy and psychoanalysis and also as an educator, responsible for the didactic and clinical training of psychiatric residents in psychotherapy.

The authors first provide a helpful systematic way to consider virtues detailing the concept of “role constituted virtues” which in the psychiatric setting must address such unique challenges as the power to seclude and treat and the fact that psychiatric patients are more vulnerable to exploitation because of the very nature of psychiatric illnesses (one could add the regressive pull of psychotherapeutic treatment as another factor). They argue that a consideration of virtues is especially suited to thinking about how to deal with such ambiguities and complexities. Despite the fact that some of their discussions seem at times to wander into

a kind of abstraction, the authors importantly tease out subtle strands and elements of the unique features of psychiatry and the qualities (warmth and empathy for example) that are required. One that is particularly pertinent to the practice of psychotherapy which is delicately and accurately captured here is that quality which the authors call “unselfing”. Indeed I believe that this, often neglected virtue, is the essential core of psychotherapeutic practice, and the most important and difficult task and skill of the psychotherapist, and one which bears great emphasis in the teaching of psychotherapy.

From the point of view of relevance to practice, this book’s greatest applicability comes in its applicability for teachers of psychiatry. It can be a tempting conceit for a reviewer or perhaps any reader to suggest that a slightly different book had been written. This is unreasonable. But for me the most interesting aspect of the book is the section that relates to teaching/training students and the way that supervisors and teachers may use the notions of these virtues to inculcate and reinforce such virtues. The section on “habituation” and the final concluding chapter on the complications of teaching virtues, (which together comprise only ten pages) were among the most interesting sections and I wish they had been expanded. “Habituation” is partially achieved by the student’s immersion in clinical process. The supervisor having these moral qualities in mind, will inevitably enunciate and reinforce them in his interactions with the student, raising the quotidian preoccupations of the work to another level. Perhaps we may hope for some future elaboration from the authors in relation to teaching virtues.

I also have some questions about the central argument of the book. I think that neither rules nor virtues are the most useful

ways to think about ethics in psychiatry. As soon as one starts to contextualize, to talk about specific situations one is immediately forced to accept the limitations of rules in the face of ambiguities, and conflicting principles and values. This is no less true of virtues. Of course one must possess virtues such as fortitude, hopeful patience, perseverance and integrity, if one is to maturely navigate these situations, but one does not start from these virtues since they too (like rules) fail to answer the 64 dollar question: "what do I do?" It seems to me, moreover, that warmth is not a psychiatric virtue. Applied warmth, however, is. Overt expression of warmth with a suspicious person may be contraindicated. Basically I do not think that a virtue is "cultivated" as such, but rather its achievement flows from the cultivation of adherence to certain clinical principles (e.g. an understanding of how to listen and facilitate).

I believe that this book is a very valuable contribution to the literature on psychiatric ethics. It compellingly outlines the unique demands and challenges of the psychiatric setting, and it describes the qualities which are needed to manage those demands in the best interests of our patients. It further stimulates thinking about such vital matters and points the way to an important aspect of the development of young psychiatrists which teachers would do very well to keep in the forefront of their thinking.

Competing Interests: None.

Acknowledgements: None.

Address for Correspondence:

e-mail: sam.izenberg@utoronto.ca

BOOK REVIEW

Relational Ethics in Practice: Narratives from Counselling and Psychotherapy

Edited by Lynne Gabriel and Roger Casemore

Routledge, 2009

Reviewed by: Derek Truscott PhD

Associate Professor, Department of Educational Psychology,

University of Alberta, Edmonton, Canada

Anyone who has ever practiced psychotherapy knows that doing the right thing is rarely simple. Professional ethics are often perceived by the non-practitioner as a set of rules dealing with what to do and what not to do in certain situations. Knowledge of these rules is thought to be sufficient to prevent us from going astray. The practitioner knows, however, that every therapeutic encounter is at once both common and unique. At one level there are commonalities of problems that clients bring to us such that rules can be helpful guides. Yet at another level the circumstances of our clients' distress are always unique, often to the extent that rules are of limited help.

After all, taking a strictly rule-based approach to being ethical would require the consideration of so many different combinations of variables that the number of rules would be almost infinite. Given that each professional circumstance—even if described by only a few possible attributes—is effectively unique, we are left to apply our professional judgment to adapting the rules within the ever-shifting context of practice. Being ethical while acknowledging, and actually honouring, the social context of our actions is the focus of relational ethics.

The editors of *Relational Ethics in Practice: Narratives from Counselling and Psychotherapy* are to be commended for attempting to contribute to this important and difficult undertaking. Unfortunately, I think they fall short of their goal. The problem begins as they define relational ethics as

a co-constructed ethical and moral encounter, with associated relationship experiences and processes, that both influences and in turn is influenced by the complex multidimensional context in which the relationship occurs. (p. 1)

I suspect that the contributors were as confused as I was by this definition because only one chapter—Subodh Dave's excellent "Relational ethics in psychiatric settings"—presents a coherent relational narrative or refers to the foundational literature in the field (e.g., Bergum & Dossetor, 2005). This is a shame—the richness of the various narratives is excellent and could serve to sensitize professionals to how the nuances of relationships influence the

ethics of mental health practice. Chapters cover such contexts as teaching, supervision, research, training, therapy with people suffering the effects of trauma, therapist self-care, and practicing in small communities. A consideration of the role of the relational aspects of these contexts could be very helpful to practitioners in their efforts to be ethical. Instead, *Relational Ethics in Practice* might be more accurately entitled *Ethics of Practice Relationships*, given that most of the chapters focus on challenging aspects of various professional relationships—such as dual roles—while looking to deontological principles for guidance.

Founded in the feminist thought of Carol Gilligan (1982) and Nel Noddings (1984), relational ethics is explicitly positioned as an alternative to deontology. Drawing on the analogy of the mothering bond to highlight that relationships are fundamental to the human condition, it is based on the observation that ethical actions always take place in relationship with others. Further, relational ethics considers behaving ethically to require us to act out of concern for and consideration of others. Ethical knowledge, reasoning and action are understood as being imbedded within a never completely predictable relational context. Being ethical is thus not a private exercise of dispassionate logical analysis—it is action in real relationship with real consequences. What is considered ethical is thereby also open to reconsideration as the context of our actions shifts in response to new events and changing relationships. Relational ethics is therefore concerned with how we ought to treat each other in particular circumstances and how certain circumstances facilitate or impede our efforts to do so.

In fairness, this is an edited book and thereby cannot be expected to avoid the limits to establishing a consistent theme or voice inherent in the form. Edited books are best suited for presenting varied perspectives and considerations in order to expand our understanding of a topic. Given that it is still a relatively new field, relational ethics in practice is, I believe, a topic appropriate to an edited book. The diffusion of content and lack of scholarly coherence in *Relational Ethics in Practice* will likely render the average practitioner bewildered rather than enlightened, however. As such, I would not recommend this book unless the reader is

already familiar with relational ethics. I fear the knowledgeable reader will be disappointed by its lack of grounding in the established scholarship, however.

References:

- Bergum, V., & Dossetor, J. (2005). *Relational ethics: The full meaning of respect*. Hagerstown, MD: University Publishing Group.
- Gilligan, C. (1982) *In a different voice: Psychological theory and women's development*. Cambridge, MA: Harvard University Press.
- Noddings, N. (1984). *Caring: A feminine approach to ethics and moral education*. Berkeley, CA: University of California Press.

Competing Interests: *Author of my own book on ethics.*

Acknowledgements: *None.*

Address for Correspondence:

e-mail: *derek.truscott@ualberta.ca*

BOOK REVIEW

Movies and Mental Illness: Using Films to Understand Psychopathology, 3rd ed.

Authors: Danny Wedding, Mary Ann Boyd, Ryan M. Niemiec

Publisher: Hogrefe, 2010

Reviewed by: Frederick W. Engstrom MD

Medical Director, Brattleboro Retreat

Brattleboro, Vermont, USA

The third edition of *Movies and Mental Illness: Using Films to Understand Psychopathology* is a treat; as the authors note in their preface, this edition is a distinct improvement over their previous editions. Their appendixes are expanded; one gives a sample of a possible course curriculum, another is an extensive list of films relevant to several topics, another lists top villains and heroes, another lists misconceptions perpetuated by movies, and another categorizes portrayals of psychotherapists as either balanced or unbalanced. The index, also new, is a spectacular addition, as it greatly aids in finding how certain films are useful (but it categorizes films but not other material in the book). The appendixes alone are worth poring over, as several of them stimulate memories and “aha” moments. Furthermore, their decision to indicate the ten films per chapter that are the “Authors’ picks” is fortuitous, and forces them to make some hard choices and recommendations. Their inclusion of some foreign language films is welcome (and I share their fondness for *Elling*). Yet American audiences are fickle: some refuse to watch films with subtitles, and see only bad American versions of excellent foreign films, such as *Fever Pitch* (British) and *Shall We Dance* (Japanese).

The strength of the book is its comprehensiveness, and while the authors promise to continue their blog, I hope that they will also put out future editions of the book. They include several films for each diagnostic category, and offers “question to consider” for the viewer. For example, in the chapter on schizophrenia, the question is posed, “Is there any relationship between John Nash’s mathematical genius (in *A Beautiful Mind*) and the course of his illness?” Later in each chapter are Critical Thinking Questions, such as “Do familial and parent roles contribute to development of mental illness in a child?”

Chapters two through thirteen each cover a diagnostic arena, ranging from anxiety disorders to substance use disorders to adjustment disorders. These chapters are followed by chapters on violence and abuse, and treatment.

As someone who uses films to teach, I wish the authors had been more explicit in how to use the material. The preface rightly notes

that “the diagnoses we present reflect hypotheses, not facts; the case studies are to generate ideas, enliven discussion and stimulate learning.” How do we help students make the bridge between film characterizations that are “hypotheses” and diagnostic categories that are more rigid? The book does not make this clear, and I would love to hear how the authors use the material in their classes. I approach the issue in the following manner. I set the stage by stating that screenwriters are acute observers of the human condition and have amazing insights; but they are not necessarily interested in strictly mental disorders (one film producer called that approach the discredited “disease of the week” phenomenon on television). Thus when we see a film, we are seeing reality as perceived by people who are not mental health professionals, and art that is enhanced by many factors other than screenplay: acting, editing, photographing, sound, etc. Before showing the film clip (I use clips rather than entire movies), I introduce the subject matter, tell the audience the summary of the entire film, tell them a bit about the clip, and usually tell them what to look for (e.g., which of the nine symptoms of major depressive disorder do you see and which don’t you see). Then once we have seen the film or film clip, in what ways does the character seem to fit the diagnostic criteria that we are examining today, and what way does she not? Furthermore, if you were evaluating this person professionally, what questions would you ask her to further elucidate the diagnosis or situation, would you interview family members, and so forth? If we were looking at paradigms of psychopathology, we might also consider how the biologic, psychological, cognitive, cultural and other factors interact to influence the characters.

I believe that the authors’ “additional questions” are fairly elementary. For example, the questions posed for *Scent of a Woman* concern Colonel Slade’s decision to commit suicide, and the possible roles of alcohol, blindness, military background, depression, and involuntary treatment in the mixture. More interesting questions, to me, include, “What character traits in Charlie Simms appeal to Colonel Slade?, What is it in their relationship that averts the suicide?, and, How does one modify therapeutic techniques to work with people with narcissistic traits?”

The authors do not live up to the good intentions implied in their first chapter (Films and Psychopathology), which describes “cinematic elements” such as sound, editing, pacing, art and others, and how they make up the film. The remainder of the book largely ignores these cinematic elements, and instead focuses almost entirely on the manifest story line and dialogue. A film producer, Andy Meyer, showed me how this could be effectively integrated when we discussed a scene from *Smoke*. In that scene, Augie Wren (played by Harvey Keitel) helps Paul Benjamin (played by William Hurt) grieve his deceased wife. In an excellent portrayal of grief work, they sit together and look at a photograph of his wife; Paul weeps; Augie puts his arm on Paul’s shoulder and says little, but allows Paul to cry without interruption or apology, and is present for him. Andy Meyer pointed out that the simple piano score (an Eric Satie piece) kept the mood serious yet undistracted, the washed out colors in the scene helped us focus on the two men talking and sitting together, and the beer bottles framed the scene to further highlight the process of two people engaged with one another without distractions. These cinematic elements both enlightened and informed a perfectly depicted grief process.

Organizing a book such as this one is tricky, as several films depict more than one psychological issue. What might be seen through one lens as violence, through another might be seen as abuse or personality disorder. In addition, films add flavor to our understanding of many aspects of human development, not just mental illness, and the authors grapple with this situation by including sections on violence, mental retardation, and physical and sexual abuse.

While the authors wisely defer to general textbooks on issues relating to pedagogical descriptions of disorders and their differential diagnoses, nonetheless this volume shows how films can make marvelous contributions to the field. Their section on differentiating between antisocial personality from psychopathy is masterfully done, and the films in that section are well chosen.

The authors note “most professors choose to use class time to show selected vignettes from pedagogically powerful films ... augment lectures ... while minimizing the total amount of class time spent watching films ...” This statement presents the challenge to the authors for their next edition: selecting vignettes rather than entire films. As a disclaimer, I wrote such a book (with 42 film vignettes, with instructions how to locate and use them) and the task is not easy. However, DVD’s are much easier to navigate than videocassettes, and it is possible to select scenes or chapters from DVD’s, and then discuss in detail what is seen in that scene. My difficulty with showing entire films rests on the limitations: clips but not films can be used in a one or two hour lecture; films demand a lot from the audience (e.g., sitting through a film that it would rather not see); the reaction of many moviegoers either to the film as a whole (“I liked it”) or the ending (“bad ending”); the difficulty focusing on just one character in an entire movie; the tendency to watch for plot and not character; the need to watch a film more than once to pick up subtleties, and so forth. I hope the authors take up the challenge of selecting some key scenes to enrich their next edition of the book.

I have difficulty with a few of the chosen films. While I believe it is essential to include an incredible variety of films in a book such as this one, I still have difficulty with the inclusion of some films in

which violence is just too much, too random, or too cruel. Thus, even the mention of *Gangs of New York*, *No Country for Old Men*, *Cape Fear*, *Blue Velvet*, *Matrix Reloaded* (at least the others have artistic value), *Kill Bill Volumes One and Two*, *Godfather*, *Fight Club*, and *Natural Born Killers* is disturbing. I work with many survivors of trauma, and these and similar (and less violent) films trigger flashbacks and nightmares. It may be useful to indicate which films are likely to be too violent to be handled by certain audiences.

Overall, this is a book that I am glad to own, and that I will turn to again and again for ideas. Unfortunately, I think we have a long way to go before we get a good compendium of film **scenes**, and before we get a satisfying integration of cinematic and psychological renderings of this material.

Competing Interests: None.

Acknowledgements: None.

Address for Correspondence:

Frederick W. Engstrom MD
 Medical Director
 Brattleboro Retreat
 1 Anna Marsh Lane
 P.O. Box 803
 Brattleboro, Vermont, USA 05302

e-mail: fengstrom@brattlebororetreat.org

BOOK REVIEW

Advanced Ethics for Addiction Professionals

Author: MJ Taleff

Publisher: Springer Publishing Company, 2009

Reviewed by: Daniel Yalisove PhD

Associate Professor, John Jay College of Criminal Justice

The City University of New York, New York, USA

The treatment of substance use disorders is a large undertaking in the United States with thousands of treatment facilities throughout the country. Most of the treatment is provided by substance abuse counselors. This relatively new profession has only modest education requirements, which often include as little as 6 hours of ethics training (Yalisove, 2006). Bissel and Royce's (1987) *Ethics for addiction professionals* written over 20 years ago has been the only available book resource for this topic. Thus, I was quite interested to review Taleff's new book *Advanced ethics for addiction professionals*.

The book is intended to help substance abuse counselors think clearly about ethical considerations that arise in clinical practice and use critical thinking solve ethical problems and dilemmas. Rather than using the traditional format of professional ethics texts, Taleff focusses most of the book on moral decisions, actions, and arguments rather than describing and explaining professional ethics.

Taleff's book comprises 14 chapters divided into two parts. In part 1, he begins by discussing ethical decisions and arguments and introduces a number of non-standard ethical terms (i.e. judging). In the following two chapters he discusses elements in making an ethical decision and how emotion can be helpful in making ethical decisions as well as cloud judgment. In the second part, he reviews a large number of ethical theories including utilitarianism, deontology and social contract theory; he discusses how common thinking practices can interfere with good ethical decision making. In Chapter 9 he summarizes critical thinking principles. Ethical fallacies are discussed in the next chapter. In chapter 11, he introduces the "addiction ethics judgment kit." In Chapter 12, He sets forth an idiosyncratic list of professional ethics principles (He lists 10 while most professional ethics texts list 5). In chapter 13, he discusses common ethical violations made by substance abuse counselors. In the last chapter, he discusses caveats in ethical thinking.

A large part of the book focuses on the many difficulties that are encountered in making an ethical decision (Four full chapters

as well as many sections of others). The two chapters on ethical theories discuss moral behavior rather than professional ethics. A large number of examples are about moral problems in general rather than professional ethical problems and dilemmas. As a consequence insufficient attention is paid to professional ethics and the important content areas including providing a rationale for professional ethics, reviewing the Association of Addiction Professionals (NAADAC) Code of Ethics, reviewing of relevant laws, regulations, and other legal considerations (i.e., reporting requirements when child abuse is suspected), informed consent, confidentiality both from an ethical standpoint and legal statutes, competence and scope of practice, dual relationships, how to deal with ethical misconduct, ethical components of multicultural counseling, and special issues for substance abuse counseling and ethics including client or counselor impairment, harm reduction as a treatment goal, and coerced treatment and the principle of autonomy. While most of these topics are touched upon, they are not carefully presented in an organized manner.

Additionally, stylistic problems plague the book. The style of writing is informal, chatty, and imprecise. For example, Taleff uses the too colloquial and not respectful expression "Bullshit detection kit for educational material" (p. 116). Concepts are often not explained clearly. Discussions and rationales are often incomplete and casual. For example, Taleff states "To be careless about record keeping is unprofessional and way to close for comfort." (p. 172) Though one of the main goals of the book is to help the counselor use critical thinking to make moral decisions, Taleff often uses casual, incomplete, and often trivial arguments to support a position. For example, he states that counselors should keep abreast of new, effective treatments (part of the the dimension of competence, which he does not mention) by arguing that by not doing so is risks doing harm; "...in addiction treatment to risk harm is unethical. Therefore, not staying current with clinical practices in addiction treatment settings is unethical." (p. 171). First, the ethical principle that should be invoked in beneficence not malffeasance. Secondly, his argument supporting the statement is trivial. Finally Taleff fails to mention that the clinician has the obligation not only to be aware of better treatments, but to learn

them and become proficient in using them.

When I have taught ethics courses for substance abuse counseling students, I have used a standard counseling professional ethics book (Welfel, 2006) and added material germane to substance abuse counseling (Yalisove, 2006). I had hoped that Taleff's book would have fully discussed these topics with consideration given to special issues for substance abuse counseling and thus provide addiction studies educators with a stand-alone text. Regrettably, this is not the case. Nor do I believe that book will help substance abuse counselors solve the many thorny ethical problems that arise in their professional work.

References:

- Bissel, L. & Royce, J.E. (1987). *Ethics for addiction professionals*. Hazelden Foundation.
- Welfel, E.R. (2006) *Ethics in counseling and psychotherapy: Standards, research, and emerging issues*. 3rd edition. Thomson, Brooks/Cole.
- Yalisove, D.L. (2006). From the ivory tower to the trenches: Teaching professional ethics to substance abuse counselors. In *Ethical challenges for intervening in drug use: Policy, research, and treatment issues*. J. Kleinig and S. Einstein (Eds). Huntsville, TX: Office of International Criminal Justice.

Acknowledgements: None.

Competing Interests: None.

Address for correspondence:

e-mail: dyalisove@jjay.cuny.edu