

Volume 23, Number 2, December 2015

Editor's Forum

Paul Byrne, MB, ChB, FRCPC, FAAP

Interim Director and Clinical Professor, John Dossetor Health Ethics Centre, University of Alberta; Medical Director, Neonatal Intensive Care Unit, Grey Nuns Community Hospital and Staff Neonatologist, Stollery Children's Hospital

The 2014 annual John Dossetor Health Ethics Centre (JDHEC) Health Ethics Symposium, Challenges in Mental Health Ethics (https://events.gobigevent. com/events-web-public/event/start/649;jsessio nid=OamKimAgtkbx6MQ5c4+inVSl?0) brought together speakers with experience and expertise in mental health ranging from professional to personal perspectives. The symposium was very successful with 88 participants. There was lively discussion of each presentation between speakers and audience. This edition of Health Ethics Today contains papers from four of the nine speakers, based on their presentations at the symposium. While the papers cannot capture the excellent discussions and interaction between symposium participants, they do illustrate serious ethical issues within mental health care. A recent Globe and Mail (2015) story on the mental health problems and suicide among Canadian armed forces veterans echoes many of the issues raised at the symposium.

The paper by Wendy Austin contains a harrowing description of the dark history of mental health care from public and professional perspectives. The paper includes shocking examples of a lack of compassion in the care of the mentally ill at the institutional level. Both the medical and legal professions contain many examples of a lack of genuine understanding and care for the mentally ill as persons until relatively recently. Austin presents frightening examples of 20th century academic leaders in psychiatry in Canada and the USA, whose breakthrough work involved treating patients with unproven and dangerous experimental methods. These practices stemmed from the

continued on page 2

nı	ıed	OΠ	nage	2	

3

8

12

14

In This Issue				
Overcoming the Legacy of Bedlam, Lobotomies, and Nurse Ratched: Contemporary Relational Challenges in Mental Health Care – Wendy Austin				
Ethical Decision-Making in Addiction Care: Is there a place for Alcoholics Anonymous? – Charl Els and Pierre Chue				
Alberta Mental Health Act: How Legislation Aligns with Respect and Ethics Carol M. Robertson Baker				
Acceptance Equals Compliance: Our Lived Experience				

with a Husband Who has Schizophrenia

- Austin Mardon

prevalent notion that the mentally ill were not deserving of the same ethical requirement of respect for persons as other individuals receive. There was also a lack of respect for the legal rights conferring protection against such medical abuses.

Austin's relational ethics research has shown how mental health professionals currently experience moral distress due to persisting institutional constraints on their clinical practice, including inadequate funding, poor infrastructure, and lack of community supports. Austin presents a challenge to the health and legal professions, to government and funding agencies, to ensure that our standard of mental health care is in keeping with the World Health Organization slogan "there is no health without mental health". Austin also challenges media to avoid common stereotypes portraying the mentally ill and mental health professionals in a distorted and stigmatized manner that promote negative attitudes towards mental health.

The presentation by Charl Els was provocative as it questioned Alcoholics Anonymous (AA) as the "standard of care" for alcohol addiction. As with other conditions where there is great variation in the natural course of illness including spontaneous recovery, effective treatment requires very high standards of evidence. Alcohol addiction appears to be a classic example. Els criticizes about a "one size fits all" approach of automatic referral to AA for alcohol addiction in the absence of convincing evidence of efficacy. This practice is also enshrined in legal practice in many jurisdictions as a pre-requisite for plea bargaining, parole, and sentencing specifics. Els argues that there is a serious ethical problem underlying this default referral to AA because of interference with other potentially effective treatment modalities, and because of the high likelihood of hopes of cure being undermined by the very low reported cure rates. Els accepts the possibility of potential broad social and personal benefits from the AA approach but argues that the above risks outweigh these benefits. The concerns raised by Els go beyond alcohol addiction. The chance of recovery of an individual from a variety of addictions requires

a comprehensive approach beyond any one therapy (Whitley, et al., 2015).

In sharp contrast to the presentation by Els, Carol Robertson Baker presented us with a clear answer to many problems experienced by individuals who find themselves detained under a formal certificate of the Alberta Mental Health Act R.S.A. 2000, cM-13. In her role as the Mental Health Patient Advocate (MHPA) she assists patients and health professionals in understanding their mutual rights under the legislation. The MHPA works to ensure that formally detained patients understand their rights, their ability to appeal, and that the process is consistent with basic ethical principles governing patient - professional relationships across the health care spectrum. The MHPA staff also investigates complaints relating to the detention, treatment decisions, and care. The MHPA's focus is on making sure that care is directed towards recovery, is patient centered, and recognizes the varying decision-making capacity of each individual detained. This requires extra vigilance to educate health care providers about the importance of protecting the rights of very vulnerable individuals detained against their will. The fact that MHPA is celebrating 25 years of service in Alberta is somewhat reassuring that we have at least one sound legal mechanism to protect those with severe mental illness against the abuses described by Austin.

The paper by Austin Mardon does not do justice to his presentation during which his sense of humour bubbled through the serious subject of living with the diagnosis of schizophrenia. Mardon's message, from his unique perspective, is truly one of hope and is educational for health care professionals, for individuals with serious mental health problems, for the families and friends of those so affected, and for society at large. His acceptance of his illness and the need for life – long medication underlies his missionary zeal in advocating for those with serious mental illness. His wonderfully articulate descriptions of the experiences of interactions with the public and with health care professionals that involve fear, stigma, and lack of respect are cause for all of us to question our behaviour. Mardon understands the

ethical conundrum of those with serious mental illness wanting to stop treatment when they feel well and subsequently losing their decision-making capacity when their illness returns. This ethical dilemma has been solved for himself because he has loved ones on whom he openly depends for many things including regular "depot medication". His personal solution is in keeping with the need for a mental health vision and priorities that value recovery of a functional life even with persistent symptoms, for those with serious mental health problems (Whitley, et al., 2015).

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Editor's Correction re: Health Ethics Today Volume 23(1) May 2015 Editor's Forum

In the May 2015 editorial of *Health Ethics Today (HET)* the following sentence incorrectly suggested that Gary Frank's paper supported an anti - speciesist perspective. "His views are in marked contrast to the widespread view that the moral standing of humans differs fundamentally from animals ". In fact this HET editorial statement referred to one of Ari Joffe's arguments against the moral justification of animal based research.

Overcoming the Legacy of Bedlam, Lobotomies, and Nurse Ratched: Contemporary Relational Challenges in Mental Health Care

Wendy Austin, RN, PhD

Professor Emeritus, John Dossetor Health Ethics Centre and Faculty of Nursing, University of Alberta

Anything we do that diminishes our clients'... humanity is unethical.

(Elkins, Why I Left Psychology (Almost))

Relationships are central to ethical mental health care but the trust necessary for them can be preempted by psychiatry's past. In my 2014 John Dossetor Health Ethics Centre symposium presentation I argued that psychiatry's dark legacy must be addressed if the promise of Canada's mental health strategy is to be realized. As a psychiatric and mental health nurse, I have lived the challenges of enacting safe, compassionate, ethical care in this specialty, "the orphan child of health care "1.

In relational ethics research, mental health clinicians described ongoing systemic barriers to adequate

¹ Commission on the Future of Health Care in Canada. (2002, November). Building on values: The future of health care in Canada-Final report. Author, p.xxxiii.

care. A study of moral distress² pointed to the way societal perspectives and pressures shaped psychiatric care. Psychiatrists' moral distress was often the result of societal demands that they use their role to control deviancy from the norm (including medical noncompliance) and to medicalize profound human experiences, like grief and loss. Nurses' moral distress centred on lack of care resources, particularly time to be with patients. Psychologists' moral distress was shaped by institutional issues and inter-institutional conflicts that constrained their practice, while social workers spent too much time bartering/bargaining with the system in efforts to make it work. A psychiatric aide described the assembly-line nature of care for psychogeriatric patients that left her anxious for their dignity. Every discipline had to deal with the discrimination that surrounds mental illness, not only in society, but within health care. Our research participants' experiences showed how healing is thwarted, leaving clinicians feeling untrustworthy and patients and families, abandoned. In my presentation I explored three high risk areas in which the present retains shadows of the past. I labelled them as Bedlam, Lobotomies, and Nurse Ratched. A synopsis is provided here.

Bedlam: The Institutional Response to Mental Illness

The history of psychiatry begins with the asylum. Initially, asylum's meaning of sanctuary was realized (e.g., in Cairo in 872 CE) but soon became perverted to overcrowded, poorly resourced places for the unwanted as well as the sick (Hunter & Macalpine, 1963). Asylums often arose in places once used for quarantining those with contagious diseases like leprosy; Canada's first asylum opened in New

Brunswick in 1835 in an old cholera hospital (Boschma & Groening, 2014). Admission to an asylum was a danger to one's social health. In 1840 a psychiatrist wrote that families "dread committing a beloved relative to a lunatic asylum" as to pronounce an individual insane is equal to separating him from every friend and abandonment of all care of him to strangers (cited in Hunter & Macalpine, p.806). Years later, Erving Goffman (1963) noted that hospitalization could be as detrimental as mental illness itself because social identity could be lost. To this day, a psychiatric diagnosis is socially potent due to stigma and fear of mental illness.

So despite good intentions for shelter, care, and recovery, asylums became intolerable places for the ill and the deviant (or defiant) where little treatment occurred. The pressure on psychiatry to deal with disrupting or dangerous behaviour continues today. Recently, in Medicine, Health Care and Philosophy, Jodi Halpern (2014) described an episode on an oncology unit. A young man became angry with nurses about to sedate his dying mother, saying he would shoot them if they tried. An emergency psychiatric consult was called as the staff wanted the son committed to psychiatric care and removed. The consultant focused instead on the son's motivation - plus the fact that he was without a gun or any weapon. It was learned that the he had left his ill mother to attend college: he was overcome with guilt and desperate to speak with her. Resolution of this incident came through empathy, not the mental health act.

A disturbing contemporary trend is the construction of mental disorders by legislators as a way to deal with nonmedical deviance. Recent legislation of the Scottish Parliament, for instance, was emergency mental health legislation to deal with high risk individuals, making possible their lifelong restriction within the health system if deemed as an ongoing public risk (Darjee & Crichton, 2002). In England, the "dangerous and severe personality disorder" (DSPD) was created by legislators despite opposition from the Royal Society of Psychiatrists who argued that there was little evidence for it, accurate identification

This was a SSHRC-funded phenomenological study of the moral distress of mental health practitioners. See: Austin, W., Kagan, L., Rankel, M., & Bergum, V. (2008). The balancing act: Psychiatrists' experience of moral distress. *Medicine, Health Care and Philosophy,* 11, 89-97; Austin, W., Rankel, M., Kagan, L., Bergum, V., & Lemermeyer, G. (2005). To stay or to go, to speak or to stay silent, to act or not to act: Moral distress as experienced by psychologists. *Ethics & Behavior,* 15(3), 197-212; Austin, W., Bergum, V., & Goldberg, L. (2003). Unable to answer the call of our patients: Mental health nurses' experience of moral distress, Nursing Inquiry, 10(3), 177-183.

was problematic, treatment cooperation unlikely, and it would negatively impact scarce resources (Feeney, 2003). Dangerous and severe personality disorder treatment facilities now exist in England.

For mental illness not created by legislators, there is significant lack of societal support and resources, shameful in its extent. Other relational ethics research, in such areas as pediatric intensive care and organ transplantation, has revealed the extraordinary gap in resources and funding compared to psychiatry. Extensive resources are available, as they should be, for a child needing a new organ transplant (or three), but often not for the child needing special care for a life-threatening psychological problem³. Systemic neglect, in terms of inadequate resources, negatively impacts ethical psychiatric care more than anything else. Closely related are policies that undermined ethical care. This, too, began early with "Bedlam" (i.e., The Hospital of Saint Mary of Bethlehem, London) providing a good example. When policy made an escaped patient's recapture financially accountable to attendants (often a week's wages), the predictable result was that restraint use became frequent and more severe. Today, nurses identify poor staffing skill mix, inadequate workplace design, and unsupported involuntary admissions as contributing to increased pressure, fear, and uncertainty on units (Ward, 2013). Again predictably, these correlate with the risk for aggressive behavior on the part of patients. The farreaching effects of laws, policies, and routine clinical practices in mental health care need to be critically evaluated from an ethical perspective.

Lobotomies: Temptations of Power and Certainty

At the symposium I made three points under the rubric "lobotomies". The first was that mental health has been disembodied. A foundational problem is that mental health and physical health are treated as separate entities. As John Connelly, a London psychiatrist in the mid-1800s, noted in his treatise on ways to better protect and care for the mentally

ill (cited in Hunter & Macalpine, 1963, p. 808), the creation of such an imaginary boundary can be used to justify unnecessary and afflicting measures against those with disorders of the mind. In the 21st century, this not only remains so, but the physical wellbeing of persons with severe, persistent mental illness is put at risk. Symptoms tend to be interpreted through their psychiatric diagnosis and annual physicals do not occur for many, despite seeing a physician or nurse several times a year. The World Health Organization (WHO) recently adopted the slogan, There is no health without mental health. (Actually WHO re-adopted it). In 1948, the WHO's first Director-General, Brock Chisholm, a Canadian psychiatrist, stipulated that without mental health there could be no health. Hopefully, the truth of this claim will eventually help re-embody psychiatry.

The second point was that the field of mental health struggles with temptations of power and certainty, even more than other areas of health care. A look back at psychiatry's history reveals that the certainty with which theories and treatment claims are made meet the criteria for delusions - fixed, false beliefs for which evidence to the contrary is not accepted. Take as example, Benjamin Rush's (Father of American Psychiatry) invention of the tranquilizing chair. Rush believed madness was an arterial disease, an inflammation of the brain. His purpose for confining a patient to the chair - leather straps secured feet, body, and hands; the head was enclosed in a box fixed to the chair - was to control blood circulation to the brain and to lower the pulse (Roback & Kiernan, 1969). The website of the Pennsylvania Hospital where Rush was on staff from 1783 – 1813 notes this about his treatments: "In actuality, they did neither harm nor good."4 Even centuries later, grievous mistakes remain unacknowledged.

Other, less distant examples include Dr. Walter Freeman, known as "the Lobotomist". He performed such surgery from 1936-1967 to rid patients of psychotic symptoms. Many of his nearly 3,500 lobotomies (one on a four-year old child) were done using a gold-plated icepick (or the one from his

³ See The Fifth Estate episode: The Boy Who Should Have Lived. Available at http://www.cbc.ca/player/Shows/ID/2661057045/

⁴ See http://www.uphs.upenn.edu/paharc/features/brush. html

home icebox). They had mixed results: some patients returned to work while others became unresponsive to the point of stupor (El-hai, 2005). In Canada, Dr. Ewen Cameron did experimental psychic driving treatments at the Allan Memorial in the 1950s and 60s⁵. His paper on this appears in a 1956 issue of the American Journal of Psychiatry⁶. While he notes that the majority of patients recovered using this treatment, in fact his work erased his patients' memories. This "brainwashing" method drew CIA funds through a fictitious foundation. Ultimately sued by former patients and their families, the CIA was required to provide compensation; the Canadian government did so, as well. These ambitious physicians hoped to discover effective new treatments. Their great failure lies in their blindness to the harm they caused. We need to learn from their mistakes. The errors of the past must be used as cautionary tales, not hidden or silenced as still occurs. Certainty which leaves no room for caution or acknowledgement of mistakes can have horrific consequences.

The third point involves the contemporary phenomenon of Big Pharma. While psychopharmacology has fostered significant advancements in the treatment of mental illness, there are some severe side effects to its dominance as a treatment approach. In the marketing of Pharma products, "psychiatric illness" also gets marketed. Charles Barber, author of Comfortably Numb: How Psychiatry is Medicating a Nation (2008), argues that the public and many physicians have come to confuse conventional sadness with clinical depression and post-traumatic stress disorder with reaction to anything bad that happens (Barber, 2013). Drugs are seen as the solution. Allen Frances (2013), the Chair of the DSM-IV Task Force, outlines similar concerns in Saving Normal, a response to the DSM-5. He wants to "save normal" as he finds aspects of everyday life are being transformed into illness. Grief, for example,

is becoming "medicalized", reducing the dignity of grief's pain, the use of consoling rituals, and the processing of loss. Unnecessary medication puts the grieving person at further risk. Neuropsychiatry and psychopharmacology have increased our knowledge of the human brain and continue to provide new tools to address psychiatric illness. It is important, nevertheless, that we are vigilant regarding the past and present harms associated with treatment "advances". Cautionary tales that allow us to recognize new temptations of power and certainty that are important if patient and societal harms are to be limited.

Nurse Ratched: The Iconic Mental Health Nurse

The unforgettable Nurse Ratched of One Flew Over the Cuckoo's Nest⁷ unfortunately still influences public perceptions of the mental health professional, as do other media images of psychiatric care. In Reel Nursing, Webster Pollard (2011) examined psychiatric nursing as represented in film, using interpretive visual inquiry to analyse films from 1948-2005. She identified "otherness" and "power/control" as primary discourses. It seems film patient-nurse relationships have an "us versus them" motif. Film nurses do not attempt to ethically engage with patients, but have shallow interactions while confidently enforcing institutional rules, rather than promoting patient recovery. Psychiatrists' public persona is hardly more accurate. Their image seems that of bearded wonder worker - the majority of psychiatrists are female who cure by uncovering an isolated trauma once the patient is on a couch, or that of "madman" who is neurotic, addicted, controlling, inept, self-absorbed, or foolish (Schulze, 2007; Thornicroft, Rose, & Mehta, 2010). Imagine being admitted to a psychiatric facility with such images shaping your care expectations.

The negative, stigmatized public image of mental health clinicians affects not only patients and their families. It affects health care students' attitudes toward clinical experiences in mental health; it impacts recruitment into the specialty, and it

⁵ The Sleep Room (1998) DVD directed by A. Wheeler, produced by B. Zukerman. Also: Collins, A. (1998) In the Sleep Room. The Story of the CIA Brainwashing Experiments in Canada. Toronto: Lester & Orpen Dennys.

⁶ Cameron, E. (1956). Psychic driving. American Journal of Psychiatry, 112(7), 502-509.

⁷ One Flew over the Cuckoo's Nest (1975, November), United Artists.

ultimately affects resource allocation for care and research. Worst of all, it sustains the stigma and discrimination of mental illness.



A New Legacy: Listening to the Voices of Those We Serve

Dark aspects of psychiatry's past remain with us today. These need to be addressed so that healing and recovery, in their broadest sense, can be ethically pursued. When the fact that mental health is integral to health is honestly embraced and given priority at the policy level in health care delivery and government, stigma and discrimination, unjust resource allocation, and the wrongful use of psychiatry for other than authentic medical purposes can be put in the past. As history reveals, the most appalling medical errors may be avoided simply by treating all recipients of care as persons deserving of respect. We must strive for a new legacy in mental health, one that is shaped by their voices.

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Ethical Decision-Making in Addiction Care: Is there a place for Alcoholics Anonymous?

Charl Els, MBChB, FCPsych, MMedPsych (cum laude), ABAM, MROCC Addiction Psychiatrist, Medical Review Officer Associate Clinical Professor, John Dossetor Health Ethics Centre and Department of Psychiatry, University of Alberta

Pierre Chue, MBBCh, FRCPsych, LMCC, FRCPC, DABPN, MSc, CCST Clinical Professor, Department of Psychiatry, University of Alberta Edmonton Zone Clinical Department Head and Site Chief, Addictions and Mental Health, Alberta Health Services

Health is a state of complete physical, mental and social well being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition. (Constitution of the World Health Organization, 1946)

Our actions, attitudes and core activities in medicine are based on fundamental principles and values of medical ethics, especially compassion, beneficence, non-maleficence, respect for persons, justice, and accountability. In adhering to our common ethical framework, reliance on high quality empirical evidence to guide clinical decision-making permeates medicine.

What if there existed a scenario in which there is a chronic, relapsing and potentially lethal condition, and our best empirical evidence does not support the most commonly prescribed and physician/societally endorsed treatment? This is not simply a question of medico-legal duty as a safeguard, but rather an ethical one involving benefits and harms. In matching a person with addictions to the appropriate psychosocial level of care that is proven to be safe, and likely to be effective, how can we advise a specific treatment modality if we lack reasonable

evidence that it works? On face value the answer is obvious. Yet, this scenario reflects the starting point for this paper, as a response to the landmark text in which Dodes & Dodes, 2014 aim to appraise the science of Alcoholics Anonymous (AA) and the highly profitable "Rehab" industry. This is a debate that has been brewing (no pun intended) for decades, and which will likely continue to raise questions. Dodes & Dodes describe addiction rather as a symptom than a disease, summarizing their description of addiction as a way of dealing with feelings of helplessness. Irrespective of the prevailing model of addiction, Dodes & Dodes do not address the ethical quandary raised by lack of good quality of evidence concerning treatment. Knowing that empirical evidence is lacking, how do we proceed in our clinical decisionmaking and treatment for matching persons with alcohol addiction to an AA group?

Background

Beverage alcohol contains a substantial amount of the psychoactive substance, ethanol (alcohol), which increases fluidity of membranes across the brain, exerting euphorogenic actions via its effects on the reward pathway. Most people consuming alcohol do so in moderation, with only a small subset becoming addicted. Problematic use of alcohol (that is drinking above the recommended safe drinking limits) can lead to serious alcohol problems or dependence, and about 15% are on the severe end of the spectrum.

People who consume excessively may also have problems with other substances contributing to serious health consequences for the person involved. Consumption of alcohol and drugs plays a significant social and economic role in most cultures. Despite its putative benefits and pleasurable effects on the individual, it has the potential for abuse and the development of addiction.

Alcoholism (Addiction, Alcohol Dependence [DSM-IV-TR], Alcohol Use Disorder [DSM-5]) is one of the most commonly diagnosed psychiatric disorders, affecting an estimated 10% of the Canadian population. It is a chronic, relapsing and potentially lethal, yet treatable, public health concern. Various treatments exist including medication (psychopharmacology) and psychosocial interventions. Psychosocial interventions are "talk therapies" that aim to identify an alcohol problem and motivate an individual to do something about it. These interventions can be performed by trained staff (for example, doctors, social workers, nurses, counselors, psychologists, etc.). Although a substantial number of persons with alcohol addiction recover without any formal treatment, i.e., so-called spontaneous recovery, the most commonly applied psychosocial intervention recommended by health professionals and others, is in fact AA.



Historical Trends

In Canada from 1918 to 1920 national prohibition of alcohol was a temporary wartime measure. Most provinces repealed their bans on alcohol in the 1920, and replaced existing legislation with a host of regulations (e.g., restrictions of sale) and excise taxation. The last provincial repeal occurred in 1948 in Prince Edward Island.

In 1935, a newly established organization, AA, consisting of laypersons, was formed. The founders were Bill Wilson (a failed stockbroker), and Bob Smith (a physician) – both who later died of tobaccorelated illnesses. At the time AA filled the apparent vacuum that existed in medicine for the treatment for problem drinking. Alcoholics Anonymous is an international fellowship of men and women who experience a problem with consumption of alcohol. It is nonprofessional, self-supporting, multiracial, apolitical, and available almost everywhere, with more than 5,000 groups in Canada alone. The only requirement for attendance is the desire to quit drinking and membership is open to anyone who wants to do so. The program follows a spiritual approach to recovery, involving a linear progression along 12 steps and seven popular slogans as key principles of successful recovery.

Alcoholics Anonymous' 12-step approaches are typically based on the assumption that substance dependence is both a spiritual and a medical illness. Hence, despite AA's predominant spiritual (not religious) framework, it made the early overtures to conceptualizing addiction (to alcohol) as an illness (Alcohol Anonymous, 1939).

If, when you honestly want to, you find you cannot quit entirely, or if when drinking, you have little control over the amount you take, you are probably an alcoholic. If that be the case, you may be suffering from an illness which only a spiritual experience will conquer.

In 1956 the American Medical Association endorsed alcoholism as a disease. By the early 1970s the disease

concept of alcoholism (referred to as addiction-as-disease) was already well established. Since the 1980s the addiction-as-disease concept enjoyed a broad cultural and political currency. The perception has continued to shift from viewing alcoholism as a moral problem to that of a psychiatric illness. Today, it is almost tantamount to scientific blasphemy to question the medical disease-base of addiction. The result is that of modern medical consensus opinion defining addiction as a disease with major medical, psychiatric, and public health consequences.

Despite the paradigm shift to addiction-as-disease, the roots of AA as the predominant response to alcohol addiction has persisted and it continues to form a central part in recovery today. This approach appears to be ingrained in culture, medicine, and law-justice (12% of AA attendees are there because of a court order). A fundamental issue in addictionology, remaining conspicuously absent from contemporary discussions, is whether the almost universally endorsed AA-as-treatment, is actually as effective as has been assumed. Alcoholics Anonymous literature cites success rates upward of 75%. However, these appear mostly anecdotal in nature. The Big Book of AA states: "Rarely have we seen a person fail who has thoroughly followed our path" (Alcoholics Anonymous, 1939).

What is the Evidence to Support AA Effectiveness?

Systematic, well-planned investigation of a health care problem, e.g., the treatment of alcohol addiction, requires resources as well as a high degree of methodological rigour to delineate the effectiveness of an intervention to achieve the desired outcome. The Cochrane Collaboration (www.cochrane.org) represents one widely accepted scientific method whereby only studies of sufficient rigour reflecting the strongest scientific evidence, are examined to support or refute a proposed treatment.

A 2006 Cochrane Collaboration review (Ferri, et al., 2006) identified 8 high-quality, randomized controlled trials (RCTs), involving a total of 3,417 research subjects. It concludes that the available experimental

studies did not demonstrate the effectiveness of AA or other 12-step approaches in reducing alcohol use and achieving abstinence compared with other treatments. However, there were some limitations with these studies. Many different interventions were often compared in the same study, and too many hypotheses were tested at the same time to identify factors determining treatment success. The result was that no published studies unequivocally demonstrated the effectiveness of AA or other 12-step facilitation approaches for reducing alcohol dependence or problems.

In a later Cochrane review (Klimas, et al., 2014), collaborators set out to determine whether "talk therapies" (e.g., AA) have an impact on alcohol problems in adult users of illicit drugs (mainly opiates and stimulants) and whether one type of therapy is more effective than another. The authors identified four studies that met the criteria for inclusion, and which examined 594 people with drug problems.

The results included only low-quality evidence for the comparisons reported in the particular review, and studies were so heterogeneous that researchers could not combine their results to answer the original question. The net result is that it remains uncertain whether "talking therapies" are effective in people who have problems with both alcohol and other drugs.

To date there is only low-quality evidence to suggest that effectiveness of different types of interventions to reduce alcohol consumption in concurrent problem alcohol and illicit drug users are similar and that brief interventions are not superior to assessment-only or to "treatment as usual".

Applying modern methodological research standards to establish AA's treatment efficacy/effectiveness poses several challenges. Alcoholics Anonymous is notoriously difficult to study – it keeps no records of attendance and as the name suggests, it is anonymous. There is a lack of evidence in the form of double-blind, placebo-controlled randomized trials to justify the almost universal recommendation of AA in addiction treatment. In the available studies of AA there is a lack of control groups in most studies

(Dawson, et al, 2006), and several studies were fraught with selection bias. Studies included in the most rigorous reviews do not support the notion that AA is effective for alcohol addiction treatment.

Can we Justify Referring Patients to AA?

Even if the modest rates of 5-8% success rates of AA are accepted (Dodes & Dodes, 2014), does this justify the universal "no questions asked" approach to referring alcohol-addicted persons to AA? It should be taken into consideration that the majority of people with addiction, who end up recovering, undergo so-called spontaneous recovery. Where does this conclusion leave health professionals in their decision on how to treat alcoholism?

Where to Now?

Perhaps the answer lies in the definition of success. If an addicted individual is socially, occupationally, spiritually, and otherwise disenfranchised, perhaps the affiliation with a group may provide additional meaning and support. This may or may not translate in long-term abstinence but may confer other health benefits. Anecdotes abound for the benefits accrued in attending AA. Included in the research, a large study (Project MATCH, 1997) investigated prognostic factors associated with interventions assumed to be successful as opposed to the effectiveness of interventions themselves. In the absence of rigourous evidence to support AA as effective addiction treatment, and no impetus to change the status quo, it is anticipated that little will change in the landscape of treating alcohol addiction, i.e., we will continue to default to the modality of AA. Perhaps the real benefits of AA may well not be measurable at the level that we would like to measure it.

More high-quality studies, such as RCTs in a specifically defined population of individuals without other substance use and other psychiatric comorbidities, are needed to definitively determine how AA fares in comparison to other treatments or treatment-as-usual.

Conclusion

Ethically justifiable decisions in healthcare are guided by clinical judgment, based on empirical evidence in support of safety and effectiveness. Addiction is a bio-psycho-social disease with a multifactorial pathogenesis including spiritual components. It is a treatable, yet often undiagnosed and undertreated, medical condition. Addiction, however, represents a unique scenario in that there exists no other disease in medicine for which health professionals almost routinely recommend a course of treatment, for which there exists no high quality evidence to support its effectiveness. Yet, the use of AA seems contrary to physicians' usual professional standards governing how we ought to act in a range of clinical situations. As such the medical profession's persistent endorsement of AA as an addiction treatment appears unethical.

Meta-ethics and normative ethics would proscribe the use of a treatment modality that is not proven to be safe and likely to be effective for a particular condition. The applied ethics response would suggest that, the knowledge of lack of effectiveness should incur a duty upon the provider to inform the patient as such, and to ensure that alternative options are offered. While this may result in physician discomfort by challenging the norm (there are apologists within AA who vehemently defend their position) it remains a duty towards respecting patient autonomy and right to self-determination.

As part of the health provider's duty of care, could referring a person to AA be beneficial or harmful? What if AA attendance creates a sense of security, hope for recovery, and faith in the recommended treatment (AA)? Could this possibly deter an individual from accessing other, evidence-based interventions such as pharmacotherapy or cognitive behavioral therapy? Further, what if AA attendance contributes to the cycle of relapse, as perhaps can be interpreted by the quote: "It is better to have been on and off the wagon than never to have been on at all"?

Does endorsement of non-evidence-based options satisfy the standard of our fundamental principles

and values of medical ethics as physicians? Practicing medicine competently and with integrity must require assessment of critical evidence in support of any treatment including AA. To continue to blindly endorse AA as a widely recommended treatment without such evidence must be questioned as unethical. Health as a state of complete physical, mental and social well-being can only be achieved by maintaining the highest level of fidelity to health professional standards of care, codes of ethics and interventions based on the best available evidence. In the absence of best evidence, continuing to apply this "AA "one size fits all" as the default approach to alcohol addiction treatment, must be questioned as a means for addicted patients to reach the goal of the highest attainable standard of health.

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Alberta Mental Health Act: How Legislation Aligns with Respect and Ethics

Carol M. Robertson Baker, BA, MEd

Alberta Mental Health Patient Advocate, Office of the Alberta Health Advocates, Government of Alberta

Imagine you've been feeling anxious and irritable for months and you go to emergency at your local hospital. After waiting a number of hours, you see a doctor and tell him that you haven't been sleeping well, that you've lost your appetite, and that it's a struggle to get out of bed. You also tell him that you have thoughts about harming yourself. You're worried about what he'll think.

A prescription to make you feel better and perhaps a referral for counselling is all you want. Instead, another doctor walks into your room soon after the first one leaves. You tell her the same story and answer her many questions. She tells you that she wants you to stay in hospital and that you've been issued

two admission certificates under the *Mental Health* Act (MHA, R.S.A. 2000, c M-13). You're now a "formal patient" and you have to stay in hospital.



You're given a hospital gown to wear and asked to stay in a room that's bare except for a bed. The door is closed and a security officer stationed outside your room glances at you through a small window on your door every few minutes. You ask security what's going on and are told that you can't leave because you're under certificates. When you ask what that means, you're told that "someone" will come and talk with you about it.

You wait in your room. Your confusion and fear turn to anger, wishing you had never come to hospital. A nurse arrives and tells you that you'll be transferred to a psychiatric unit when a bed becomes available and that you have to stay in hospital for one month. You're told that the doctors who met with you think you have an illness and are concerned that if you don't stay in hospital that you may harm yourself. You're surprised as you came to the hospital for a prescription and referral, not to get locked up. You're told of your right to apply to an independent body called the Review Panel for cancellation of the certificates, your right to a lawyer, and your right to contact the Mental Health Patient Advocate (MHPA).

This scenario is commonly heard by the MHPA. The MHPA, appointed under the MHA is celebrating 25 years of service to Albertans. The MHPA and staff help patients detained in a facility under one or two admission or renewal certificates, persons subject to a community treatment order, and those acting on their behalf to understand and exercise their rights that are enshrined in the MHA. They also investigate complaints regarding patient rights, detention, treatment, and care. As a result of the investigations, recommendations may be made to appropriate parties including the board, regional health authority or issuing psychiatrist to improve the quality of life and care of the patient and to ensure the person's rights are protected (MHA, R.S.A. 2000, c M-13, s.45(1)).

The MHA not only enshrines rights but also provides the authority, criteria, procedures, and timelines for the apprehension, detention, admission, treatment and other provisions that apply to persons who fall under the MHA (R.S.A. 2000, c M-13). People who contact the MHPA often say that they just want to be

treated with dignity and respect. Isn't this what all of us want? How does the MHA align with this basic human need and ethics?

Ethical principles of justice, autonomy, beneficence and non-maleficence are interwoven throughout the MHA by way of a number of checks and balances. Take, for example, justice or fairness and the procedure for the issuance of admission certificates and patient rights. To detain someone against their will is very serious and viewed by some as an infringement on a person's right to liberty. In order to have formal status, the person must be personally examined independently by two physicians and each physician must issue a Form 1 admission certificate within 24 hours (MHA, R.S.A. 2000, c M-13, s.1(1)(e), s.2, s.5(2)(3)). On the form, the doctors document the facts they observed and the facts communicated to them by others that resulted in their opinion that the person meets all of the three criteria in the MHA for the issuance of an admission certificate (MHA Forms Regulation, 136/2004 and 170/2012, s.2).

Formal status provides the authority to care for, observe, examine, assess, treat, detain and control the person in hospital for one month (MHA, R.S.A. 2000, c M-13, s.7(1)). Some of the rights of formal patients include the requirement of the "board" (MHA, R.S.A. 2000, c M-13, s.1(1)(c)(i)(ii)(iii)) to notify the patient both verbally and in writing of the reason for the issuance of the certificates in simple language and the right to apply to the Review Panel for cancellation of the certificates. The authority and period of detention and the function, address, and right to apply to the Review Panel for cancellation of the certificates must be provided in writing. In the event of language difficulty, a "suitable interpreter" must be obtained to provide the information (MHA, R.S.A. 2000, c M-13, s.14). Furthermore, any decision of the Panel can be appealed to the Court of Queen's Bench (MHA, R.S.A. 2000, c M-13, s.43(1)). All of these checks and balances exist to support the importance of the principle of justice or fairness.

Respect for the principle of autonomy is found in the MHA as a formal patient has the right to consent or refuse to consent to treatment under certain

circumstances. For some, there may be an assumption that if a person has formal status that they are incompetent to make treatment decisions. Not so. Under the MHA, a person is mentally competent to make treatment decisions if they can understand the subject-matter relating to the decisions and can appreciate the consequences of making the decisions (MHA, R.S.A. 2000, c M-13, s.26). If a doctor, however, deems a person incompetent to make treatment decisions, then a substitute decision maker who is available and who is willing to make the decision in the best interest of the patient and in accordance with the MHA makes the decision (MHA, R.S.A. 2000, c M-13, s.27, s.28). Furthermore, a patient deemed incompetent has the right to apply to the Review Panel for a review of the physician's opinion (MHA, R.S.A. 2000, c M-13, s.27(3)).

Relationships are built on trust and respect. A fundamental truth in health care is that health care

providers base their practice on doing good and doing no harm. It is critical that they are aware of the MHA and respect and protect patient rights during this vulnerable time in a patient's journey. Part of being a champion for recovery and patient centred care is to encourage patients living with a mental illness to be active partners with the interdisciplinary team to the best of their ability, to provide patients with the information they need to make informed decisions, and to treat patients with dignity and respect by protecting their rights. The MHPA and staff undertake this as a duty under their legislative mandate, and more so because it's the right thing to do. Let us all be champions for those touched by mental illness.

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Acceptance Equals Compliance: Our Lived Experience with a Husband Who has Schizophrenia

Austin Mardon, PhD, CM

Assistant Adjunct Professor, John Dossetor Health Ethics Center and Department of Psychiatry, University of Alberta

The following presentation was given at the 2014 annual John Dossetor Health Ethics Centre Health Ethics Symposium, Challenges in Mental Health Ethics.

I certainly never expected to be here today. By this time in my life, my family had expected that I would be a professor teaching geography somewhere. By the time I was 30 years old, I had a Bachelor and two Masters degrees, and was working on a PhD. I had been to the Antarctic with NASA looking for meteorites, decorated with the US Navy's Antarctic Service Medal, and routinely presented research papers at scientific conferences. Then one day like



a veil coming down, that all ended. I was diagnosed with schizophrenia.

I of course knew what that word meant. My mother was diagnosed with schizophrenia when I was just 5 years old. We were "that" family with the sick mom. As it turns out, perhaps that was actually a blessing for my life. I'm convinced I have never gone off my medication in part because I saw what that did to my mother. I'm sure it also helped that I was older when I had my first psychotic break. I had an extra decade's worth of education and life experience to draw upon to aid in my recovery than most other people with this illness.

Even so, on the old, first generation medications, I just existed. My world wasn't much larger than my small basement apartment. When the atypical medications came on the market my world expanded dramatically. I began to volunteer. It got me out of the house and out of myself. Even if I couldn't hold a full time job, I could once again become a contributing member of society. The interaction aided my cognitive abilities to the point I was able to return somewhat to my academic pursuits. I couldn't do field work, but could do research and write short academic papers. Being able to present research papers at conferences again and giving speeches gave me some of my lost selfesteem back.

Then 8 years ago, I made my latest medication change. I went from taking Risperdal by tablet to the injectable form called Consta. I went from sleeping 12-14 hours a day, to sleeping 7-8. That means I am awake 40 hours more a week. I now have so many more hours to do research, or follow my wife around the house.

I often get asked how I have done so well in life even though I have schizophrenia. The answer is simple. I have never consciously gone off my prescribed medication. I will admit that my wife has to remind me when I doze off in the evening before taking it. As to why I have never gone off my medication that is a much harder question to answer.

I'm told that a relatively small percentage of us take our medication as prescribed. That's not just for schizophrenics, that's also for diabetics or people on high blood pressure medication. If you have diabetes and you don't take your medication, you might go blind or lose limbs. If you don't take your high blood pressure medicine, you might have a stroke or kidney failure. If you don't take your neuroleptics, you might become psychotic.

I can understand not wanting to lose legs or eyesight. That would be a big incentive for me. Avoiding psychosis is a bit different. When you are first diagnosed with schizophrenia, you think your life is over. You don't think that you will ever have a decent job or a wife and family. You face a life of stigma and ostracization. You will probably live near or below the poverty line. You will live in the poor part of town that is home to drug dealers and prostitutes. You will have few friends and may even be afraid to leave your home

Yet, when you are off your medication and psychotic, you might be King Arthur, or a Templar Knight. You might be able to fly or read minds. Your voices are your closest friends and they stay with you no matter what. So how do you convince a person to stay on their medication when you are competing against that kind of rich fantasy life? You have to give us a reason to stay on our medicine.

We seem to do a good job of finding things for the physically disabled to do to give them a reason to get up in the morning, a reason to go on living. We haven't done a very good job in finding things in the lives of those with schizophrenia to give them a good reason to stay on their medication.

I have lots of reasons to stay on my medicine. I have a wife and a son, and a very spoiled basset hound. I have lots of friends, many of them fellow schizophrenics. However, I didn't have any of these things when I first became ill. My father somehow convinced me to take the medicine. My mother moved in with me for the first several months until I got stabilized on my medicine.

After those first few months, when the reality of my life settled in, I can understand why some people will want to fall back into psychosis. I had to find a purpose in satisfaction in fighting against stigma. I am honored

to be allowed to give these speeches. I think it is important. It is easy to read about schizophrenia in text books, but truly understanding what it feels like, takes close interaction with someone like me.

I think another large reason that schizophrenics go off their medication is stigma. Some think that if they aren't taking the medication, that they don't have to have the illness. This is an illness where it is easier to be in the closet. I guess this was never an issue for me. I almost feel as if I have been fighting the stigma of schizophrenia since I was old enough to remember. Where the earliest memories that many of my friends have of their mothers are warm and fuzzy, one of my oldest memories is seeing my mother in a straightjacket. There was the constant fear of being placed in foster care, or of my parents divorcing, of my father dying from his heart condition because of the stress and leaving me alone to care for my mother.

We haven't made a lot of progress on stigma. There are people in the United States sitting on Death Row with schizophrenia that refused to put forth a defense based on their illness. They would rather go to their graves known as cold blooded killers than schizophrenics. There are people with this illness serving life sentences in Canada too. I don't think we are going to make a real dent in stigma until someone famous comes down with the illness. That's what it took for AIDS.

So how do we give people enough hope for the future, a reason to get up in the morning, a real reason to want to stay on their medications? I believe the answer is relationships. Early on in my illness, I helped start a local Club House. Making friends with other people with schizophrenia allowed us all to support each other in making good decisions. It's far too easy though to limit ourselves to that small circle out of fear of rejection from normal people.

Even when we try to establish relationships that can anchor us to reality, the illness can get in the way. Since this illness robs us of the ability to understand body language, it can make us seem abrupt or rude or even clueless. Add to the negative symptoms of the illness the side effects of the medication, and relationships are nearly impossible to maintain.

Yet, relationships are crucial to our well-being. Imagine being the doctor for someone my age and size with schizophrenia. I'm already afraid that the government wants to implant tracking chips in my body. I'm also having chest pains. How are you going to convince me to have an angiogram? How are you going to talk me into allowing you to insert a catheter into my heart? I mean, isn't a stent just a miniature antenna for you to listen to my thoughts?

In my case, it would be my wife talking me into the procedure. She would be easing my fears, assuring me that it would save my life. If I said no, she'd just have to get out her rolling pin and then I'd agree. For others with this illness, it would be much harder. Good relationships are key to good health for those with schizophrenia. These relationships can be with family members, social workers, neighbors, other schizophrenics, club members, fellow parishioners, or even a pet.

Good relationships give us a reason to get up in the morning. They give us a reason to want to stay healthy and live long stable lives. If we find something to be passionate about, it gives us a reason to stay in reality and stay on our medicine.

Sometimes the most important things in our recovery are things that others might discount. I might not look like it, but I am very careful about my diet, or at least my wife is for me. Weight gain is a common side effect of these medications. I believe that a diet that is low in fat and high in fiber is not only good to combat a few side effects of the medication, but also to hopefully stave off diabetes. I also believe in taking vitamins, especially fish oil and turmeric. I don't often speak about this to groups of consumers though, and I think that is a real shame. In Alberta we have a gentleman who is allowed to market a former pig vitamin as a cure, not a treatment, but a cure for bipolar and schizophrenia. I'm afraid if I discuss how certain vitamins and supplements can help with our recovery or stability that I may be giving someone an excuse to go off their medications entirely.

It's the stigma we carry with us. We are vulnerable to snake oil salesmen offering cures. We would almost do anything to no longer have this illness and the labels that go along with it. Twenty five percent of all people diagnosed with Schizophrenia go into remission, and can go off their medication. If someone has cancer, and they go into remission, they have parties. They tell all their friends and family the good news and they go out and do cancer walks as a survivor.

Yet, they still know that for the rest of their lives they will need to monitor their condition for relapse. Someone who is able to go off schizophrenia medications won't do the same. If they speak about it at all, they will tell people that they had been misdiagnosed. The fact that they should monitor themselves because they may be susceptible to relapse later in life will go unrealized.

Twenty five percent of those with this disease are like me. We have to take medication for the rest of our lives, but we can lead near normal lives. We have to be careful about having too much stress or becoming overtired. That can lead to breakthrough symptoms. The next 25% are people who, even with adherence to the medication regime, cannot live without significant social supports. The last 25% have the hardest time. Fifteen percent are either permanently hospitalized, jailed, or live on the street. Ten percent are dead within 10 years of diagnosis, most by suicide. At least 40% of those diagnosed with schizophrenia attempt suicide.

For all the public complaints about our health care system, had I been born in another place or time, I might well be chained to a tree, locked in a basement or even burned at the stake. Instead, I received an appropriate diagnosis, have access to a psychiatrist and the most modern medication for my illness that is available, which I take gratefully. I'm not in a padded room, I'm not living on the street eating out of a dumpster, but I'm also not trying to run away from the reality of my illness.

I could pretend I'm not sick. I could hide in the closet and hope it will go away. Denial doesn't help anything in the long run, it just delays acceptance. With acceptance can come healing, not a cure, but a chance at a happy, healthy life. I can understand trying alternative treatments as an addition to regular medical care, or when traditional treatments are

non-existent or no longer working. I remember a time when those diagnosed with AIDS would try any alternative treatment possible because there were no real treatments available.

I don't have to tell you present today that one of the biggest hurdles when dealing with someone with this illness, is getting them to take their medication. I have a friend who refuses to believe that he is ill. He's deeply religious, and says that the only reason he agrees to take his medication is as a personal penance. Many would rather live on the street, eating out of dumpsters, than admit to having this illness and seeking appropriate medication. Once you start the medicine it is as if you are forever branded with a scarlet "S."

When I was first diagnosed, the doctor told me that my life was basically over. That the medications would shorten my life substantially, and that I would get cirrhosis of the liver by the time I was my current age. Not terribly helpful. For some reason that I can't explain, I never gave up hope. I never gave up the hope of finding someone to share my life with. I never gave up hope of having my own home. I never gave up hope of being able to contribute to society. That hope kept me fighting. It kept me on my medications, it gave me a reason to get up in the morning.

When I first met my wife, I was afraid to tell her about my illness. I have had research partners break off communication with me when they found out. I have family members who won't speak to me because they are embarrassed to be related to me. When I finally got up the courage to tell her, her response was to say, "that's interesting, so what." I thought that meant she didn't know what the word meant. I kept pressing her to discuss it, and she asked me if I was on my medicine, and planned to stay on it. I said yes. Then she said it wasn't an issue. That made me think that she simply didn't understand what the word schizophrenia meant.

What I didn't understand at the time is that she had in her former legal practice over 100 clients with serious mental illnesses. She would rather be married to a schizophrenic on their medicines than a diabetic who didn't monitor his blood sugar or a heart patient who wouldn't take their medications. Fortunately, I didn't smoke. She said that would have been a deal breaker. She obviously didn't go out to find a schizophrenic to marry, but her experiences allowed her to be willing to take a chance on me.

When I introduced her to my friends, most of them asked her if she also had schizophrenia. We found out later that the ones, who didn't ask, just assumed that she did, and were shocked to learn later that she didn't have it. A couple of them are still convinced she must have it and is just lying about it. If I were blind, people wouldn't automatically assume she had to be blind too. I guess they think I'm too damaged to marry a normal woman. I thought that for a long time too.

Whether she was born this way, or if she developed it over the years of working with the mentally ill, she can separate the person from the illness. When I have breakthrough symptoms, and for example think the TV is talking to me, she doesn't get mad or scared. She tells me that if the TV is talking to me, that I should turn it off and go to bed.

I'm sure it can't be easy to be my wife. Her friends and family thought she had lost her mind. One of the biggest issues with schizophrenia is that we can't read body language. We don't understand things like hidden agenda or nuance. Because I don't read body language, I don't understand what it is like to be able to do so. When my wife can tell by the expression on my face that I'm upset about something, I don't automatically understand that she can read my face, so I assume that she must be reading my mind. Well, there is a good reason they call it paranoid schizophrenia.

For me, the relationship that gives me a reason to stay stable is my wife. Talking about these kinds of relationships though make people very uncomfortable. One of my first speeches after we were married sticks out in my mind. It was at a hospital in Ottawa to mostly the parents of those with schizophrenia. I pointed out my wife in the rear of the room. People were stunned to hear she didn't have schizophrenia too. After the speech she got swarmed by parents wanting to know how to get their sons

girlfriends. There weren't any parents of daughters in the group surrounding her.

There is a fear of the disabled becoming married, especially those with mental illnesses or mental disabilities. For some reason, lots of people are aghast at the idea that disabled people might have sex. I suppose they are afraid of the un-normalness of it, or that there might be children produced who are also disabled.

My wife showed me an article once that the fastest growing personal injury lawsuits in Israel are being brought by disabled children, or their parents, against the doctors they believe should have discovered they were going to be born with disabilities and aborted them. They are called wrongful life lawsuits where the plaintiff believes it would be better to be dead than disabled. Parents are afraid if their children with schizophrenia get married, that instead of one person with a mental illness to take care of, they will end up with two or three.

I think one of the saddest things about this illness is that people automatically feel sorry for us. It's as if when you are disabled and poor, that you are supposed to be miserable. I refuse to be miserable. I refuse to allow stigma or society's expectations stop me from living a full life. The last 9 years of my life have been the best of my life. I just wish that all of my friends with mental illnesses could find that same happiness. Lots of them truthfully don't believe they deserve to be happy. I think that is much sadder than any illness they may have.

That's all I have. We are willing to take any questions you may have. Thank you for having us.

Upcoming Dossetor Centre Health Ethics Seminars:

Friday, 15 January 2016

ETHICAL ISSUES IN INNER CITY HEALTH

Kathryn Dong

Associate Clinical Professor, Department of Emergency Medicine, University of Alberta;

Director, Inner City Health and Wellness Program & ARCH, Royal Alexandra Hospital

Friday, 5 February 2016

TBA

Kimberly Young

Director, Donation & Transplantation

Canadian Blood Services

Friday, 18 March 2016

AUTHENTICITY IN THE CLINICIAN-PATIENT RELATIONSHIP

Gary Goldsand

Assistant Clinical Professor and Clinicial Ethicist, Faculty of Medicine & Dentistry and

John Dossetor Health Ethics Centre

Tuesday, 5 April 2016

TBA

Presentation in collaboration with Alberta Innovates Health Solutions

Friday, 8 April 2016

ETHICIAL TENSIONS IN REHABILITATION: WHO WANTS TO TALK ABOUT THE ELEPHANT IN THE ROOM?

Shanon Phelan

Assistant Professor, Faculty of Rehabilitation Medicine, Department of Occupational Therapy and

Assistant Adjunct Professor, John Dossetor Health Ethics Centre

Except for April 8 seminar, all seminars take place in Dvorkin Centre (2G2.07), Walter Mackenzie Health Sciences Centre, University of Alberta, 12:00 – 1:00 pm. Seminars available via Alberta Health Services' Telehealth Videoconference.

To register for Telehealth: http://www.bioethics.ualberta.ca/Health%20Ethics%20Seminars.aspx or contact dossetor.centre@ualberta.ca / 780-492-6676, or your local Telehealth provider.

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PUBLICATION AGREEMENT NUMBER: 40064803
RETURN UNDELIVERABLE CANADIAN ADDRESSES TO
University of Alberta
John Dossetor Health Ethics Centre
5-16 University Terrace
EDMONTON, AB T6G 2T4
Email: dossetor.centre@ualberta.ca

Health Ethics Today

Editor • Paul Byrne

Assistant Editor • Carol Nahorniak

Distribution • Stacy Cabral

Layout • Carol Nahorniak

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John Dossetor Health Ethics Centre
University of Alberta
5-16 University Terrace
Edmonton, Alberta, Canada T6G 2T4
Telephone: (780) 492-6676 • Fax: (780) 492-0673
Website: www.bioethics.ualberta.ca/
Email: dossetor.centre@ualberta.ca

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