

JEMH News

It is a distinct honour for the Journal of Ethics and Mental Health (JEMH) to be publishing in this issue a number of articles emerging from the Brain Matters-New Directions in Neuroethics Conference held in September 2009 in Halifax, Nova Scotia. We extend our thanks and appreciation to the following authors for their diligence in and commitment to submitting their conference papers: Walter Glannon, Farah Focquaert, Dirk De Ridder, Daniel Buchman, Emily Borgelt, Judy Illes, Philippe Couillard, A Keith W Brownell, Edith Deleury, Marie-Claude Côté and Jacquelyn Shaw.

JEMH has recently decided to approve the International Committee of Medical Journal Editors' "Uniform Requirements for Manuscripts (URM)". Instructions to authors and the "Uniform Disclosure Form for Potential Conflicts of Interest" will soon be available on the JEMH web site.

You will note on the JEMH web site that we have an exciting conference scheduled for May 13th to 15th, 2010 in Peterborough Ontario. This is the fourth JEMH conference since the inception of the Journal. This year's conference theme is: "Running the Moral Rapids". Planning is underway for the 2011 conference and preliminary details should be available in the near future.

Enjoy the current issue of JEMH. As always, we invite your comments. We also encourage authors to submit content to our Journal. In accordance with the goals of the Journal of Ethics in Mental Health we particularly invite authors to submit content on ethical issues that bring into focus the perspectives and experiences of frontline workers in the mental health and addiction field.

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CONFERENCE REPORT

Brain Matters - New Directions in Neuroethics

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While Halifax can be a distant destination for many people, it is a charming city to visit and take a few extra days to enjoy its surroundings. Autumn is a lovely time of year to visit Nova Scotia. In addition to offering a very favourable place and time, this conference's programme promised a wide range of neuroethics' emergent and familiar topics and questions for registrants to learn about and debate.

Yet in spite of the global economic downturn, over one hundred people from ten countries attended the "Brain Matters" conference from September 24th to 26th, organized and hosted by the Novel Tech Ethics team at Dalhousie University. These numbers are a testament to the calibre of the invited speakers, the relevance of the programme's content as well as to the conference's energy and aesthetic appeal. The Lord Nelson Hotel proved an ideal setting because the rooms for dining, presentations, and networking were small enough to promote good conversation yet large enough to be comfortable and moving among the concurrent sessions' rooms proved quite easy (in other words, no running needed!). Several "knowledge exchange" formats added to the conference's quality: plenary sessions, posters, panels, and individual/group presentations.

The plenary sessions were generally high quality, two of which stood out for me. Dr. Caroline Tait from the University of Saskatchewan's Department of Native Studies discussed the necessity of including indigenous people's perspectives and experiences in all ethical analyses and debates and including them routinely. I was struck by what an important caveat this is to the growing demand that western bioethics move from its local focus to a global focus. The caveat is that bioethicists don't necessarily need to only look outside their national borders for different sources of wisdom and meaning. They can legitimately look within their country's own borders to those people and their histories who constitute a different "nation" and yet have been marginalized or rendered invisible. As an aside, I am currently reading John Ralston Saul's most recent book, *A Fair Country: telling truths about Canada*, wherein he compellingly argues---based on history and sociology---that native Canadians' values must be more explicitly acknowledged and embraced as part of our nation's "lived authenticity" (my words, not Saul's). Tait's talk reminded the audience that while individuals' health qualifies as a good worth pursuing

and preserving, its meaning, its value relative to other goods and how it is to be achieved must be tailored to different communities' values and ways of living together.

Professor Neil Levy from the University of Melbourne spoke about the need to better understand something so routine, or so taken for granted, that it often escapes academics' and non-academics' attention: our moral intuitions. How valid are they? How reliable? In his plenary talk, he was responding to researchers' recent scientific investigations of how people reason morally or develop morally. Levy's exploration of the epistemic and practical value of such intuitions was illuminating because it returned us to examining the everyday world of moral insights and justifications. This echoes theorists and academics who remark that they rarely or never hear healthcare workers or patients justify their actions by referring explicitly to virtues, self-determination, or deontology.

There was a rich diversity of topics and questions offered to conference attendees in the presentations, panels, and by the posters. Grouping them in rough categories, they included: neurotechnologies' understanding of and impact on identity/authenticity/free will, possible limits to enhancing interventions, imaging technologies' excessive authority, contested definitions of death and PVS, invasiveness of brain surgery and deep stimulation techniques, unauthentic memory modification, inappropriate legal use of neurological findings, and the moral status of people with psychopathology. Other presenters shared their curricula for teaching healthcare students and practitioners about neuroethics. And finally, some sessions were about topics traditionally captured under "medical" or "clinical" ethics: advance care planning, advance directives, and substitute decision making for people with neurological diseases or conditions.

Colleagues from Europe and Asia were among the presenters, which, in my view, is a very welcome complement and corrective to what can be over-reliance on U.S.A.-based ethics work. Certainly the U.S. has the highest concentration of ethics specialists and academic centres, which have thankfully expanded the ethical inquiry within healthcare over the past quarter century. But it's important, I think, to recognize that different countries live by different ethical commitments or foundations and their citizens' presence at North American neuroethics conferences is valuable

indeed. This conference reminded me, too, how fortunate Canadian ethics specialists and ethics committees because there are three active neuroethics centres in our country. In addition to the Dalhousie team, there are teams at UBC (www.neuroethics.ubc.ca) and at the Institut de Recherches Cliniques de Montréal (www.ircm.qc.ca/neuroethics/en), each of whom sent members to the conference.

Of the presentations I attended, a high percentage of them were informative and engaging (the same cannot be said of every conference I have attended over the years). When I talked with attendees for whom this conference was their first ethics conference, an intriguing remark was repeated time and again. They expressed surprise about the directness of the question-and-answer periods that followed a presentation or plenary talk. They commented on the forthrightness of the challenges made to the speakers, something quite different from their own professions' conferences wherein audience members tend to compliment a speaker and, at most, expand positively on statements made. Surprise fortunately was followed by heightened interest once these attendees saw the speakers take such challenges in stride. According to each attendee who made such comments to me, the openness to real debate increased their assessment of the conference's value.

In summary, the conference was excellent in terms of inquiry, dialogue, and networking, and it sets a high standard for all other neuroethics conferences.

Neuroscience, Free Will and Responsibility

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ABSTRACT

Some cognitive neuroscientists and psychologists claim that our conscious mental states and actions can be explained entirely in terms of unconscious mechanical processes in the brain. This suggests that our belief in free will is an illusion and that we cannot be responsible for our actions. I argue that neuroscience as such does not threaten free and responsible agency. The real threat to free will is not normal brain function but brain dysfunction that impairs or undermines our capacity for agency.

Please note: A glossary of some of the philosophical terminology used in this article may be found following the article.

Key words:

Compassion Fatigue, Moral Stress, Marginalized Populations

Introduction

Some cognitive neuroscientists and psychologists claim that our motivational states and actions are determined by and can be completely explained in terms of unconscious mechanical processes in the brain. This suggests that our actions are not within our control because our conscious mental states and events play no causal role in what we do. Yet if we are not the source of our actions and if our mental states and events have no causal force, then our idea of conscious free will is an illusion. Further, if free will is an illusion, then presumably no one can be responsible for their actions, since being responsible rests on the assumption that we have free will.

I argue that neuroscience does not undermine free will because it does not demonstrate that deterministic mechanical processes in the brain completely explain human behavior. Any plausible conception of free will is consistent with the idea that some conscious mental states can causally influence actions while having physical causes in the brain. Causal determinism is not equivalent to coercion or compulsion, which do undermine free and responsible behavior. Because the brain generates and sustains the mind, and the mind in turn influences the brain, any satisfactory account of human action must include both

unconscious physical and conscious mental states and events among its causes. My aim is not to argue on practical grounds that, even if our belief in free will were an illusion, we would still hold people responsible for what they do or fail to do. Rather, my aim is to show that the argument from illusion is misguided and flawed on theoretical grounds.¹

Free Will as an Illusion

Psychologists Joshua Greene and Jonathan Cohen claim that “every decision is a thoroughly mechanical process, the outcome of which is completely determined by the results of prior mechanical processes.”² They make this claim partly on the basis of experiments that they and others have conducted on human subjects using functional brain imaging. From this, they conclude that “neuroscience will undermine people’s common sense libertarian conception of free will.”³ Among other things, this should make us revise our retributive view of punishment. Although these claims by Greene and Cohen are made in the context of the implications of neuroscience for the law, they challenge a common assumption about free will. Expressing a slightly different view, psychologist Daniel Wegner claims that “the real causal mechanisms underlying behavior are never present to consciousness.”⁴ Psychologist Henry Roediger and colleagues more confidently assert: “Clearly conscious intentions cannot cause an action if a neural event that precedes and correlates with the action comes before conscious intentions.”⁵

These claims present three distinct but related worries from neuroscience regarding free and effective action. One worry concerns determinism. If the brain is a deterministic system, then we cannot be free because free will is incompatible with determinism. Another worry concerns mechanism. If our conscious mental states are reducible to brain mechanisms, then we cannot be free because free will is incompatible with the idea that all natural phenomena can be explained by natural causes and mechanical principles. A third worry concerns epiphenomenalism. If our conscious mental states and events are not causally efficacious, then none of our actions results from these states and events. Together, these arguments appear to threaten free will in two respects: that we are the authors of our actions; and that as agents we have a causal impact on events in the world. Determinism, mechanism, and epiphenomenalism together form the argument from illusion.

To assess the argument from illusion, we need to place it within the historical philosophical debate on free will. In a basic sense, having free will implies that our choices and actions are within our conscious control. We can control the choices we make and the actions we perform by identifying with the beliefs, desires, emotions, and intentions that issue in our actions. Control implies that we can guide these mental states in the appropriate way to what we choose and do. It also implies that at least some of these mental states play a causal role in our decisions and actions. For philosophers, the main threat to this sense of control has come from causal determinism. This says that natural laws and events in the past jointly determine a unique future. If causal determinism is true, then any action one performs at a particular time is the only action one could have performed at that time. This rules out alternative possibilities (APs) to do otherwise than what one actually does. Incompatibilists hold that APs are necessary for free will and that causal determinism precludes APs. Hard incompatibilists believe that causal determinism is true and that we do not have free will. Libertarian incompatibilists believe that we have free will and that causal determinism is false. Compatibilists claim that we choose and act freely when we are not constrained, coerced, or compelled. Since causal determinism does not entail constraint, coercion, or compulsion, free will is compatible with causal determinism.

Philosopher Robert Kane insists that AP is too thin a basis on which to rest the case for libertarianism. Kane says that, in addition to the forward-looking AP condition, a backward-looking condition of ultimate responsibility (UR) is necessary for libertarian free will. UR consists in “the power of agents to be the ultimate creators (or originators) and sustainers of their own ends and purposes.”⁶ Kane emphasizes that this condition “puts the emphasis for being up to us not in the power to do otherwise, but on the *source* or *explanation* of the action that is actually performed: that source must be in us.” We must be the “ultimate, buck-stopping originators of our actions.”⁷ For a libertarian such as Kane, we cannot be the originators of actions if the mental states and events from which they issue are causally determined by antecedent events. I take Greene and Cohen to be referring to a version of UR when they write of “people’s common sense libertarian conception of free will.” On their view, the threat to libertarian free will is not from natural laws and events in the past. Rather, the threat is from mechanical processes and physical events in the brain and the idea that they, not our conscious mental states and events, are the ultimate and only effective source of our choices and actions. Neuroscience suggests that the UR condition cannot be met. Insofar as neuroscience implies that brain processes do all of the work in the causal pathway leading to action, we cannot be ultimately responsible for our choices and actions because “we” are not the authors of them.

Defusing the Threat

The claims by Greene and Cohen, Wegner, and Roediger et al. that mechanistic unconscious processes in the brain completely determine all behavior suggest that these processes completely explain my behavior. But consider the following example. Suppose that I have distinct desires to begin writing an essay and exercise at the same time. Each of these desires corresponds to a proximal urge in my brain. But whether I form and execute an intention to do one thing rather than the other cannot be explained

satisfactorily in terms of unconscious neural urges. Each of these competing desires is influenced by distinct long-range plans of mine to be more productive in my scholarship and healthy. My decision to write or exercise at a particular time depends on how I respond to the reasons for performing these actions. My response to these reasons will be influenced by my conscious response to factors external to my brain, such as the weather, the volume of noise in my home, or the deadline for submitting the essay. These reasons involve more than proximal urges in my brain. They also involve conscious beliefs whose content reflects features of the external environment. In addition, the reasons for performing either action reflect the fact that I live in a culture that values both scholarship and health. Appeal to the brain alone cannot explain why I perform one action instead of the other.

Mechanical processes in the brain are part of the pathway leading to my decision and action. But one must not mistakenly infer from the fact that a decision has an unconscious cause that the decision itself is unconscious. Unconscious mental states may initiate actions. Yet this does not imply that conscious mental states play no causal role in forming and executing proximal intentions in actions.⁸ An unconscious urge to act may be influenced by a conscious distal intention involving long-range planning, where this planning is in turn influenced by cultural and environmental factors. Events in the brain are not doing all of the causal work in the process leading up to and resulting in action and as such causally *underdetermine* it. At least some mental states and events are doing some of the causal work. This, in addition to the fact that factors external to me and my brain influence my plan and course of action, indicates that more than just the brain is involved in what I choose and do.

Most cognitive neuroscientists and psychologists give more weight to libertarianism than it has in philosophical debates on free will. Libertarians are a minority among philosophers writing about this issue. The majority are compatibilists. For most compatibilists, causal determinism just means that our motivational states and actions are the products of antecedent physical events, such that if the latter did not occur, the former would not occur. Mental states are necessarily generated and sustained by brain states. Free will is compatible with the fact that our mental states are caused by normal brain processes when this type of causation is not equivalent to constraint, coercion, or compulsion. This is consistent with what Hume calls “liberty of spontaneity.” He argues that since the existence of causal laws governing our actions does not undermine this type of liberty, there is no conflict between causal determinism and moral responsibility.⁹ Locke expresses a similar view in presenting his example of a man who finds himself in a room whose door is locked. Because this fact does not affect his choice to remain in the room at that moment, he chooses freely even though he could not have done otherwise.¹⁰ These examples illustrate a negative default account of free will. Many compatibilists offer positive accounts as well.

Philosopher Harry Frankfurt has developed one of the most influential positive compatibilist accounts of free will. He defines persons as individuals with the capacity to form first-order desires to perform certain actions. They also have the capacity to form second-order desires to have certain first-order desires. The will is the effective first-order desire that moves one all the way to action. One wills and acts freely when one’s effective first-order

desires align with one's second-order desires, and one identifies with both.¹¹ Identification follows from a process of critical self-reflection, after which the relevant desires become part of the set of the person's motivational states. This reflective process enables one to make the mental springs of action one's own. If neuroscience threatens only libertarianism and not also compatibilism, then the threat to free will might not be so great after all. Still, the challenge from psychologists such as Wegner and Roediger et al. is not that brain processes interfere with identification, or that they coerce or compel us to act. Instead, the challenge is that brain processes alone may account for all of the events in the pathway leading to action. These processes seem to render mental states epiphenomenal.

Our first-order desires may very well be causally determined in the sense that they are necessarily generated and sustained by events in the brain. But this does not put these and other motivational states and events beyond our conscious control or render them causally inert. Our capacity to make these desires conform to second-order desires, to identify with, and translate them into actions may provide us with enough conscious control over our motivational states to make them our own. The effects of psychotherapy on cortical brain functions indicate that there is both brain-mind and mind-brain causal interaction, which shows that our mental states can be causally efficacious in shaping brain states and how they issue in our behavior.¹² This may be enough for us to be "ultimate buck-stopping originators" of at least some of our actions. In this respect, Frankfurt's version of compatibilism can satisfy a condition analogous to UR. We do not need to endorse a libertarian rejection of causal determinism to satisfy it. Unlike libertarians such as Kane, for Frankfurt and other compatibilists what matters in having or lacking free will is not so much whether external sources influence our mental states and actions. Indeed, they do. What matters more is whether we have the internal resources to identify with our desires, beliefs, and intentions and execute them in actions. Just because these resources have physical causes in the brain does not mean that we cannot consciously identify with or act on them. Some would claim that social factors beyond our control have such a strong influence on our thought and behavior that they are not up to us.¹³ These external sources play such a significant role in the causal history of our choices and actions that they preclude free will and responsibility. This may be a legitimate challenge to compatibilism. Yet it is not the challenge to free will from neuroscience, which is not concerned with social factors but events and processes in the brain.

There are four main problems with the argument from illusion. This is by no means an exhaustive list. But these problems are enough to expose flaws in the argument.

First, claims about neuroscientific determinism and mechanism stripping us of authorship of our actions and rendering our mental states epiphenomenal presumably are based on empirical evidence. Most of this evidence is from neuroimaging. Functional brain imaging experiments conducted by neuroscientists and cognitive psychologists such as Greene and Cohen show correlations between brain activity and some cognitive and affective mental states. Correlation is not causation, however. Images of increased or decreased brain activity produced by fMRI or PET scans are not identical to events and processes occurring at the neuronal level. They are visualizations of statistical averages based on

large numbers of images and are more accurately described as scientific constructs than pictures of what is actually occurring in the brain. The claim that every decision is a thoroughly mechanical process determined by prior mechanical processes in the brain is a causal claim. Some correlations may be strong enough to suggest causation, especially if one can eliminate other factors in explaining the relation between brain activity and behavior. An example would be a case where wrongful behavior is associated with a tumor in the prefrontal cortex. If the behavior resolved with the removal of the tumor, then this could support the claim that there was a causal connection between the tumor and the behavior.¹⁴ But this is an example of brain *dysfunction*. It does not support the claim that imaging establishes a causal connection between normal brain *function* and a particular action or pattern of behavior. In most cases, correlations between normal brain activity and behavior are not strong enough to indicate causation. Moreover, claims of a causal connection between brain events and conscious decisions assume that decisions are based on localized brain activity, when in fact the activity that underlies them is distributed throughout the brain. Neuroimaging experiments do not support claims of determinism or mechanism because they fail to establish the necessary empirical evidence showing a causal connection between brain activity and behavior.

Second, the argument from illusion involves a mistaken inference about causation. The fact that a mental state or event has a physical cause in the brain does not imply that it is not among the causes of an action. Just because an action is preceded by unconscious brain events does not mean that no conscious mental states have a causal role in the pathway leading to that action. As philosopher Alfred Mele points out, "not only is there no rule against causes themselves having causes, it is also the *norm* for causes to have causes (How many causal processes start with uncaused causes?)"¹⁵

Third, the idea that conscious mental states and events have no causal role in action and are epiphenomenal offers an impoverished account of human agency. It suggests that we never do anything on the basis of our conscious desires, beliefs, emotions, intentions, and decisions. All of our behavior is the product of unconscious mechanical processes. It seems to explain away practical and moral reasoning and decision-making. Indeed, if we define persons as essentially agents who act in virtue of conscious mental states and events, then on this account persons do not exist. This is an extremely implausible form of skepticism about the will. Neurosurgeon and philosopher Grant Gillett points out that "a decision is. . . not a circumscribed event in neuro-time that could be thought of as an output, and an intention is not a causal event preceding that output, but both are much more holistically interwoven with the lived and experienced fabric of one's life."¹⁶ Decisions and actions are more than just a function of discrete events in the brain occurring at specific times. They are a function of what the subject needs to navigate in and adapt to the world, which involves a more temporally extended process. Mental states emerge from the brain in order to provide human agents with an accurate map of the natural and social environment, a map that brain processes cannot provide on their own. As one aspect of neuroplasticity, the interaction of the subject with the environment influences the activity of neurons and can change the morphology and functions of the brain. This casts doubt on the claim that brain processes and their relation to behavior are deterministic or mechanistic. Every human agent enlists unconscious and

conscious mental states and events to enable this interaction. The mind is neither reducible to nor independent of the brain. Mind and brain mutually influence each other in a nested series of feed-forward and feedback loops that promote the adaptability of the subject to the world.

Fourth, if our behavior just consists of neurons all the way up and down, then it is unclear what motivates the claim that we should revise our retributive practices. This is an attempt to pull a normative rabbit out of an empirical hat, which turns the argument from illusion on its head. There is a need to explain how one can derive the normative “ought” from the empirical “is.”

In earlier work, neuropsychologist Patrick Haggard made causal claims about the relation between the brain and behavior similar to those made by Wegner and Roediger et al. In a recent paper, he notes that networks in the pre-supplementary motor cortex, anterior prefrontal cortex, and parietal cortex underlie voluntary and responsible action. Yet Haggard suggests that mental states may causally influence the brain in saying that “responsibility might depend on the reason that triggered a neural process culminating in action and on whether a final check should have stopped the action.”¹⁷ Reasons can be either external or internal to human agents. External reasons are associated with rules or norms of behavior recognizable by any rational person as a subject in a social and cultural environment. These reasons obtain independently of particular agents. Internal reasons consist of combined desires and beliefs regarding actions that one should or should not perform. They may be prudential, concerning one’s own interests, or moral, concerning the interests of other agents. Haggard appears to use ‘reason’ in both senses. While internal reasons depend on neuronal processes, one can plausibly assume that these reasons are not identical to these processes but are emergent mental states with nonreducible psychological properties. Insofar as these reasons can function as a “check” on our actions, they can influence events at the neuronal level. If so, then we have at least some control of our behavior because of processes operating at the conscious mental level.

Haggard further notes that our ability to respond to external reasons for or against actions can also influence processes at the neuronal level: “Interestingly, both decisions [to act or not to act] have a strong normative element; although a person’s brain decides what they carry out, culture and education teach people what are acceptable reasons for action, what are not, and when a final predictive check should recommend withholding action. Culture and education therefore represent powerful learning signals for the brain’s cognitive-motor circuits.”¹⁸ Haggard adds: “Although neuroscientific detection of the brain circuits that generate actions and conscious awareness can contribute to an evidence-based theory of responsibility, it is unclear whether they can capture all the nuances of social and legal concepts of responsibility.”¹⁹ Given the role that Haggard attributes to internal and external reasons and associated normative practices surrounding actions, it appears that neuroscience cannot capture these nuances.

There are three points that are worth making in light of Haggard’s claims. First, they suggest that the social environment can influence the brain and how it mediates the mental states associated with voluntary action. Second, they suggest that mental states associated with internal reasons and one’s response to external reasons can

influence events in the brain and our actions. Third, the upshot of the first two points is that neural networks alone cannot satisfactorily explain human behavior. The brain itself does not “decide” what we do. As psychiatrist Sean Spence puts it: “no account of human action (and therefore human moral responsibility) is complete in the absence of a subjective report . . . so when we wish to apportion responsibility, we are not merely identifying an organism. . . . we are saying something about ‘its’ underlying volitional processes: the symmetry pertaining between desires and deeds, intentions and actions.”²⁰ A satisfactory explanation of behavior must include not only neuronal processes but also internal and external reasons. These reflect the normative dimension of voluntary action and how this dimension is shaped by the social and cultural environment in which human subjects live and act. All three points indicate that free will and responsibility are not just metaphysical notions involving considerations of causation, determinism, possibility, and necessity based on empirical studies of the brain. They are also normative notions reflecting the fact that we are social beings who act and interact with each other and whose expectations of what we can and should do are grounded in this interaction. The most plausible model of free will and responsibility is one that consists of complementary empirical and normative dimensions reflecting causal interaction and influence between and among the brain, the mind, and the environment.

Nothing about the structure and function of the brain, or how it generates and sustains the mind, implies that we are mistaken in believing that we have the capacity to respond to reasons and to consciously form and execute intentions in actions. Normal neurological function does not provide grounds for questioning the conviction that we can control our thought and behavior. It is possible that future advances in neuroscience may call into question the belief that we have free will and can be responsible for our actions. If it does, then it will remain unclear how empirical findings about the brain will influence normative judgments of moral and legal responsibility. Even with refinements in neuroimaging, there will always be a need for behavioral and normative criteria in making and upholding these judgments. There is an additional problem with the idea that neuroscience might cause us to question our belief in free will. How brain function mediates the cognitive capacity for decision-making is described entirely in objective terms. But there is an essential subjective aspect of the will. A description of cognitive-motor circuits cannot capture the first-person experience of deliberating and choosing, or how this experience is shaped by the world in which we act and live.

Conclusion

Neuroscience does not threaten free will and responsibility because it does not show that we are not the authors of our actions or that our conscious mental states and events play no causal role in our behavior. It is mistaken to infer that, just because a desire or intention has a physical cause in the brain, these and other mental states and events do not influence our ability to act. From the fact that conscious mental states and events are generated and sustained by unconscious mechanical processes in the brain, it does not follow that they play no causal role in action. Causation is not equivalent to compulsion and does not imply that we have

no conscious control over what we do or fail to do.

The real threat to free will is not from normal brain function but brain dysfunction that impairs or undermines the capacity for agency. This includes seizure disorders, loss of motor control in Parkinson's or Huntington's disease, and damage to the prefrontal cortex making one unable to inhibit violent urges. It also includes psychosis in schizophrenia making one unable to accurately perceive or engage with the world, the anhedonia and avolition in schizophrenia and depression making it difficult to will oneself to act, and the alien and overwhelming desires and beliefs in obsessive-compulsive disorder. These conditions impair or undermine free will when they interfere with one's cognitive, affective, and volitional capacities to identify with one's motivational states and initiate and complete actions. Persons are not responsible for their behavior when brain dysfunction causes them to lose these capacities.

Brain dysfunction does not always strip persons of their agency, however. In some cases, they may retain an important aspect of the will in trying to act and make sense of their condition and the world around them. One illustration of willing as trying is the autobiography of the Russian soldier Zazetsky, written in collaboration with neuropsychologist A. R. Luria.²¹ During the Battle of Smolensk in 1943 during the Second World War, Zazetsky sustained a severe head injury from a bullet wound with extensive damage to the left occipital-parietal region of his brain. This caused his memory, visual field, and body perception to become fragmented. It left him with the experience of a constantly shifting and unstable self in what for him had become a shattered world. To cope with this fragmentation, he kept a journal for twenty years, recording thoughts and memories as they occurred on a daily basis. In doing this, he attempted to reshape his lost self by reconstructing the unity and integrity of his psychological properties. Because of his mental impairment, Zazetsky was not able to completely re-establish psychological continuity with his pre-injury state. But his effort enabled him to retain a basic autobiography and adjust its later chapters to his post-injury state while retaining his basic interests and values. Zazetsky's determination in trying to reshape his identity and construct a meaningful narrative of his experience with a brain injury shows how one can retain and exercise the will to some degree despite neurological and psychological impairment. It is an example of the human capacity to recognize, invent, and realize possibilities of action despite being constrained to some extent by a damaged brain. Neuroscience can tell us much about persons, but not everything. Although it is necessary to understand human thought and behavior, it does not explain away free will and moral responsibility.

References

¹ Different arguments leading to the same conclusion have been advanced by Adina Roskies, "Neuroscientific Challenges to Free Will and Responsibility," *Trends in Cognitive Sciences* 10 (2006): 419-423, Chris Kaposy, "Will Neuroscientific Discoveries about Free Will and Selfhood Challenge Our Ethical Practices?," *Neuroethics* 2 (1) (2009): 51-59, and Nancy Murphy and Warren S. Brown, *Did My Neurons Make Me Do It? Philosophical and Neurobiological Perspectives on Moral Responsibility and Free Will* (New York: Oxford University Press, 2007).

² "For the Law, Neuroscience Changes Nothing and Everything," *Philosophical Transactions of the Royal Society of London* 359 (2004): 1775-1785, at 1775.

³ *Ibid.*, 1775.

⁴ *The Illusion of Conscious Will* (Cambridge, MA: MIT Press, 2002), 97.

⁵ H. Roediger, M. Goode, and F. Zaromb, "Free Will and the Control of Action," in J. Baer, J. Kaufman, and R. Baumeister eds., *Are We Free? Psychology and Free Will* (Oxford: Oxford University Press, 2008), 208. See also Martha Farah, "Neuroethics: The Practical and the Philosophical," *Trends in Cognitive Sciences* 91 (2005): 34-40.

⁶ *The Significance of Free Will* (New York: Oxford University Press, 1996), 4.

⁷ *Ibid.*, 34.

⁸ Alfred Mele presents a similar set of arguments in *Effective Intentions: The Power of Conscious Will* (New York: Oxford University Press, 2009).

⁹ *A Treatise of Human Nature*, ed. L. A. Selby-Bigge, rev. P. H. Nidditch, second edition (Oxford: Clarendon Press, 1978), 407 ff.

¹⁰ *Essay Concerning Human Understanding*, ed. P. H. Nidditch (Oxford: Clarendon Press, 1975), Book II, Chapter XXI.

¹¹ "Freedom of the Will and the Concept of a Person," and "Identification and Externality," in Frankfurt, *The Importance of What We Care About* (New York: Cambridge University Press, 1988), 11-25, 58-68. See also John Martin Fischer, *The Metaphysics of Free Will: An Essay on Control* (Cambridge, MA: Blackwell, 1994) and Fischer and Mark Ravizza, *Responsibility and Control: An Essay on Moral Responsibility* (New York: Cambridge University Press, 1998).

¹² H. Mayberg, K. Goldapple, Z. Segal, et al., "Modulation of Cortical-Limbic Pathways: Treatment-Specific Effects of Cognitive-Behavior Therapy," *Archives of General Psychiatry* 61 (2004): 34-41.

¹³ This claim has been made by "source incompatibilists" such as Galen Strawson in "The Impossibility of Moral Responsibility," *Philosophical Studies* 75 (1994): 5-24, and Derk Pereboom in *Living without Free Will* (New York: Cambridge University Press, 2001).

¹⁴ J. M. Burns and R. H. Swerdlaw, "Right Orbitofrontal Tumor with Pedophilia Symptom and Constructional Apraxia," *Archives of Neurology* 62 (2003): 437-440.

¹⁵ *Effective Intentions*, 72.

¹⁶ "Intention, Autonomy, and Brain Events," *Bioethics* 23 (6) (2009): 330-339, at 333.

¹⁷ "Human Volition: Towards a Neuroscience of Free Will," *Nature Reviews Neuroscience* 9 (2008): 934-946, at 944.

¹⁸ *Ibid.*, 944.

¹⁹ *Ibid.*, 944.

²⁰ *The Actor's Brain: Exploring the Cognitive Neuroscience of Free Will* (Oxford: Oxford University Press, 2009), 236.

²¹ A.R. Luria, *The Man with a Shattered World: The History of a Brain Wound*, trans. L. Solotaroff (New York: Basic Books, 1972).

Glossary

Alternative Possibilities

We can choose and act in ways other than how we in fact choose and act. A necessary condition of libertarian incompatibilism.

Anhedonia

An inability to experience pleasure from normally pleasurable life events.

Avolition

A general lack of motivation and inability to initiate action plans.

Causal Determinism

Laws of nature and events in the past jointly determine a unique future. This implies that an action one performs at a particular time is the only action one could have performed at that time.

Compatibilism

Free will is compatible with causal determinism because causal determinism does not constrain, coerce, or compel one's choices and actions.

Epiphenomenalism

Mental events are caused by physical events in the brain, but mental events have no effect on any physical events.

Hard Incompatibilism

Causal determinism is true and therefore we do not have free will.

Incompatibilism

Free will is incompatible with causal determinism.

Libertarian Incompatibilism

Causal determinism is false and therefore we have free will.

Mechanism

All natural phenomena can be explained by natural causes and mechanical principles.

Ultimate Responsibility

We are the authors and originators of our actions, which are not determined by any antecedent events. A necessary condition of libertarian incompatibilism

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Direct Intervention in the Brain: Ethical Issues Concerning Personal Identity

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ABSTRACT

Personal identity has been the focus of philosophical and ethical debate for centuries. During the last decades, different techniques for intervening in the brain, and hence our mind, are being developed and refined. Neuromodulation techniques, such as direct stimulation of the brain via implanted electrodes (e.g., deep brain stimulation), target the brain's capacity for reorganization to exert their effects and might directly or indirectly influence our mental states. In this paper, we investigate whether the possibility of altering our personal identity provides a valid argument against neuromodulation research and treatment for severe, treatment-refractory neurological or neuropsychiatric conditions. Since narrative rather than numerical identity is at stake when considering neuromodulation research and treatment, our paper focuses on narrative identity changes. We argue that arguments against this kind of research and treatment for neuropsychiatric conditions based upon the possibility of narrative identity changes are ethically unconvincing.

Key words: personal identity; narrative identity; deep brain stimulation; neuromodulation; neuropsychiatric disorders; neuroethics.

Introduction

Several philosophical and ethical worries about personal identity are voiced in relation to direct interventions in the brain, very similar to those vis-à-vis psychopharmacological treatment and enhancement techniques in general (DeGrazia, 2005; Levy, 2007). One of the most salient worries related to personal identity is the fear of creating a *new person*, of radically

changing a person's self up to the point where they can no longer be considered the same. In the introduction of *Intervening in the brain*, Merkel et al. (2007) point to the widespread philosophical worry that one's personal identity might be comprised as a result of brain interventions: "The fear is often expressed that an individual may no longer be "the same person" he or she used to be prior to an intervention in the brain. In other words (i.e. philosophical terms), these interventions are said to threaten personal identity". These worries are not restricted to direct interventions in the brain (e.g., brain implants), but equally face psychopharmacological (e.g., Prozac) and, perhaps to a lesser extent, psychotherapeutic interventions (e.g., psychoanalysis) (Levy, 2007). A lot of the philosophical worry related to identity changes revolves around the possibility of (radical) personality changes due to brain interventions (see, e.g., Glannon, 2009), rather than personal identity in general. In this paper, we discuss whether interventions in the brain threaten our personal identity, and if the possibility of identity changes provides a sound ethical argument against these techniques.

We particularly focus on one type of neuromodulation (i.e., essentially reversible, *direct* alteration of endogenous neural activity): surgical intervention/stimulation via implanted electrodes (Merkel et al., 2007). This technique involves the placement of electrodes in the brain (cortically or subcortically) to directly apply low or high-frequency electrical current to the brain tissue. These electrodes are connected to a kind of 'pacemaker' near the collarbone, the abdomen or thigh, which can be set on/off with a remote control (the intensity of the stimulation can also be adjusted by means of the remote control, and the patient can switch between several different programs for optimal efficacy depending on the situation). As such, electrical current can be applied directly to the brain tissue to reduce symptoms. A well-known example is deep brain stimulation (DBS) of the subthalamic nucleus (STN) in patients suffering from Parkinson's disease (PD). DBS as it is now being practised goes back to the work of Benabid et al. (1987) who were the first to report successful stimulation for tremor in PD. The

technique is now the most frequently performed surgical procedure for Parkinson related movement disorders that are refractory to pharmacological therapy (Hardesty & Sackeim, 2007; Merkel et al., 2007). Over 55 000 patients have been treated for movement disorders today. There are undoubtedly pros (e.g., fully reversible, flexibility of stimulation) and cons (e.g., potential risk of infection, hemorrhage or seizures during or after surgery) to be given when considering neuromodulation via implanted electrodes, many of which are related to the more technical aspects of the procedure (Chou et al., 2007). Importantly, this procedure is still experimental or investigational in nature with respect to most neuropsychiatric conditions. The FDA recently approved DBS for obsessive compulsive disorder (OCD) based on a humanitarian exemption and two clinical trials for major depression have been launched in the past year (Miller, 2009). There are long-term successful results for OCD and promising results have been obtained for, among others, Tourette syndrome, major depression, and cluster headache. It is important to mention that this technique targets treatment-resistant disorders, resulting in high success rates and often involving dramatic and durable benefits. Moreover, certain other techniques, such as electroconvulsive therapy, show higher relapse rates compared to stimulation via implanted electrodes (Bussone et al., 2007; Greenberg et al., 2006; Hardesty & Sackeim, 2007; Mayberg et al., 2005; Wichmann & DeLong, 2006).

Personal identity

Nearly all personal identity related worries regarding direct interventions in the brain (e.g., DBS for neuropsychiatric disorders) rest upon a conflation of narrative and numerical identity (DeGrazia, 2005). Issues concerning personal identity through time or the *persistence question* are about numerical identity. The persistence question asks under what possible circumstances a person who exists at one time is identical to someone (or something) existing at another time? (Olson, 2008, Stanford Encyclopedia of Philosophy). It therefore asks whether or not an individual is one and the same *despite* change (DeGrazia, 2005). Issues concerning narrative identity or the *characterization question* focus on the characteristics that truly or genuinely constitute a person's identity (Schechtman, 1996). According to DeGrazia (2005) narrative identity reflects "what is most central and salient in a given person's self-conception" (266), including personality traits and mood. Narrative identity overlaps with recent notions of personality in psychology and psychiatry, in which personality is defined as "a dynamic and organized set of characteristics in a person that uniquely influences his or her cognitions, motivations, and behaviors in various situations" (Synofzik & Schlaepfer, 2008, p. 4). While it is self-evident that altering an individual's numerical identity is wrong, it is much less clear that altering one's narrative identity is ethically problematic. Whereas unintended radical narrative identity changes are potentially problematic, unintended mild or moderate narrative identity changes are not necessarily problematic. Mild and moderate narrative identity changes are part of our daily life and may result from a variety of life-changing experiences or circumstances. For example, becoming a parent may change an individual from being somewhat irresponsible to becoming responsible. The loss of a loved one may change someone from being optimistic, to being depressed and without hope. Medication or stimulation-induced narrative

identity changes come about 'differently' and more abrupt, but are essentially the same as those that come about just by living our daily lives. Whether or not such changes are found to be problematic, depends first and foremost on the person in question and his or her loved ones (Schermer, 2009).

Personal identity through time or numerical identity revolves around the necessary and sufficient conditions for a person at one point in time to be the same person (or being) at another point in time. Psychological approaches describe these conditions in terms of continuity of psychological connections or experiential contents, such as memory of earlier experiences (i.e., episodic memory) or continuity of basic psychological capacities such as a basic capacity for reasoning or consciousness. Biological approaches describe these conditions in terms of continuity of biological life. DBS for neuropsychiatric disorders does not affect the continuity of one's biological life, and it unlikely affects the continuity of one's psychological connectedness or one's basic psychological capacities. Philosophical and ethical worries about personal identity are typically about cases in which stimulation is successful in alleviating the patient's symptoms, but at the same time leads to changes in one's mental states (e.g., changes in personality traits, e.g., changing from an outgoing to a more introvert person). Hence, they are about changes in narrative identity rather than numerical identity (Glannon, 2009). Narrative identity changes may involve changes in cognition, personality traits, emotions and mood.

Neuromodulation via implanted electrodes can influence narrative identity directly and indirectly: directly only in as far as the personality and self-perception network is involved in the brain intervention. Indirectly, neurostimulation can alter personality via its modulation of the major neurotransmitter systems (serotonin (Carver & Miller, 2006), dopamine (Depue & Collins, 1999) and noradrenalin (Bond, 2001), which all influence personality. Neuroplasticity is the capacity of the nervous system to modify its organization to changing input (Bavelier & Neville, 2002) and neuromodulation techniques such as DBS are using the brain's capacity for reorganization to exert their effects (Pascal-Leone, 2006). As personality and self-perception are the result of specific brain circuits, these could be altered by changing input as well. Although narrative identity changes are possible, neurostimulation techniques for neurological and neuropsychiatric disorders target the disorder in question and do not intend to alter one's narrative identity.

Current findings on cognition, personality traits, emotions and mood

The following questions need to be answered: which aspects of our narrative identity are (likely or unlikely) altered due to stimulation for neurological and neuropsychiatric disorders? Do these alterations involve drastic changes? And if yes, are such changes common? And importantly, how do these compare to other available treatments? Let's turn to the data. We will first look at data from DBS in PD, since larger groups of individuals have contributed to studies assessing possible side effects related to narrative identity.

Parkinson's disease

Although DBS for PD is associated with possible adverse effects in terms of verbal fluency, working memory and processing speed, recent studies show that it does not lead to a general cognitive decline (Castelli et al., 2006; Contarino et al., 2007; Deuschl, 2009; Heo et al. 2008; Witt et al., 2008). Castelli et al. (2006) performed a neuropsychological assessment before and after surgery (n=72) with a mean follow-up of 15 months, focusing on a variety of items related to cognition (e.g. executive functioning, memory). The researchers conclude that the study shows that STN DBS is "cognitively safe" (the only significant change found was a small decrease in verbal fluency tasks, overall 4.5% experienced a relevant decline) (p. 136). Witt et al. (2008) compared a group of individuals receiving DBS (n=60) versus a group receiving the best medical treatment (n=63). They found no differences in scores between both groups in terms of overall cognition, although verbal fluency showed significantly greater declines in the DBS group. However, the observed cognitive impairments after DBS had no effect on the quality of life of these participants. Moreover, the authors report that DBS led to a significant improvement of motor functions and quality of life in the DBS group compared to the best medical treatment group. Weaver et al. (2009) compared an even larger group of patients (n=255) in a randomly assigned trial, and found slight decrements in working memory, processing speed, phonemic fluency and delayed recall in the DBS group (and slight improvement in the best medical therapy group). Nevertheless, the majority of measures assessing language, executive functioning, learning and memory functioning remained unchanged in both groups. Again, the DBS group experienced significantly better results in terms of motor control and quality of life assessment compared to the best medical therapy group.

A meta-analysis by Temel et al. (2006), involving 1398 patients, revealed depression in 8% of patients, hypomania in 4%, anxiety disorders in less than 2% and changes in personality traits and emotional changes (e.g. hyper-sexuality, anxiety, aggressiveness) in less than 0.5% (compared to 41% cognitive changes). Specifically with respect to personality traits, Castelli et al. (2006) found a small improvement in obsessive compulsive and paranoid personality traits (7% experienced a postoperative worsening, while 20% showed a clinically relevant improvement). Other personality traits (e.g. antisocial, schizoid) remained stable. They also found an overall small improvement in mood (although a clinically relevant mood worsening was found in 10% of patients), no overall modification in anxiety or apathy before and after surgery, while thought disorders (i.e., hallucinations and delusions) worsened significantly. One patient experienced psychosis postoperatively. Although disturbances (e.g., worsening of anxiety and mood) in individual cases are found, overall, patients experienced small improvements in mood and specific personality traits. Extreme disturbances (e.g., psychosis) are relatively rare. Houeto et al. (2006) report no changes in patient's personality traits or any adverse psychiatric effects following STN DBS, based upon self-report questionnaires, in 20 patients with PD. A more recent study by Castelli et al. (2008) (n=14) using an explorative test suggests "that there is no evidence of personality change in PD patients submitted to STN-DBS" (p. 8). Specifically, regarding personality traits, mood and related changes, Witt et al. (2008) found that anxiety was significantly reduced, and mood slightly elevated, in the DBS group (n=60) but unchanged in the BMT (n=63)

group. There were no significant changes after DBS in psychiatry scale scores, and an overall improvement in depression was found (although the effect size was small). 12.8% of the DBS group and 10.3% of the BMT group experienced severe psychiatric adverse effects. 4 patients in the DBS group experienced depression, and 4 psychosis. There was one case of apathy, and one suicide. The authors conclude that *most* psychiatric side effects are transient (e.g., depressive symptoms remitted by the time of 6-month follow-up). Moreover, systematic evaluation did not reveal any psychiatric deterioration, which suggests, according to the authors, that such side-effects can indeed be managed (Witt et al., 2008). Weaver et al. (2009) similarly revealed no significant difference in psychiatric side effects. Importantly, quality of life changed significantly in the DBS group, but not in the BMT group.

Recently it has also been shown that DBS in PD can improve drug induced narrative identity changes. Dopamine and especially D3 receptor agonists (such as pramipexole or ropinirole) might be responsible for the development of pathological gambling and hypersexuality in 18.4% of pharmacologically treated PD patients (Bostwick, Hecksel, Stevens, Bower & Ahlskog, 2009). The PG and hypersexuality abates when decreasing the dose or stopping the use of pramipexole or ropinirole. When DBS is successful, and medication can be tapered down this can result in remission of the pathological gambling (Bandini, Primavera, Pizzorno & Cocito, 2007; Smeding et al., 2007; Gallagher, O'Sullivan, Evans, Lees & Schrag, 2007).

Neuropsychiatric disorders

The first study on DBS for severe, treatment-refractory OCD by the Leuven-Antwerp group, involving three patients (two of which were successful at improving symptoms), did not reveal any additional personality disorders other than the ones already present before stimulation, or adverse personality traits after one year of stimulation (Gabiëls, Cosyns, Nuttin, Demeulemeester & Gybels, 2003). In fact, case three failed to fulfill criteria for dependent personality disorder after stimulation, which was diagnosed at baseline. These findings were assessed both by using self-rated personality inventories, as well as by interviewing close family members or peers. A recent study on DBS in severe, treatment-refractory Gilles de la Tourette syndrome, involving eighteen individuals, reports no serious permanent adverse effects (Servello, Porta, Sassi, Brambilla & Robertson, 2008). All four components of the Yale Global Severity Rating Scale improved significantly postoperatively (social impairment is one of them). Co-morbid symptoms such as anxiety and obsessive compulsive symptoms decreased after DBS. Mallet et al. (2008) found no significant effects of stimulation on measures of depression and anxiety in a double-blind, crossover trial of STN stimulation in 17 individuals with OCD. Serious adverse effects (e.g., anxiety, hypomania) were reported in 7 of the patients during stimulation, but none of these persisted. McNeely et al. (2008) found no adverse neuropsychological effects except for transient manual motor slowing (i.e., finger tapping) after DBS for treatment-resistant depression in a 12 month follow-up of 6 individuals. In most cases, performance on various cognitive tasks improved after stimulation. Lozano et al. (2008) report robust improvements in depression in these and 14 additional patients undergoing DBS for treatment-

resistant depression. After 12 months, 55% of participants were 'responders' and 35% of these were in or close to remission. Neuropsychological testing found no cognitive adverse effects.

There are few studies to date on neuropsychiatric conditions that specifically investigate changes in personality traits and cognitive, emotional and mood-related side-effects. Overall, many studies report that possible adverse effects of stimulation, such as an increase in anxiety, are mostly transient and/or subtle (e.g., Greenberg et al., 2006). Greenberg et al. (2010) discuss worldwide findings on DBS for OCD obtained collaboratively over 8 years in four centers, and report that acute stimulation-induced changes in mood, anxiety, cognition, and sensory and motor effects are rapidly reversed with parameter changes (except for one case where hypomania persisted over days). Of course, despite preliminary promising results in terms of cognitive, emotional and mood-related side-effects, promising results from large(r)-scale randomized controlled trials are needed. It is crucial that a standard battery of neuropsychological tests, as well as standardized personality tests, and interviews with patients and family members are conducted pre- and post-operatively. Long-term monitoring of possible changes in personality traits and cognitive, emotional and mood-related side-effects is needed to ensure that patients receive as much information as possible on possible side effects during the informed consent process. Moreover, the patients need to be aware of the possibility of unforeseen side-effects in terms of cognition, personality traits and mood.

Discussion

The above findings show that mild to moderate changes in one's narrative identity are observed in individual cases, while radical alterations are rare. Changes in personality traits, emotions and mood due to DBS are relatively uncommon in PD and neuropsychiatric disorders, and might even be improved if changes in personality traits, emotions or mood are induced by dopamine agonists. Cognitive changes in PD are relatively common, but similar changes are present with medications and whereas best medical therapy doesn't increase quality of life, DBS does. On the one hand, it is important to keep in mind that such side effects, if not transient by themselves, can often be alleviated through parameter change (i.e., changing the site of stimulation), and if necessary, can be reversed by interrupting stimulation. Moreover, recent functional imaging studies of the brain are elucidating the autobiographical self-network (Platek, Keenan, Gallup & Mohamed, 2004; Ruby & Legrand 2007; Buckner, Andrews-Hanna & Schacter, 2008) and its associated personality traits (Gusnard et al. 2003; Turner, Hudson, Butler & Joyce, 2003). So knowing these networks and its major connections can limit the direct modification of personality traits via electrical stimulation. Increasing knowledge of the personality circuits and their modulating systems will therefore decrease the unpredictability of possible narrative identity changes occurring in brain stimulations, decreasing the perceived and real risks involved. On the other hand, it could be argued that certain changes can be beneficial by restoring rather than changing the patient's identity, similarly to what happens in PD. Chronic pain is associated with personality traits such as hypochondriasis and hysteria, and it has been demonstrated that these personality traits assessed in younger adults relate to the number of chronic

pain conditions reported 30 years later (Applegate et al. 2005). However, a (chronic low back) pain condition might also alter narrative identity (Hansen, Biering-Sorensen & Schroll, 1995), based on neuroplasticity of the default networks (Baliki, Geha, Apkarian & Chialvo, 2008) which are involved in self-perception and personality networks (Svoboda, McKinnon & Levine, 2006; Buckner et al., 2008). Hence, it could be suggested that if DBS is successful in removing the narrative identity changing symptom it might restore one's identity that was altered due to the pathology. More studies are needed to fully explore this, but the possibility of restoring one's identity due to neuromodulation techniques is an important concept to be considered in the ethical debate.

We now briefly discuss more general ethical arguments against techniques that have the potential to directly alter narrative identity: (a) socio-economic inequality, (b) fear of using it frivolous reasons, (c) possibility of a slippery slope, and (d) inauthenticity.

- (a) One can argue that neurological interventions might create even larger socio-economic inequality than we are faced with today. This is an important argument that might justify that certain techniques are only used under specific, limited conditions, rather than becoming widely available without restrictions. For example, because higher socio-economic status is already associated with higher intelligence, the argument is made that the availability of neurological enhancements (e.g., by means of electrode implants) will make the gap even greater. The fear exists that such enhancement techniques will only, or mostly, be available to the wealthy or wealthier individuals in society, who are already better off in terms of socio-economic status. Hence, neurological enhancements, if widely available, will add to the already existing socio-economic equality in the world, both within and between countries (Levy, 2007). However, neuromodulation for psychiatric disorders is aimed at alleviating human suffering *under very specific conditions*. Only those individuals that suffer from severe, treatment-refractory psychiatric disorders are considered as potential candidates.
- (b) As DeGrazia (2005) put forward, it could be ethically problematic to pursue brain interventions for frivolous reasons. This is especially the case with respect to neurostimulation via implanted electrodes because of the invasive nature of the procedure. The risks of this procedure are warranted from a cost/benefit perspective if an individual's quality of life is very low and no other treatment is working. Neurostimulation via implanted electrodes is a last-resort technique for severe, treatment refractory disorders. It has been argued that this technique should not be used for enhancement (Kringelbach & Aziz, 2009).
- (c) Opposing DBS for neuropsychiatric disorders because of slippery slope arguments (e.g., creating elite soldiers without a conscience) is not persuasive in the face of severe, treatment-resistant disorders. Moreover, as Merkel et al. (2007) mention: "As *everything* can be misused, the mere fact that it *could* be misused towards unjustified goals cannot count as an argument against it (or we would have to object to even the most banal artefacts, such as hammers)" (281). Potential misuse does not justify withholding beneficial treatments for severe disorders. It does however point to the importance of regulation to make sure that potential misuse can be prosecuted and prevented.

(d) One may oppose neurostimulation via implanted electrodes because of reasons pertaining to authenticity. This argument is, unlike the former arguments, an 'in principle' argument against DBS. DBS has the potential to 'artificially' change one's narrative identity, which runs counter to a so-called 'ethic of authenticity' (Elliot, 1998). However, authenticity arguments are to a greater or lesser extent the expression of a cultural, social or political preference, rather than a purely ethical norm (Bostrom & Sandberg, 2009). Our day to day lives are already immersed by such practices, just think of the use of all sorts of electronic devices to enhance our reasoning skills, diet pills and esthetic surgery to enhance our physical appearance, and the like. In terms of their artificial nature, what makes those kind of interventions any different from DBS? Although inauthenticity claims hold some ethical weight when presented in the enhancement debate (e.g., compromising our appreciation of the given, see, Sandel, 2007), they clearly lack any weight in the treatment debate because of the severe, treatment-refractory nature of these disorders and the potential quality of life improvements. It is therefore up to the patient whether or not the possibility of artificial alteration of his or her narrative identity poses a reason to refrain from treatment.

Conclusion

Overall, from a cost/benefit perspective, the possible benefits of DBS for treatment-resistant neurological and neuropsychiatric disorders outweigh the possible harm of narrative identity change. Even if reasonable more general arguments can be given to avoid alterations of our narrative identity (e.g., in the enhancement debate), opposing DBS for treatment-refractory disorders for such reasons is not ethically defensible. These arguments are overridden by the severity of these disorders and the amount of suffering involved, as well as the extent to which a patient's quality of life can be improved due to neuromodulation techniques. Indeed, successful stimulation can restore self-control and thereby increase a patient's quality of life tremendously. In relation to neurostimulation for PD, Glannon (2007) states that "It can mean the difference between having no control and having a considerable control over one's body and life" (p. 137). Similarly, by successfully reducing the symptoms of severe neuropsychiatric disorders, patients may regain control of their own life. In this debate, involving individuals with severe, treatment-resistant psychiatric disorders, it is the patient who should decide if the possibility of narrative identity change is a reason to refrain from treatment (provided that the individual in question is fully informed and has decision-making capacity). In order to achieve valid informed consent, potential narrative identity changes need to be comprehensibly communicated to the participants in question. In case of research, patient selection should be limited to individuals with decision-making capacity, except in very specific cases where proxy consent may be warranted (e.g., individuals with early onset dementia and combined chronic, extreme, treatment-resistant aggression). DBS research in individuals with end-stage Alzheimer's disease is ethically controversial. However, a categorical exclusion of these individuals is equally dubious if sufficient evidence for possible benefits exists (Kuhn et al., 2009). In case of Alzheimer's disease or minimally conscious individuals, advance directives may provide a partial solution. Minors should

be excluded from DBS research protocols. In case of treatment-refractory disorders for which DBS has been accepted as a standard treatment, such as treatment-refractory movement disorders, parent proxy consent is warranted provided that the children or adolescents in question take part in the decision-making process according to age and competency.

References:

- Applegate, K.L., Keefe, F.J., Siegler, I.C., Bradley, L.A., McKee, D.C., Cooper, K.S., & Riordan, P. (2005). Does personality at college entry predict number of reported pain conditions at mid-life? A longitudinal study. *Journal of Pain*, 6, 92-97.
- Baliki, M.N., Geha, P.Y., Apkarian, A.V., & Chialvo, D.R. (2008). Beyond feeling: Chronic pain hurts the brain, disrupting the default-mode network dynamics. *Journal of Neuroscience*, 28, 1398-1403.
- Bandini, F., Primavera, A., Pizzorno, M., & Cocito, L. (2007). Using STN DBS and medication reduction as a strategy to treat pathological gambling in Parkinson's disease. *Parkinson & Related Disorders*, 13, 369-371.
- Bavelier, D., & Neville, H. (2002). Developmental Neuroplasticity. in Ramachandran, V. (Ed.) *Encyclopedia of the Human Brain* (pp. 561-578). Amsterdam: Academic Press.
- Benabid, A.L., Pollak, P., Louveau, A., Henry, S., & de Rougemont, J. (1987). Combined (thalamotomy and stimulation) stereotactic surgery of the VIM thalamic nucleus for bilateral Parkinson disease. *Applied Neurophysiology*, 50, 344-346.
- Bond, A.J. (2001). Neurotransmitters, temperament and social functioning. *European Neuropsychopharmacology*, 11, 261-274.
- Bostrom, N., & Sandberg, A. (2009). Cognitive enhancement: Methods, ethics, regulatory challenges. *Science and Engineering Ethics*, 15, 311-341.
- Buckner, R.L., Andrews-Hanna, J.R., & Schacter, D.L. (2008). The brain's default network: anatomy, function, and relevance to disease. *Annals of the New York Academy of Sciences*, 1124, 1-38.
- Bussone, G., Franzini, A., Cecchini, A.P., Mea, E., Curone, M., Tullo, V., Broggi, G., Casucci, G., Bonavita, V., & Leone, M. (2007). Deep brain stimulation in craniofacial pain: seven year's experience. *Neurological Sciences*, 28, S146-S149.
- Carver, C.S., Miller, C.J. (2006). Relations of serotonin function to personality: current views and a key methodological issue. *Psychiatry Research*, 144, 1-15.
- Castelli, L., Perozzo, P., Zibetti, M., Crivelli, B., Morabito, U., Lanotte, M., Cossa, F., Bergamasco, B., & Lopiano, L. (2006). Chronic deep brain stimulation of the subthalamic nucleus for Parkinson's disease: Effects on cognition, mood, anxiety and personality traits. *European Neurology*, 55, 136-144.
- Castelli, L., Perozzo, P., Caglio, M., Rizzi, L., Zibetti, M., Lanotte, M., & Lopiano, L. (2008). Does subthalamic stimulation induce personality modifications in Parkinson's disease? A Rorschach test explorative study. *Acta Neurologica Belgica*, 108, 5-8.
- Chou, Y-C., Lin, S-Z., Hsieh, W.A., Lin, S.H., Lee, C.C., Hsin, Y.L., Yen, P.S., Lee, C.W., Chiu, W-T., & Chen, S-Y. (2007). Surgical and hardware complications in subthalamic nucleus deep brain stimulation. *Journal of Clinical Neurosurgery*, 14, 634-649.
- Contarino, M.F., Daniele, A., Sibilia, A.H., Romito, L.M.A., Bentivoglio, A.R., Gainotti, G., & Albanese, A. (2007). Cognitive outcome five years after bilateral chronic stimulation of subthalamic nucleus in patients with Parkinson's disease. *Journal of Neurology*,

- Neurosurgery & Psychiatry*, 78, 248-252.
- DeGrazia, D. (2005). Enhancement technologies and human identity. *Journal of Medicine and Philosophy*, 30, 261-283.
- Depue, R.A., & Collins, P.F. (1999). Neurobiology of the structure of personality: dopamine, facilitation of incentive motivation, and extraversion. *Behavioral and Brain Sciences*, 22, 491-517; discussion, 518-469.
- Deuschl, G. (2009). Neurostimulation for Parkinson Disease. *Journal of the American Medical Association*, 301, 104-105.
- Elliott, C., (1998). The tyranny of happiness: Ethics and cosmetic psychopharmacology. In Parens, E. (Ed.) *Enhancing human traits. Ethical and social implications* (pp. 177-188). Washington: Georgetown University Press.
- Gabriëls, L., Cosyns, P., Nuttin, B., Demeulemeester, H., & Gybels, J. (2003). Deep brain stimulation for treatment-refractory obsessive-compulsive disorder: psychopathological and neuropsychological outcome in three cases. *Acta Psychiatrica Scandinavica*, 107, 275-282.
- Gallagher, D.A., O'Sullivan, S.S., Evans, A.H., Lees, A.J., & Schrag, A. (2007). Pathological gambling in Parkinson's disease: Risk factors and differences from dopamine dysregulation. An analysis of published case series. *Movement Disorders*, 22, 1757-1763.
- Glannon, W. (2007). *Bioethics and the brain*. Oxford: Oxford University Press.
- Glannon, W. (2009). Stimulating brains, altering minds. *Journal of Medical Ethics*, 35, 289-292.
- Greenberg, B.D., Malone, D.A., Friehs, G.M., Rezai, A.R., Kubu, C.S., Malloy, P.F., Salloway, S.P., Okun, M.S., Goodman, W.K., & Rasmussen, S.A. (2006). Three-year outcomes in deep brain stimulation for highly resistant obsessive compulsive disorder. *Neuropsychopharmacology*, 31, 2384-2393.
- Greenberg, B.D., Gabriëls, L.A., Malone, D.A. Jr., Rezai, A.R., Friehs, G.M., Okun, M.S., Shapira, N.A., Foote, K.D., Cosyns, P.R., Kubu, C.S., Malloy, P.F., Salloway, S.P., Giftakis, J.E., Rise, M.T., Machado, A.G., Baker, K.B., Stypulkowski, P.H., Goodman, W.K., Rasmussen, S.A., & Nuttin, B.J. (2010). Deep brain stimulation of the ventral internal capsule/ventral striatum for obsessive-compulsive disorder: worldwide experience. *Molecular Psychiatry*, 15, 64-79.
- Gusnard, D.A., Ollinger, J.M., Shulman, G.L., Cloninger, C.R., Price, J.L., Van Essen, D.C., & Raichle, M.E. (2003). Persistence and brain circuitry. *Proceedings of the National Academy of Sciences USA*, 100, 3479-3484.
- Hansen, F.R., Biering-Sorensen, F., & Schroll, M. (1995). Minnesota Multiphasic Personality Inventory profiles in persons with or without low back pain. A 20-year follow-up study. *Spine*, 20, 2716-2720.
- Hardesty, D.E., & Sackeim, H.A. (2007). Deep brain stimulation in movement and psychiatric disorders. *Biological Psychiatry*, 61, 831-835.
- Heo, J.-H., Lee, K.-M., Paek, S.H., Kim, M.-J., Lee, J.-Y., Kim, J.-Y., Cho, S.-Y., Lim, Y.H., Kim, M.-R., Jeong, S.Y., & Jeon, B.S. (2008). The effects of bilateral subthalamic nucleus deep brain stimulation (STN DBS) on cognition in Parkinson disease. *Journal of the Neurological Sciences*, 273, 19-24.
- Houeto, J.-L., Mallet, L., Mesnage, V., Tezenas du Montcel, S., Béhar, C., Gargiulo, M., Tornay, F., Pelissolo, A., Welter, M.-L., & Agid, Y. (2006). Subthalamic stimulation in Parkinson Disease. Behavior and social adaptation. *Archives of Neurology*, 63, 1090-1095.
- Kringelbach, M.L., & Aziz, T.Z. (2009). Deep brain stimulation. Avoiding the errors of psychosurgery. *Journal of the American Medical Association*, 301, 1705-1707.
- Kuhn, J., Gaebel, W., Klosterkoetter, J., & Woopen, C. (2009). Deep brain stimulation as a new therapeutic approach in therapy-resistant mental disorders: ethical aspects of investigational treatment. *European Archives of Psychiatry and Clinical Neuroscience*, 259, S135-S141.
- Levy, N. (2007). *Neuroethics. Challenges for the 21st Century*. Cambridge, UK: Cambridge University Press.
- Lozano, A.M., Mayberg, H.S., Giacobbe, P., Hamani, C., Craddock, R.C., & Kennedy, S.H. (2008). Subcallosal cingulate gyrus deep brain stimulation for treatment-resistant depression. *Biological Psychiatry*, 64, 461-467.
- Mallet, L., Polosan, M., Jaafari, N., Baup, N., Welter, M.-L., Fontaine, D., Tezenas du Montcel, S., Yelnik, J., Chéreau, I., Arbus, C., Raoul, S., Aouizerate, B., Damier, P., Chabardès, S., Czernecki, V., Ardouin, C., Krebs, M.-O., Bardinet, E., Chaynes, P., Burbaud, P., Cornu, P., Derost, P., Bougerol, T., Bataille, B., Mattei, V., Dormont, D., Devaux, B., Vérin, M., Houeto, J.-L., Pollak, P., Benabid, A.-L., Agid, Y., Krack, P., Millet, B., & Pelissolo, A. (2008). Subthalamic Nucleus Stimulation in Severe Obsessive-Compulsive Disorder. *The New England Journal of Medicine*, 359, 2121-2134.
- Mayberg, H.S., Lozano, A.M., Voon, V., McNeely, H.E., Seminowicz, D., Hamani, C., Schwab, J.M., & Kennedy, S.H. (2005). Deep brain stimulation for treatment-resistant depression. *Neuron*, 45, 651-660.
- McNeely, H.E., Mayberg, H.S., Lozano, A.M., & Kennedy, S.H. (2008). Neuropsychological impact of Cg25 deep brain stimulation for treatment-resistant depression. Preliminary results over 12 months. *The Journal of Nervous and Mental Disease*, 196, 405-410.
- Merkel, R., Boer, G., Fegert, J., Galert, T., Hartmann, D., Nuttin, B., & Rosahl, S. (2007). *Intervening in the brain. Changing psyche and society*. Berlin: Springer.
- Miller, G. (2009). Rewiring faulty circuits in the brain. *Science*, 323, 1554-1556.
- Olson, E.T. (2008). Personal identity. Stanford Encyclopedia of Philosophy. <http://plato.stanford.edu/entries/identity-personal/>
- Pascual-Leone, A. (2006). Disrupting the brain to guide plasticity and improve behavior. *Progress in Brain Research*, 157, 315-329.
- Platek, S.M., Keenan, J.P., Gallup, G.G.Jr., Mohamed, F.B. (2004). Where am I? *The neurological correlates of self and other*. *Brain Research, Cognitive Brain Research*, 19, 114-122.
- Ruby, P., & LeGrand, D. (Eds.) (2007). *Neuroimaging the self*. Oxford: Oxford University Press.
- Sandel, M.J. (2007). *The case against perfection*. Boston: Harvard University Press.
- Schechtman, M. (1996). *The constitution of selves*. Ithaca, London: Cornell University Press.
- Schermer, M. (2009). Changes in the self: The need for conceptual research next to empirical research. *The American Journal of Bioethics - Neuroscience*, 9, 45-47.
- Servello, D., Porta, M., Sassi, M., Brambilla, A., & Robertson, M.M. (2008). Deep brain stimulation in 18 patients with severe Gilles de la Tourette syndrome refractory to treatment: the surgery and stimulation. *Journal of Neurology, Neurosurgery and Psychiatry*, 79, 136-142.
- Smeding, H.M.M., Goudriaan, A.E., Foncke, E.M.J., Schuurman, P.R., Speelman, J.D., & Schmand, B. (2007). Pathological gambling after bilateral subthalamic nucleus stimulation in Parkinson disease. *Journal of Neurology, Neurosurgery & Psychiatry*, 78, 517-519.

- Svoboda, E., McKinnon, M.C., Levine, B. (2006). The functional neuroanatomy of autobiographical memory: A meta-analysis. *Neuropsychologia*, 44, 2189-2208.
- Temel, Y., Kessels, A., Tan, S., Topdag, A., Boon, P., Visser-Vandewalle, V. (2006). Behavioural changes after bilateral subthalamic stimulation in advanced Parkinson disease. A systematic review. *Parkinsonism and Related Disorders*, 12, 265-272.
- Turner, R.M., Hudson, I.L., Butler, P.H., & Joyce, P.R. (2003). Brain function and personality in normal males: a SPECT study using statistical parametric mapping. *Neuroimage*, 19, 1145-1162.
- Weaver, F.M., Follett, K., Stern, M., Hur, K., Harris, C., Marks, W.J. Jr., Rothlind, J., Sagher, O., Reda, D., Moy, C.S., Pahwa, R., Burchiel, K., Hogarth, P., Lai, E.C., Duda, J.E., Holloway, K., Samii, A., Horn, S., Bronstein, J., Stoner, G., Heemskerk, J., & Huang, G.D. (2009). Bilateral deep brain stimulation vs best medical therapy for patients with advanced parkinson disease: A randomized controlled trial. *Journal of the American Medical Association*, 301, 63-73.
- Wichmann, T., & DeLong, M.R. (2003). Pathophysiology of Parkinson's disease: The MPTP primate model of the human disorder. *New York Academy of Sciences*, 991, 199-213.
- Witt, K., Daniels, C., Reiff, J., Krack, P., Volkmann, J., Pinski, M.O., Krause, M., Tronnier, V., Kloss, M., Schnitzler, A., Wojtecki, L., Bötzel, K., Danek, A., Hilker, R., Sturm, V., Kupsch, A., Karner, E., Deuschl, G. (2008). Neuropsychological and psychiatric changes after deep brain stimulation for Parkinson's disease: a randomised, multicentre study. *The Lancet Neurology*, 7, 605-614.

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Core Strategies for the Development of a Clinical Neuroethics Education Program for Medical Residents in the Clinical Neurosciences

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ABSTRACT

Advances in clinical neuroscience have created an unprecedented need for medical residents in the clinical neurosciences to discuss and learn pragmatic approaches to ethics. The challenges of ethics in the clinical neurosciences involve a wide range of issues that span acute interventions in the neurosurgical theatre to long-term care for individuals living with mental illness in the community. Often, these challenges involve difficult treatment and end-of-life decision-making, and have become even more significant in the face of rapid scientific progress. Past research suggests that physician proficiency in clinical ethics is limited largely to experiential learning with little formal training or exposure to scholarly material. Furthermore, knowledge of ethical issues relating specifically to the brain sciences is unknown. This paper is an invited follow-up to the first presentation of a pilot educational program designed to bring neuroethics to the forefront of medical training and practice for medical residents in Neurology, Neurosurgery, and Psychiatry, presented at the Brain Matters Conference held in Halifax, Nova Scotia in September 2009. We describe core components of the program here, including journal clubs on tough neuro-clinical cases, seminars on cutting edge topics in neuroethics, and opportunities for residents to innovate in research. We compare and contrast the relative strengths and limitations of the strategies implemented, and present a vision for next steps based on what we have learned to date.

Key words: clinical neuroethics; clinical neuroscience; education; medical residents.

Introduction

In this paper we describe a new education program in ethics for medical residents in the clinical neurosciences – Clinical Neuroethics – that integrates teaching material from medicine, neuroscience, and biomedical ethics. Our approach to the initiative is characterized by interdisciplinary engagement, learner-centered curricula and inquiry-based learning. The emergent field of neuroethics in which we ground our efforts lies at the intersection of novel developments in neurotechnology and the implications of those developments for society, in the laboratory, the home, the courthouse, the classroom, and the clinic. Neuroethics integrates research ethics in the biomedical sciences and public health ethics with brain science and neuro- and moral philosophy. Scholars in neuroethics study the relevant ethical, legal, social, cultural, policy, and clinical challenges associated with new ways to think about, maintain and manipulate brain function.

In this context, (1) we explore the importance of ethics education and training in the clinical neurosciences; and (2) we describe our approach to complementing existing ethics requirements established for example, in Canada, by professional organizations such as the Royal College of Physicians and Surgeons of Canada (RCPSC) and the British Columbia College of Physicians and Surgeons (BCCPS). The

program is still in its nascent phases and evolves with continual input and evaluation by participating residents from Neurology, Neurosurgery and Psychiatry.

Ethics Education in Clinical Neuroscience Training

Ethics in clinical medicine has enjoyed a long history since Hellenistic and Roman times. Modern landmark cases in both medical research and clinical practice, such as the infamous Nuremberg trials, Tuskegee Syphilis experiments and The Willowbrook Study, brought issues in medical ethics to a greater public awareness than ever before. Clinical ethics, as a formalized discipline, emerged as a branch of applied biomedical ethics in the early 1970s to proactively address complex ethical issues that arise in healthcare settings.

Within the last thirty years, teaching the foundations of medical ethics has emerged as a priority within the medical establishment, and all North American medical schools now require that ethics be incorporated into the curriculum. The integration of ethics activities at the resident level is a more recent phenomenon as, up through the early 1980s, many residency directors, at least in the United States, did not consider ethics to be a valuable asset to resident education (Perkins, 1989).

Despite the Accreditation Council for Graduate Medical Education requirements for bioethics training for Neurology residents (ACGME, 2008), efforts have been made only recently to increase the availability of ethics education for residents in the clinical neurosciences. The American Academy of Neurology (AAN) has developed an Ethics Section on its website (AAN, 2008), in addition to offering a Neurology elective in clinical ethics. In Canada, the RCPSC requires residency training programs to teach biomedical ethics as a condition of accreditation (RCPSC, 2004) and maintains a well-developed online Bioethics Education Project that includes cases, primers in areas such as moral theory and research ethics, educational objectives, and the opportunity to participate in interactive modules. Despite these significant strides in North American residency training and accreditation, it is unclear whether residents effectively, efficiently, and appropriately address ethical issues as they arise, either generally or in the specific domain of neuroscience and emerging neurotechnologies for diagnosis, prediction of disease and intervention. In one past study, Schuh and Burdette (2004) evaluated a case-based ethics curriculum for Neurology residents developed by the American Academy of Neurology's Ethics, Law and Humanities Committee. Post-survey satisfaction scores improved over pre-participation scores by 19%. Many residents reported that the course increased their confidence in understanding and addressing ethical issues in practice, and that the time commitment required was acceptable. Another study for neurology residents was performed by Watling and Brown (2007) who were concerned with the limited communication training available to residents. Neurology residents participated in six case-based pilot workshops that emphasized skills and ethically reflective practice. In post-test evaluations of this program, residents rated the workshops as effective and relevant.

The education program in Clinical Neuroethics that we discuss

here builds upon such past efforts and on the strong foundation for ethical awareness and practice established by the AAN and RCPSC. The Program provides a scaffold for ethics content about specific clinical neuroscience contexts and encourages residents to inform their own ethics training by identifying cases and issues that are most relevant to their practice. In this regard, this program serves the dual purpose of providing an educational platform to medical residents specifically about ethical challenges in the neurosciences, and creating a forum for active dialogue.

Foundations of an Educational Model

It has been suggested that knowledge dissemination in the sciences is most effective when it places person-centered, experiential knowledge and situational analysis on par with factual findings (Miles, Lane, Bickel, Walker, & Cassel, 1989; Kothari, et al., 2005). Understanding the dynamics of interpersonal connections and decision-making therefore must be at the centre of curriculum and instruction. As we have discussed elsewhere (Buchman, Lomber, Venkatachary, Tairyan, & Illes, forthcoming), learning simultaneously transforms what one knows and what one practices when this is achieved. Like Gagne (1980) who believed that "the central point of education is to teach people to think, to use their rational powers and to become better problem solvers" (p. 85), our conceptual framework for clinical neuroethics education reflects communication, responsiveness and non-hierarchical relationships between the constituencies of researchers, clinical practitioners and ultimately the translators of the knowledge of these relationships to clinical practice. Indeed, our goal is to reduce the gap between 'know what' and 'know how'.

Vygotsky (1978) argued that education is a matter of engaging learners within their zone of proximal development. This zone is the space that falls between what learners can do on their own and what they can do with expert guidance. In alignment with this view, the humanities have historically embraced a developmental approach to education under the premise that learning is a personal search for meaning. In such a developmental approach, teachers and programs support the learners through dialogue and questioning. We embody these principles in two key related features of our Clinical Neuroethics education program:

- (1) A commitment to exploring the foundations of biomedical ethics deeply with resident physicians and to translate these foundations into practice in the clinical neurosciences.
- (2) A focus on the process of addressing ethical issues through dialogue and reflection.

The second feature has been highlighted before by others as a *hidden curriculum* (Hafferty & Franks, 1994; Miles, Lane, Bickel, Walker, & Cassel, 1989), one that implicitly fosters collaboration, communication, problem solving, and critical and creative thinking as fundamental competencies. Our approach to program design, development, implementation and evaluation takes the learners on board in such a partnership role.

Clinical Neuroethics for Medical Residents in the Clinical Neurosciences

Foundational Principles

In Jonsen, Siegler and Winslade's (1998) seminal work, *Clinical Ethics*, the authors define clinical ethics as "a practical discipline that provides a structured approach for identifying, analyzing, and resolving ethical issues in clinical medicine" (p. 1). The authors note that medicine – and by extension all healthcare – is a process of engagement and exchange between human beings and thus resides within a moral context. Scholarly engagement and skill development in neuroethics, like bioethics, is not an innate skill and requires specialized training. Singer, Pellegrino and Siegler (2001) conceive of the process of *being ethical* as a series of professional skills. Learning and developing professional skills and traits – practical wisdom – reflects an agent-based virtue ethic that places the integrity of the clinician, and virtues such as trust, benevolence, and compassion, at the core of clinical medicine (Lakhan, Hamlet, McNamee, Laird, 2009; Pellegrino, 2002). This notion of practical wisdom is reflected in the Aristotelian virtue of *phronesis*. To possess *phronesis* is to develop capacity to consider the method and action to promote change, particularly in improving quality of life (Aristotle, 1999). Indeed, competency in ethics is associated with increased quality of patient care (Goold & Stern, 2006),

A Pragmatic Approach

There is considerable debate about whether teaching the "virtues of medical professionalism" is too vague of a mandate for medical education. Some scholars argue that medical professionalism may not be a value than can be taught, particularly if taught by ethicists (Buyx, Maxwell, & Schöne-Seifer, 2008). Indeed, practical wisdom may be best absorbed experientially through bedside work and interactions with physician mentors. Accordingly, the Clinical Neuroethics program is intended to be a piece of a bigger puzzle insofar as it is designed to illuminate a path for medical residents to adapt themselves to the challenges of the bedside and to develop the ability to translate ethical reasoning into medical action.

Our working hypothesis is that by engaging medical residents in clinical neuroethics their ability to care for patients and families will improve through heightened critical reflection on the ethical underpinnings of their work. Our approach is pragmatic. We focus on challenging clinical ethics issues that exist in real-world settings and embrace different points of view. To achieve real, work-able solutions, we use a methodology that supports inquiry, discussion, negotiation, and reflection (Fins, Bacchetta & Miller, 2003) about the many contextual variables at play in any particular case (e.g., religious views of the patient, family structure, socioeconomic status, legal parameters of the jurisdiction). The approach relies on a loose principle-based framework that guides deliberation in diverse scenarios rather than on fixed ethical principles. It is entirely in keeping with the four pragmatic objectives of the ethics education program for Neurologists at the American Academy of Neurology (Fryer-Edwards, 2009) to:

- foster trainee professional development
- provide knowledge, skills, attitudes that will lead to improved patient care

- integrate multidisciplinary with relevance to clinical practice
- pursue rigorous standards and clear expectations and benchmarks for achievements.

The Program

Program Launch

The Clinical Neuroethics program is designed to expand critical thinking skills with regard to clinical ethics and to fortify cutting-edge clinical neuroscience and technology research with ethics knowledge. At this stage, delivery of the program is executed in discipline-specific groups: \neg Neurology, Neurosurgery, and Psychiatry. Content and discussion are tailored to each group's particular interests. Consider, for example, different views on answers to questions such as: Will advances in neuroscience shed light on issues of decision-making capacity in individuals who experience symptoms of psychosis? How will psychiatry use this knowledge to respond to issues of autonomy and shared medical decision-making? What ought a resident in neurosurgery consider when obtaining consent from an individual for deep brain stimulation when all other treatment efforts for depression have failed? What discussions are needed with families who, through the exuberance of the media, hear of hopeful treatment for conditions such as minimal states of consciousness but for which research is not ready to be applied clinically? What are the obligations for the ethical management and allocation of medical resources for brain diseases for which there are no cures in a public health system? The opportunity to engage residents in joint, cross-disciplinary sessions that can bring greater breadth to these vital discussions in ethics is a goal for the future.

To establish a baseline of substantive ethics content, we provide a primer in biomedical ethics during initial sessions based largely on the "four principles": respect for autonomy, beneficence, non-maleficence, and justice (Beauchamp & Childress, 2001). Given our pragmatic approach and residents' previous exposure to foundational concepts in biomedical ethics, our ethics education model quickly moves beyond consideration of these principles and focuses on resident-generated tough case discussions. Here the emphasis is on didactic teaching where the residents inform the pedagogical output upstream (Reimschisel, 2009). For instance, during initial brainstorming sessions, residents in neurosurgery indicated that they were interested in learning about the current state of the bioethics literature with regard to deep brain stimulation to treat symptoms of Parkinson's disease and treatment-resistant depression. To meet the need, we engaged the residents in a journal club based on a case study of a patient who revoked consent during awake craniotomy for the implantation of deep brain stimulation electrodes (Ford et al., 2007). This case stimulated considerable discussion on issues of capacity, consent, safety and autonomy, and prompted an evaluation of a risk-benefit calculus for this type of procedure as compared to other less non-invasive neurosurgical operations. Several neurosurgery residents discussed the possibility that the patient may have incurred more harm by demanding that the procedure be stopped. Others suggested that the patient's expressed wishes at the time of the surgery must be honored in consideration of autonomy, irrespective of any possible future benefit that the surgeons believed might result from the

intervention. By contrast, one resident challenged the autonomy position altogether, arguing that the patient lacked capacity to make a decision as serious as to revoke consent.

A different but noteworthy experience emerged in a session with the psychiatry residents. When planning a journal club, the residents in psychiatry suggested another approach - they preferred to discuss a tough case that was drawn from our files. For this particular journal club, we developed "The Case of the Model HIV Patient, Parts I & II" (Box 1). Through the course of the discussion, and drawing upon the methodology of casuistry (Jonsen, 1991), we offered prompts and parallels so that the psychiatry residents had opportunity to consider many facets of the case, possible ethical analytical approaches, and similarities to other classic and contemporary cases. The psychiatry residents were able to refer to bioethical principles and values such as autonomy, beneficence/nonmaleficence, and the duty to care, and drew heavily upon their own experiential knowledge and learning. Accordingly, they informed the content of this session in a different but equally valuable way than the residents in neurosurgery: the psychiatry residents molded a didactic experience to best address their learning needs.

We have also developed a tough case template that residents can use to report or create, real or fictional, challenging ethics-related cases. We use those submissions to directly inform content of future interactive sessions. The design and structure of the template has undergone several iterations informed by feedback from the residents themselves, culminating in a format that primarily accommodates narrative descriptions about the details and concerns about a case. In addition to substantial room for case description, the template features baseline questions such as, "Are other services involved?" "Does the patient have contributing co-morbidities?" "Capacity to make decisions?" "An advance directive?" "Surrogate decision-maker?". The template has inspired significant documentation of tough clinical cases, and requests have been made from various departments for electronic access and wide accessibility.

Initial "tough case" submissions served as a means for residents to frame and transmit their first learning needs. For one early Neurology resident journal club, we chose two provocatively titled cases - the "Case of the Life Not Worth Living" and the "Case of the Life Not Worth Saving" (Box 2) - that could be informed by the same ethics frameworks and concepts. We worked through them in the following three-step format:

1. presentation of the cases and ethical concerns
2. presentation of fundamental ethical frameworks, concepts, and/or "classic" cases to inform ethical analysis
3. in-depth, interactive discussion of the cases

The cases of the 'lives not worth living and saving' were mapped onto a background of models of patient-physician relationships and concepts of respect for persons (what it does and does not mean), quality of life (what it means and who defines it), and medical futility. The deliberation was stimulating, if not cathartic - residents postulated how they might beneficially handle similar cases and questions in future practice, and reflected on past cases in a meaningful way.

Program Evaluation

Formal measurements of the strengths and weaknesses of the program over the long-term will be critical to its ensuring success. To date, we can report on preliminary evaluations by neurosurgery, psychiatry, and neurology residents about their respective clinical neuroethics sessions that are largely positive and constructive. The evaluations are provided using a standardized Likert-scale questionnaire (1: strongly agree - 5: strongly disagree), with an optional comments section. Each resident group evaluated their most recent session, for instance psychiatry evaluated the discussion of "The Case of the Model HIV Patient" (Box 1), and neurology and neurosurgery on tough cases in medical futility. Across all resident groups (n = 34), 97% of residents reported that their respective session was relevant to their practice and 85% agreed that they learned something new. Of the 5 evaluators who did not agree that they learned something new, 3 were neutral and 2 disagreed.

Next Steps

Encouraged by the positive response to the program to date, we will continue on the trajectory described here and, in addition, expand the program in several new directions: resource materials, electronic newsletter, and community engagement. One arm of the new resource materials is a glossary of useful terms, literature and cornerstone cases in Clinical Neuroethics that we are developing in response to resident requests for relevant background in basic terminology, seminal texts, and practical resources. The glossary is designed to be concise rather than encyclopedic, with rapid access to front-line information and links to extensive readings. The second arm of the resources initiative is a Clinical Neuroethics Resource Guide with listings of local clinical ethics consultant and committee contact information, relevant journals, and texts that highlight and support the clinical ethics structures already established within our local community represented by the Vancouver Coastal Health Authority.

The electronic newsletter is intended to keep busy residents up-to-date with relevant readings, activities, and case analyses. It will also be made widely available in print and online to faculty and allied health professionals in the community. Inspired by the international network of successful science cafes (www.cafescientifique.com), we look forward to piloting and evaluating a community engagement initiative we are calling "Café Neuroethique." Characterized by its informal setting, open invitation to the local medical, academic, and public communities, and cooperative approach, the forum aims to stimulate discourse around issues relevant to neuroethics, to provide information in an accessible manner, and to inspire further consideration, collaboration, and research in the community.

Conclusions

Training in ethics that has both roots in bioethics and is up to date with clinical neuroscience promises to positively impact quality of care at the bedside. Competency in ethics, like practical wisdom, takes time to mature. It requires an examination of the particular

situation at hand, space for dialogue, reflection on decisions made and those in progress, and opportunity for collaboration.

In reflecting upon the guiding principles for the Clinical Neuroethics program and pilot experiences, we summarize our approach to shaping education in neuroethics as follows:

- We start with the learner's/resident's point of view and use experiential bridges between the learner's experience, ways of knowing, and educational goals.
- We continually incorporate resident direction and feedback.
- We aim to develop a responsive curriculum that is relevant and meaningful to the residents' own practice and ethical challenges.

Creativity and flexibility are core factors in ensuring a close alignment of ethics instruction, neuroscience advancements, and clinical practice. In an era of constant progress in clinical neuroscience, our ultimate goal mirrors that of medical educators and trainees – parallel progress in clinical neuroethics and quality of care.

Case of the Model HIV Patient – Part I

Mr. Jones is a 40-year-old white male with diagnoses of both bipolar disorder and HIV. He has been HIV positive for approximately 10 years, and his physician describes him as “a model HIV patient” – he is diligent with his treatment, engaged in understanding his disease, and never misses a dose of medication or a check-up. Rigorous maintenance of HIV treatment is, he understands, essential to the mitigation of his viral load and the delay of AIDS onset.

In addition to a physician for HIV, Mr. Jones regularly sees a psychiatrist for treatment of his bipolar disorder. As a young man, he initially accepted treatment for bipolar disorder but later took a prolonged “vacation” from medication until his mid thirties. At the time, he found the vacation “liberating” and believed that it allowed him to “think at his full capacity.” His behavior was frenetic, marked by risky sexual promiscuity and drug use. It is likely that Mr. Jones contracted HIV and infected others during his manic states in this period. Following the strong recommendation of his physician, Mr. Jones renewed efforts to treat his bipolar disorder in order to stabilize his mood and behavior.

Today he presents to his psychiatrist's office complaining that – despite several years of attempting different medications and dosages – he still feels “muted” by his bipolar disorder medications, faces uncomfortable side effects, and prefers the way he experiences life off medication. Mr. Jones announces that he intends to stop taking medication for bipolar disorder entirely and asks for advice about weaning.

The psychiatrist believes that Mr. Jones' prognosis without medication is poor at best and fatal at worst. The psychiatrist is also concerned that if Mr. Jones stops his medication he may re-engage in his risky sexual behaviors. It is his professional opinion that medication is directly necessary to manage bipolar disorder and indirectly necessary to manage HIV.

Case of the Model HIV Patient – Part II

As a technologically savvy psychiatrist, you are aware of the hotbed of imaging studies on bipolar disorder as well as the remarkable impact that brain scans have on decision-making. For example, individuals are more likely to accept muddy scientific reasoning if it is illustrated with a scan (McCabe, 2008) and surveyed patients predict an increased willingness to maintain treatment if their mental illness is “legitimized” with an image (Illes, 2008).

You are also aware of the limitations of current imaging technology as it applies to psychiatric diagnosis and treatment.

Would you consider ordering a scan for Mr. Jones, knowing that it could make his disorder “real” to him and convince him to continue treatment (and, indirectly, potentially prolong his life in a significant way)?

Box 1. Example psychiatry cases

Case of a Life Not Worth Living

A 50-year old man is in the ICU. After a lung transplant 20 years earlier, his lung function is now limited such that he is ventilator dependent at night. He is tracheostomised, and he faces recurrent infection with multi-drug resistance. The patient is awake, however, and can still be taken on outings with great effort.

In light of his situation, the ICU staff convinces the patient that his life is not worth living and that he should not use the ventilator any further.

Case of a Life Not Worth Saving

60-year old male was admitted with a right anterior cerebral artery stroke and a right middle cerebral artery stroke. These contributed to an increased risk of herniation. The neurology team felt that a hemicraniotomy would save the patient's life. Neurosurgery felt that it would not save quality of life, however.

Surgery was not done, and the patient died due to herniation.

Box 2. Example neurology “tough cases.”

References:

- Accreditation Council for Graduate Medical Education [ACGME]. (2009). *Accreditation Council for Graduate Medical Education*. Retrieved October 30 2009, from <http://www.acgme.org/acWebsite/home/home.asp>
- American Academy of Neurology [AAN]. (2009). *Ethics section -- American Academy of Neurology*. Retrieved October 30, 2009, from <http://www.aan.com/?page=295.133.35>
- Aristotle. (1999). *Nicomachean ethics*. (T.H. Irwin, trans.) Indianapolis: Hackett Publishing Company.
- Beauchamp, T.L., & Childress, J.F. (2001). *Principles of biomedical ethics* (5th ed.). New York: Oxford University Press.

- Buchman, D., Lombera, S., Venkatachary, R., Tairyan, K., & Illes, J. Interdisciplinary Education and Knowledge Translation Programs in Neuroethics. In (E. Slingerland & M. Collard, Eds) *Integrating the Sciences and the Humanities*, Oxford University Press. Forthcoming.
- Buyx, A.M., Maxwell, B., Schöne-Seifer, B. (2008). Challenges of educating for medical professionalism: Who should step up to the line? *Medical Education*, 42(8), 758-764.
- Fins, J.J., Bacchetta, M.D., Miller, F.G. (2003). Clinical pragmatism: A method of moral problem solving. In G. McGee (Ed.). *Pragmatic Bioethics*, 2nd Ed. (pp.39-44). Boston: The MIT Press.
- Ford, P.J., Boulis, N.M., Montgomery, E.B., Rezai, A.R. (2007). A patient revoking consent during awake craniotomy: An ethical challenge. *Neuromodulation*, 10(4), 329-332.
- Fryer-Edwards, K. (2009). Why teach ethics? Education colloquium: Ethics and education. In L. Schuh (Ed.). *Education Colloquium: Ethics and Education* (pp.12-19). American Academy of Neurology 61st Annual Meeting: Seattle, WA.
- Gagne, R.M. (1980). *The conditions of learning*. Holt, Rinehart & Winston: New York.
- Goold, S. & Stern, D. (2006). Ethics and professionalism: What does a resident need to learn? *American Journal of Bioethics*, 6(4), 9-17.
- Hafferty, F.W. & Franks, R. (1994). The hidden curriculum, ethics teaching, and the structure of medical education. *Academic Medicine*. 69(11):861-71.
- Jonsen, A.R. (1991). Casuistry as methodology in clinical ethics. *Theoretical Medicine and Bioethics*, 12(4), 295-307.
- Jonsen, A.R., Siegler, M., & Winslade, W.J. (1998). *Clinical ethics: A practical approach to ethical decisions in clinical medicine* (4th ed). New York: McGraw-Hill.
- Kopelman, L. M. (1995). Philosophy and medical education. *Academic Medicine*, 70, 795-805.
- Kothari A, Birch S, Charles C. (2005). "Interaction" and research utilisation in health policies and programs: does it work? *Health Policy*, 71,117-125.
- Lakhan, S., Hamlet, E., Mcnamee, T., Laird, C. (2009). Time for a unified approach to medical ethics. *Philosophy, Ethics, & Humanities in Medicine*. 4(13). Available at: <http://www.peh-med.com/content/4/1/13>.
- Miles, S.H., Lane, L.W., Bickel, J., Walker, R.M., Cassel, C.K. (1989). Medical ethics education: Coming of age. *Academic Medicine*, 64(12), 705-714.
- Pellegrino, E.D. (2002). Professionalism, profession and the virtues of the good physician. *Mount Sinai Journal of Medicine* 69(6), 378-84.
- Perkins, H.S. (1989). Teaching medical ethics during residency. *Academic Medicine*, 64(5), 262-266.
- Reimschisel, T. (2009). Is it ethically permissible to teach ethics without a curriculum? The basics. In L. Schuh (Ed.). *Education Colloquium: Ethics and Education* (pp.12-19). American Academy of Neurology 61st Annual Meeting: Seattle, WA
- Royal College of Physicians and Surgeons of Canada [RCPC]. (30 June 2004). *Biomedical Ethics*. Retrieved November 8, 2009, from http://rcpsc.medical.org/residency/accreditation/positionpapers/bioethics_e.php
- Schuh, L. A., & Burdette, D. E. (2004). Initiation of an effective neurology resident ethics curriculum. *Neurology*, 62(10), 1897-1898.
- Singer, P.A., Pellegrino, E.D., Siegler, M. (2001). Clinical ethics revisited. *BMC Medical Ethics*, 2(1). Available at: <http://www.biomedcentral.com/1472-6939/2/1>.
- Suhler, C., & Churchland, P (2009). Psychology and Medical Decision-Making, *American Journal of Bioethics*, 9 (6-7), 79-81.
- Watling, C. J., & Brown, J. B. (2007). Education research: Communication skills for neurology residents: Structured teaching and reflective practice. *Neurology*, 69(22), E20-E26.
- Vygotsky, L.S. (1978). *Mind in Society: the development of higher psychological processes*. Harvard University Press, Cambridge, MA.

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Educating Future Neuroscience Clinicians in Neuroethics: a Report on One Program's Work in Progress

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ABSTRACT

If the new and rapidly expanding discipline of neuroethics is to have a significant impact on patient care, the neuroscience clinicians must become familiar with the discipline, and be competent and comfortable in applying its cognitive base and principles to clinical decision-making. Familiarity with and practical experience in the application of basic biomedical knowledge and principles to clinical decision-making in the neurosciences becomes the essential foundation on which to begin to integrate neuroethics into medical education. The place where the building of this foundation and the initial exposure to neuroethics must begin is in the residency program. This article describes the approach developed in the neurology residency education program at the University of Calgary to move toward achieving this goal. The key elements for the development and successful implementation of the program are outlined and a brief overview of the topics covered in the sessions is described.

Key words: neuroethics, medical education, neurosciences.

Introduction

Neuroethics has two distinct components. First, it encompasses all aspects of ethical decision-making involving patients suffering from neurologic and psychiatric diseases. Second, it elucidates the neuroscientific basis of ethical decision-making.¹

Training programs for adult and pediatric neuroscience clinicians (primarily neurologists, neurosurgeons and psychiatrists) have a responsibility to incorporate educational activities focused on neuroethics within their teaching programs. This will ensure future neuroscience clinicians begin to develop capacity and expertise in clinical neuroethics to better prepare them for the ethical challenges they will face upon entry into careers in clinical practice or as clinician scientists. In addition, the Royal College of Physicians and Surgeons of Canada (RCPSC), the body which determines objectives for training programs as well as accrediting them, currently mandates training programs to do this^{2,3,4}. A recent letter in Science highlights the need for neuroethics teaching in neuroscience research education programs.⁵

This report outlines the development and current status of neuroethics teaching in the adult neurology training program in the Department of Clinical Neurosciences at the University of Calgary. We believe that our experience may be of value to other clinical neuroscience training programs which are developing programs of their own.

How We Arrived at Where We Are Today

The formal teaching of neuroethics began in 2001. The fact that a faculty-wide accreditation visit by the RCPSC was scheduled for early in 2003, undoubtedly helped move the initiative forward. Since 2006, there has been a minimum of six, one-hour sessions per year devoted to neuroethics and professionalism as part of the formal, weekly academic half-day program. The sessions are typically held over the noon hour and the program provides lunch.

Initially the content of the sessions was determined by the faculty member (KB) who was the lead for the program. In 2006, regular resident (PC) input into planning and leadership for the sessions was initiated. In 2007, intermittent formal neuroethics expertise (WG) was added.

Current Demographics of the Neurology Residents

For the 2009-2010 academic year, there are 18 trainees – 4 Post-Graduate Year 5 (PGY5), 3 PGY4s, 2 PGY3s, 3 PGY2s, 5 PGY1s and 1 resident who is currently completing a PhD in neuroscience. 7 of the trainees are International Medical Graduates of whom 4 have their training supported by Saudi Arabian funding, while the other 3 are landed immigrants who had completed their medical degrees in their home countries prior to coming to Canada. Canadian graduates are from 6 different medical schools. The male and female numbers in the program are 12 and 6 respectively.

Structured Versus Unstructured Curriculum

A more structured approach, focusing on acquiring an appropriate cognitive base for neuroethics, was attempted by using the American Academy of Neurology Ethics, Law and Humanities Committee's Case-Based Curriculum for Neurology Residents. Another structured initiative, consisting of 4 sessions, each one focusing on one of the 4 principles (respect for autonomy, nonmaleficence, beneficence and justice) as per the work of Beauchamp and Childress⁷ was developed. Selected readings from their widely read text served as reading material on which the discussion would be based. Unfortunately, both of these initiatives failed to engage the residents. As a result, it was decided to switch to a more unstructured curriculum as described below. This approach was successful in engaging the residents in the sessions and thus has been continued.

Nature of the Current Teaching Sessions

All sessions are informal and attendance is not recorded, but they are mandated by the training program. A semi-open group reflects the residents' reality of alternating schedules of call and vacation. Pediatric neurology trainees participate in the program via a telehealth link-up. Reading material or summaries of cases for discussion are pre-circulated electronically. Occasionally a guest speaker may be invited to serve as a resource person for a particular topic being addressed. At the start of the program there was a greater emphasis on discussion of issues of professionalism, but currently the greater emphasis has switched to neuroethics.

Examples of Topics Discussed

1. Big Pharma and its role in marketing of drugs like Plavix® and Neurontin®.
2. Proposed policy for Academic Medical Centers for dealing with industry.
3. Industry funding of medical education.
4. fMRI in relation to emotional engagement in moral judgment.
5. Organ donation after cardiocirculatory death.
6. Incidental findings in experimental brain imaging.
7. The scientific basis of influence and reciprocity.
8. Scientific integrity, publication and retractions.
9. Professional/ethical obligations in the face of risks to personal health (in relation to the anticipated HNI pandemic).
10. Dealing with medical errors.

Examples of Cases Discussed

1. A young man living at home with his spouse and 3 small children was found to have cocaine with him when hospitalized with an acute delirium secondary to cocaine addiction. The discussion focused on whether or not the treating neurology team had a responsibility to notify Child Welfare about the situation.
2. A patient with Creutzfeldt-Jacob Disease and the neurology team's responsibility in providing information about the diagnosis to family members when there was a wish by some members to withhold the information from others.
3. A patient with an end-stage glioblastoma multiforme for whom the family wanted "all available treatment including cardiac resuscitation" undertaken to attempt to maintain the patient's life.

4. A patient with a large, benign frontal lobe tumor declined recommended surgical treatment. The discussion focused on whether or not the patient had capacity to make this decision.
5. A young woman with end-stage amyotrophic lateral sclerosis requiring ventilation and nutrition via a G-tube when the only place available to provide this level of support was in an intensive care bed in the acute care hospital. The discussion focused on what level of health care the patient could justifiably expect to receive versus justice to others in terms of using a limited resource.
6. A patient who attempted suicide was admitted to the ICU, as ventilation was required. The neurologist involved felt that continued support and observation was required to determine whether or not there would be recovery. The family insisted that ventilatory support be withdrawn and only comfort measures offered. There was no advance directive and no one had been designated as a power of attorney. The discussion focused on what should be done.

Discussion

Little has been written about ethics teaching in adult neurology training programs. A 1996 publication in *Neurology*⁸ reported results of a 1991 survey conducted by the Ethics and Humanities Subcommittee of the American Academy of Neurology on ethics education (the term 'neuroethics' had not yet been coined) in neurology residency programs in the United States. No program that responded to the survey reported any formal education activities in ethics. In 2004, Schuh and Burdette⁹ reported their experience with a formal neurology resident ethics curriculum. No further reports were found.

In informal discussions with others, it appears that regular teaching sessions devoted to neuroethics within a formal academic teaching program are uncommon in neurology training programs in Canada. We believe that the initial and then continuing enthusiastic support of the program director, Dr William Fletcher, has been critical to the success of the program. It was his decision to assign time for ethics in the formal educational program which demonstrated to residents and staff that this was not simply an add-on topic to be learned on an ad hoc basis.

There have been challenges to offering our program. Although our program is of modest size in comparison to other Canadian programs, the actual number of residents in any one year is small. Thus the program has to be designed to appeal to all level of trainees. This will necessarily lead to some repetition of material from year to year and occasional presentation of material for which more junior trainees may be less prepared. However, the current focus on case-based discussion makes this less of a problem as trainees at all levels experience these clinical challenges. We also believe that as an adequate moral space, it goes beyond conventional seniority.

We believe that our approach provides the residents with the opportunity to develop their sensitivity to the neuroethical dimensions of clinical care and an approach to learning how to

deal with the issues. At the same time, by framing discussions and decision making in terms of specific ethical principles, the cognitive base of the discipline can be learned as well.

We have been unable to come up with a satisfactory method of evaluating our program to determine if we are meeting these goals. There is no doubt that having a more formal, didactic program with an evaluation at the end⁹, would show short-term outcomes in terms of acquisition of cognitive material. However, this would not tell us anything about whether we were making a difference in the long term (for example once the trainees enter practice), which is the goal of our work.

Although our trainees are becoming more comfortable with identifying and approaching neuroethical issues in their patients, they frequently have difficulty engaging their attending staff in discussing and arriving at plans to deal with the issues. An ongoing program for staff aimed at facilitating their abilities to verbalize their understanding of and approach to decision making would be one way to deal with this. Another option would be to have Neuroethics Ward Rounds for the team supported by someone with ethics expertise on a regular basis. One way of developing this expertise would be to have an ethics elective for a resident interested in taking an active part in teaching neuroethics to trainees. To date we have not implemented any of these initiatives.

A final challenge is the issue of sustainability of resident and preceptor leadership. Currently another staff physician has agreed to begin participating in the sessions with the long-term plan of taking over the role of program leader to replace KB, who has been involved with the program since its inception. PC, the resident leader will be completing his residency this academic year, and a search for a replacement resident leader who has an interest in neuroethics as well as interest in developing expertise needs to be initiated. Additionally, a new program director has just taken over leadership of the program.

For those clinical neuroscience programs considering developing a formal program in neuroethics, we offer the following recommendations.

1. Obtain a commitment of support for the proposed program from the program leadership.
2. Identify a teacher/clinician as the leader of the program and provide that person with the opportunities to develop their expertise in the discipline of neuroethics if they do not have that expertise already.
3. Identify a resident to be co-leader of the program and provide that person with opportunities to develop their expertise in the discipline. One such opportunity would be an ethics elective for that resident.
4. Identify an ethicist (ideally a neuroethicist) to act as a consultant to the program leaders and to occasionally participate in sessions.
5. Didactic presentations should generally be avoided. Ethical principles need to be named and discussed within the framework of case or literature discussions.

6. Case-based discussions should focus on cases that residents have dealt with or observed during the course of their clinical rotations.

Conclusion

In this report we make the case for the inclusion of neuroethics teaching within the formal academic education programs of clinical neuroscience training programs and describe the approach and experience of the adult neurology training program in the Department of Clinical Neurosciences at the University of Calgary in doing this. A number of recommendations are made for programs, which are considering developing neuroethics teaching.

References:

1. Roskies A. (2002) Neuroethics for the new millennium. *Neuron*, 35, 21-23.
2. [http://rcpsc.edu/information/index.php?specialty=145&submit=Select - Neurology](http://rcpsc.edu/information/index.php?specialty=145&submit=Select-Neurology).
3. [http://rcpsc.edu/information/index.php?specialty=329&submit=Select Neurosurgery](http://rcpsc.edu/information/index.php?specialty=329&submit=Select-Neurosurgery).
4. <http://rcpsc.medical.org/information/index.php?specialty=165&submit=Select-Psychiatry>.
5. Sahakian B.J., Morein-Zamir S. (2009) Neuroscientists need neuroethics teaching. *Science*, 325, 147.
6. Bernat J., Beresford, H.R., Cranford, R.E. Goldblatt, D., Mackin G.A., McQuillen M. et al. Ethical dimensions of neurologic practice: A case-based curriculum for neurology residents. (2000) Retrieved on October 14th, 2009 from <http://www.aan.com/globals/axon/assets/2321.pdf>
7. Beauchamp T.L., Childress J.F. (2008) *Principles of Biomedical Ethics*. 6th ed. New York: Oxford University Press.
8. Wichman A, Foa R. (1996) Ethics education in neurology residency programs: results of a survey. *Neurology*, 46, 1481-83.
9. Schuh L.A., D.E., Burdette D.E. (2004) Initiation of an effective neurology resident ethics curriculum. *Neurology* 62, 1897-98.

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Quebec's Science and Technology Ethics Commission and Expanded Uses of Psychotropics: Ethical Issues and Recommendations

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ABSTRACT

If the new and rapidly expanding discipline of neuroethics Recently, the use of psychotropic drugs has increased in Quebec. Several factors may explain it, including expanded uses which aim to improve cognitive function in the absence of known mental problems. These uses involve ethical and social choices, which go beyond the medical setting and include the public participation of experts and citizens.

This article lays out the position of the Quebec's Science and Technology Ethics Commission, which has addressed this issue and published a position statement in autumn 2009. We present two categories of expanded uses, namely the "Medical" and the "Lifestyle". Then we focus on values and ethical issues related to expanded uses. These ethical issues pose a challenge for the individual, the State, the media and the pharmaceutical industry; and they play out in the short, medium and long term. In addressing these issues, the Commission makes several recommendations.

Key words: ethics, psychotropics; off-label.

Introduction

The Commission, established in 2001 by the Government of Quebec, has a twofold mission. It is firstly to inform, raise awareness, gather opinions, foster reflection and organize debate on the ethical development of science and technology; and secondly, to propose general guidelines for stakeholders to refer to in their decision making.

In November 2006, the Commission decided to produce a position statement on psychotropic drugs. Several factors have motivated the Commission's interest. The leading factor is that Canadians

and Quebecers are large consumers of psychotropic drugs. For example:

- In 2002, Canadians were among the leading users of psychotropic drugs worldwide (Rehm & Weeks, 2005).
- During 2000, 19.4% of Quebecers over 65 years of age received at least one prescription for benzodiazepines (RAMQ, 2001).
- Among minors, between 1993 and 1999, prescriptions for psychostimulants increased by over 200% (Collège des médecins du Québec & Ordre des psychologues du Québec, 2001).

Among other factors which have attracted the attention of the Commission may be noted: the popularity of nonprescription products that stimulate cognitive functions ("smart drinks", Omega-3, etc.); the development of this branch in the pharmaceutical industry; the immense hopes, both in people suffering from mental disorders and among "healthy" people, to maintain or enhance the cognitive functions, or to regulate their moods; and finally, the incomplete information on long-term side effects on the nervous system.

This article presents a part of Commission's position statement. It is divided into two parts. First, we will describe the state of the Commission's reflection on ethical issues raised by the expanded uses of psychotropic drugs. Then, we will explain the recommendations and cautionary notes that have emerged from this reflection.

Two Types of Expanded Uses

It is important to clarify what is meant by "expanded use". For its part, the Commission has defined the term "expanded use" as use going beyond the scope of established practices, and has for this

reason identified two types of “expanded uses”: the “Medical” type and the “Lifestyle” type.

These two categories are not completely independent of one another. On the one hand, several stakeholders and contextual elements are common to both categories. On the other hand, scientific research and applications are guided by standards which are culturally determined. However, the two categories have been distinguished for the purposes of demonstration.

Expanded Uses of the “Medical” Type

This kind of use is primarily within the sphere of expertise of physicians and in a context of professional practice which is perhaps not unique to Quebec, but is nonetheless part of the set of problems at issue here: the non-optimal organization of health-care network and the emphasis on the concept of prevention resulting in individuals taking medication. Some aspects are more common: scientific uncertainty due to lack of knowledge about brain function and the modes of action of psychotropic drugs; diagnosis of a mental or neurological disease may be harder to establish on an objective basis than a physical disorder; the well-known but nonetheless real difficulty of distinguishing between “therapy” and “enhancement”.

Given that physicians are with few exceptions the only professionals in Quebec authorized to prescribe drugs, the Commission has focused on factors likely to influence their prescribing practices, in particular:

- The limits of knowledge about psychotropic drugs as well as mental and neurological illness: this factor involves the limited nature of evidence, mostly drawn from clinical trials which replicate little of everyday reality.
- The influence of the pharmaceutical industry: pharmaceutical companies promote their products, whether targeting doctors, pharmacists or the general public.
- The organization of the Quebec health and social services system: it operates as a series of silos, and has to contend with a fairly widespread shortage of human resources; in that context, prescription drugs can be seen as tools offering temporary relief.
- Patient demand: Before consulting a health professional, an individual has access to abundant sources of information: television, the Internet, books and scientific or general-interest magazines, etc. Thus, he may have made up his mind in advance and have specific requests.

As is the case with any use of medication, expanded uses of the “Medical” type lead to consequences, one of them being a main anticipated benefit and four being potentially adverse consequences.

- The main anticipated benefit is the advance of knowledge through clinical use in a population with a diverse life and health profiles.
- Accessibility and quality of care may be reduced as a result of

expanded uses of psychotropics if physicians promote a drug therapy “by default” so as not to leave people without care. Paradoxically, the increase in consultations could result in less screening and inadequate follow-up for users diagnosed with mental and neurological illnesses.

- Individual safety is at stake, since increased use of psychotropics may be accompanied by increased risks of the prevalence of adverse reactions. Also, the safety of others is at stake since workplace or traffic accidents may increase, that could bring consequences at the collective level, given that Quebec’s social security net provides for compensation in both cases.
- Trivialization of psychotropic drugs. Given the diagnostic uncertainty and the daily disruptions experienced by people with mental disorders, there is a possibility of “overdiagnosis” and “overprescribing” psychotropics. But the fact a medical diagnosis has been made may change an individual’s perception of his situation because it implies that illness is involved. Moreover, when the expert proposes that a patient take medicine, this has the effect of legitimizing treatment. As a result, there exists a risk of medicalizing life events whereas they do not necessarily belong to the field of medicine.
- The role played by physicians in promoting meliorism. Several reasons may explain why physicians prescribe or not; however, in prescribing psychotropic drugs for non-clearly-therapeutic purposes, physicians are contributing to the trend of meliorism and performance as well as to the trivialization of drug use.

Expanded Uses of the “Lifestyle” Type

The values of performance, efficiency and enhancement have been positive ones throughout history and in different societies, although the fact they are perceived in idealized terms raises questions. What ought to be “a means to an end” has become an end in itself.

Some psychotropic medications are used to meet social expectations – performance, health, “youth”, etc. These practices necessarily involve the idea of “normality”, which can be understood as a statistical concept, or may reflect social or subjective decisions. Moreover, “normality” and “norm” are intimately linked: social or axiological normality may lead to a norm, i.e. to a statement describing what to do or to refrain from doing. People deviating from these norms, through behaviour deemed inappropriate or, more generally, who do not “perform well” may be stigmatized.

This normalization of conduct and mood may lead to social homogeneity. The definition of *normality* changes, when people use psychotropic medications in pursuit of certain standards or an ideal: if it is “normal” to use drugs for non-therapeutic purposes, then *normality* becomes a *medicated normality*.

In its analysis, the Commission has singled out three particular factors that may influence expanded uses of the “Lifestyle” type, namely:

- The influence of the pharmaceutical industry: Pharmaceutical

companies have recognized the market growth potential of psychotropic uses for the purposes of enhancement. Their promotion reinforces the perception that medicines are useful, even necessary, in non-medical life situations.

- The Media and the Internet: The media are major sources of information that generally present medications in a positive and uncritical light, reinforcing the same compelling picture of life. Also, people may decide to buy medicines at cyberpharmacies, based on inadequate information or even minimal awareness about the risks associated with lack of knowledge of the product being purchased.
- Differences between psychotropic drugs and other CNS stimulants/depressants: Some people liken taking psychotropic medications to taking products such as coffee and alcohol, which are nonetheless recognized to be harmful when consumed in large quantities – which nevertheless remain both accessible and popular – whereas for psychotropics, the long-term effects are poorly documented.

In terms of consequences, expanded uses of the “Lifestyle” type present the same risks as of the “Medical” type, although other risks are specific to “Lifestyle” type uses. The Commission has singled out three anticipated benefits¹, namely:

- The enhancement of certain cognitive abilities. People stand to gain both personally and socially when they enhance mental abilities. In this perspective, enhanced cognitive functions also contribute to meet the demands of the labour market, which represents a gain both for employers and employees.
- The regulation of mood, behaviours and personality traits. Psychotropic drugs can quickly make people feel better, while promoting better integration; at least that is what many users hope. Feelings of grief and sadness decrease, while self-esteem and a sense of performance and of efficiency are expected to increase.
- An increase in cognitive functions leads to a rise in incomes and an improved quality of life. Several factors increase cognition: healthy eating, physical exercise, intellectual stimulation, etc. However, some people have limited cognitive abilities and are unlikely to improve them; these people stand most to gain from a pharmacological enhancement of their cognitive functions.

But expanded “Lifestyle” uses do not just involve benefits. Risks are associated with this type of use, and some social factors that contribute to this type of use also constitute issues of their own:

- Risks to personal safety: In the short term, the use of psychotropic drugs provided by friends or bought illegally exposes consumers to the risks associated with the use of psychotropics and those relating to the unknown characteristics of medications ingested. In the long term, science cannot tell what the effects of psychotropic medications are on the brains of healthy people.
- Psychological dependence: For people using and benefiting from psychotropic medications, the fear of losing such

benefits is a powerful motivation for continuing to take the medications, even when medical conditions no longer indicate such use.

- External pressures: Social pressures, even to the point of coercion, have an impact on the process of individual decision-making. People resort to expanded “Lifestyle” type uses in pursuit of a certain ideal, self-image and group, both in their professional and personal life.
- Trivialization of psychotropic drugs: The point has already been discussed but it is even more a concern for expanded uses of the “Lifestyle” type. Indeed, in this case, the use of psychotropic medications is designed to help fulfill idealized norms, images or values. Also, the fact that consumers overstate the desired benefits and under-estimate the risks increases the trivialization of “Lifestyle” uses.

Summary

- the first category is more of an extension of therapeutic uses of psychotropics while the second illustrates expanded uses in the absence of a therapeutic objective;
- the same stakeholders are often involved;
- the motivations underlying expanded use have different purposes; as a result, there are multiple perceptions about drugs and their uses;
- it is not always easy to distinguish between therapy and enhancement, and as a result it is relatively easy for anyone to justify resorting to psychotropics;
- the idea of normality is central to the concept of improvement;
- a widely available and transparent scientific information of a high quality is important; however this precondition is not always met, neither for the public nor for professionals;
- regardless of the categories used here, the increased use of psychotropics raises the broader question of the identity and the representation of the human being.

Recommendations and Cautionary Notes

In considering expanded uses for the purposes of enhancement/regularization, the Commission has identified four essential values, namely:

- the protection of individual health and safety;
- autonomy and the affirmation of individual freedom;
- equity;
- representations of the human being.

These values in turn have led the Commission to make eleven recommendations.

Recommendations

These recommendations are organized around six themes:

1. Acquisition of knowledge about the current uses of psychotropic drugs and their different potential impacts on the central nervous system on the short, medium and long term.

In order to be able to quantify and qualify the short, medium and long term effects of psychotropics in Quebec, the Commission makes a three-point recommendation, calling to survey current uses and their evolution over time; to study qualitatively and quantitatively the use of psychotropic drugs and their various impacts; and to document the practices of physicians with respect to psychotropic drugs.

2. Objective and exhaustive transmission of scientific information related to the central nervous system, psychotropic drugs, recognized non-pharmacological treatments and, in general, information on mental and neurological diseases.

This theme relates specifically to the transmission of scientifically valid information. Stakeholders have different knowledge profiles and access different modes of information transmission. Given the importance of this issue, the Commission makes four recommendations concerning the Internet quality of scientific information and the general public; addressing the responsibility of the stakeholders in the field of information to disseminate critical and balanced scientific information to their audiences; relating to the modes of information transmission for general practitioners who provide care for the majority of patients suffering from mental or neurological disorders; and referring physicians to the social dimension of their role, in the phenomena of medicalization and medicamentation of life situations.

3. Regulation of direct-to-consumer advertising of prescription drugs.

The fact that drugs are approved by Health Canada and are prescribed by physicians tends to reinforce the perception of safety. Thus, transparency and accuracy of information about the risks and benefits of medications are central to the trust people place in monitoring authorities, pharmaceutical companies and prescribers. In this regard, the current Canadian regulatory framework – which prohibits direct advertising of the kind found in the United States – is not well adapted, since the ban is easily circumvented.

4. The drug licensing process.

While the various initiatives of regulatory agencies regulators to have all research results disclosed in a registry are definitely a step forward, they are based essentially on the goodwill of pharmaceutical researchers and companies. A disclosure of

clinical trials and of all results compulsory, in an accessible, public and updated registry, is needed.

5. Organization of the health and social services network, particularly regarding integrated practices in mental health and service delivery.

The Commission has focused on the impact that current organization of the network may have on the value of “equity”. Three recommendations are made in this regard relating to the coordination of care since disruptions in the continuity of care and services would contribute to expanding “Medical” and “Lifestyle” uses; concerning non-drug therapies, in which the costs of consultations are not covered by the public system when they take place in private clinics, but not all Quebecers have access to private insurance plans. This situation leads to unequal access to care and services for non-medical services and is particularly disturbing, given that in the case of several mental and neurological diseases, the combination of “drug therapy/psychotherapy” provides better short-term results; and to demonstrate the potential positive effects of greater access to non-drug therapies.

6. Participation of civil society in social and ethical debates related to expanded uses of psychotropic drugs.

The desire for improvement is part of the human condition, but the question of enhancement by means of psychotropic medications – influencing the functioning of the brain, which is the organ representing the seat of the soul, and of personal identity – leads to debates on the nature of the human being, on what it means to live a successful life and on self-realization. Whether representations of the human being are religious in nature, based on naturalism or based on dualism, they are being rocked by advances in neuroscientific knowledge.

When it comes to defining what is meant by health, therapeutic use and cognitive enhancement, there is a lot of debate but not much consensus. Given the democratic and pluralistic nature of contemporary societies, it is difficult to invoke a single overarching vision of the common good. Political authorities are well-suited to arbitrate between different visions and to ensure that the community values are not subordinated to the interests of the few. However, expanded uses go far beyond the frameworks of expertise of health professionals and the “expert/political class” relationship. Several other stakeholders are concerned, starting with the citizen-as-user, and should participate in social and ethical debates on expanded uses of psychotropics. Excluding them would undermine the legitimacy and effectiveness of decisions taken by others.

Cautionary notes

In cases where it seems impossible to make a recommendation on a given issue, the Commission provides cautionary notes. Two particular factors identified as issues in the position statement:

The first cautionary note concerns the value of “autonomy and the affirmation of individual freedom”.

By placing too much emphasis on autonomy and individual responsibility, one risks forgetting the other factors that influence an individual's health, such as the physical environment and the social milieu, as well as the responsibilities of other stakeholders. In addition, some expanded uses of psychotropic medications meet the expectations of society while camouflaging the social causes of these expectations.

The second cautionary note relates to equity and the accessibility of medications. A reading of statistics as well as scientific literature suggests 1) that expanded "Medical" and "Lifestyle" uses will continue to increase and 2) that new psychotropic drugs are more expensive than drugs previously used. Therefore, the Commission is concerned about the impact this increase may have on the list of medications eligible for reimbursement², the affordability of drug insurance plans and the possibility that people suffering from pathologies could be faced with unmanageable financial obligations.

Conclusion

Issues and ethical values associated with expanded uses of psychotropic drugs affect both individuals and society as a whole; these issues and values challenge the individual, the State, the media as well as the pharmaceutical industry, and are playing out over the short-, medium- and long-term. These issues call for ethical and social choices that go beyond the medical setting and illustrate the need to broaden the debate.

Footnotes:

1. These potential benefits depend largely on public perceptions, since the few scientific studies devoted strictly to the use of psychotropics for the purpose of enhancement do not make it possible to confirm the existence of such benefits.
2. Since 1997, all Quebec citizens benefit from universal coverage of prescription drug insurance, either through the government-run prescription drug insurance plan or a private group insurance plan.

References:

Collège des médecins du Québec & Ordre des psychologues du Québec [College of Physicians of Quebec & Order of Psychologists of Quebec] (2001). *Le trouble déficit de l'attention hyperactivité et l'usage de stimulants du système nerveux central*. Lignes directrices du Collège des médecins du Québec et de l'Ordre des psychologues du Québec. Montréal: Collège des médecins du Québec & Ordre des psychologues du Québec.

Commission de l'éthique de la science et de la technologie (2009). *Psychotropic Drugs and Expanded Uses: an Ethical Perspective*. Québec: CEST. Available at www.ethique.gouv.qc.ca.

Régie de l'assurance maladie du Québec (RAMQ) [Quebec Health Insurance Board] (2001). *Portrait quotidien de la consommation médicamenteuse des personnes âgées non hébergées*. Québec: Régie de l'assurance maladie du Québec.

Rehm, J., & Weeks, J. (2005). *Abuse of Controlled Prescription Drugs*. In Canadian Centre on Substance Abuse (Ed.), *Substance Abuse in Canada: Current Challenges and Choices*. Ottawa: CCSA.

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One Step Forward, Two Steps Back: a Charter Analysis of s.39 of Nova Scotia's *Involuntary Psychiatric Treatment Act*

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ABSTRACT

Nova Scotia's recently updated *Involuntary Psychiatric Treatment Act* significantly updated mental health law in the province in many respects. However, s.39 of the Act deviates from this record in that it contains a clause that permits overriding the competent prior wishes of involuntarily committed psychiatric patients. This is problematic because it displaces established Canadian common law and legislation on advance directives for psychiatric patients but not other patients, suggesting possible discrimination. The paper explores whether s.39 might survive challenge under s.15 of the *Canadian Charter of Rights and Freedoms*, as either an affirmative action program under s.15(2) of the Charter or as an overriding societal concern under s.1 of the Charter.

Key words: non-consensual treatment; treatment refusal; advance directive; discrimination.

In 2005, Nova Scotia updated its mental health legislation with the *Involuntary Psychiatric Treatment Act*¹ ('IPTA'), a long-awaited improvement over earlier legislation that termed psychiatric patients 'lunatics' or 'the insane.'² While IPTA no longer uses disrespectful language, it remains problematic in another way, however.

IPTA's s.39 empowers a substitute decision-maker to make treatment decisions for an involuntarily committed psychiatric patient³ using patients' prior capable informed expressed wishes, unless doing so endangers the patient's (or others') "physical or mental health or safety", whereupon "best interests" are substituted.⁴ These words harbour radical negative effects: imposing treatment despite capable prior wishes displaces Canada's common law⁵ and legislation governing advance directives.⁶ Requiring only mentally but not physically ill persons⁷ to have medical decisions imposed upon them seems intuitively unacceptable and suggests blatant discrimination.⁸ Mentally ill persons have endured a long history of discrimination, inconsistent with modern *Charter* values. It is disappointing to see this same dynamic within IPTA,⁹ one of Canada's most recent provincial mental health statutes.

This paper argues that IPTA s.39 violates the *Canadian Charter of Rights and Freedoms*¹⁰ s.15(1) equality guarantee. First, applying the vision of substantive equality elucidated in *R. v. Kapp*,¹¹ I explore whether s.39 creates a distinction under s.15(1). Next,

in light of disadvantages affecting psychiatric patients, I ask if s.39 constitutes affirmative action, under s.15(2) of the *Charter*, immunizing it from challenge. If not, does s.39 violate the equality guarantee of s.15(1), in its treatment of patients? Finally, I examine whether any infringement may be upheld as a policy decision under s.1 of the *Charter*.

Does s.39 draw a distinction based on an enumerated or analogous ground?

A long history of exclusion, shame, fear, segregation, and mistreatment has been associated with mental illness. Under s.39 patients detained involuntarily due to mental illness may be treated with mind-altering pharmaceuticals against their express wishes, made earlier, while competent. While some may claim such treatment to be beneficent and aimed at furthering the patient's best interests, in reality, such forced treatment seems to have more in common with historical mistreatment, because it suggests that these patients' wishes are not worthy of respect and that their legal rights are trivial. This does not seem in keeping with the concepts of equality and human dignity central to the *Charter*.

Section 15(1) of the *Charter* states: "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on ...mental or physical disability."¹² In *Law v. Canada*, the purpose of s.15(1) of the Charter was found to be:

...to prevent the violation of essential human dignity and freedom through the imposition of disadvantage, stereotyping, political or social prejudice, and to promote a society in which all persons enjoy equal recognition at law as human beings or as members of Canadian society, equally capable and equally deserving of concern, respect and consideration.¹³

In turn, s.15(1)'s purpose is to identify discrimination (against individuals or groups), defined as:

...a distinction, whether intentional or not, but based on grounds relating to personal characteristics of an individual or group, which has the effect of imposing burdens, obligations or disadvantages on such individuals or groups, not imposed on others, or which withholds or limits access to opportunities, benefits and advantages available to other members of society.¹⁴

IPTA s.39 satisfies the threshold criteria for a s.15 *Charter* challenge. Section 39 constitutes sufficient State involvement and reveals evidence suggesting (a) a distinction or differential treatment of one group compared with another, (b) in which one group receives greater benefits, legal protection or other advantage, without justification. Section 39 permits overriding prior wishes in involuntary psychiatric patients but not patients without mental illness, but suffering from physical illness.¹⁵ In both groups, patients have competent prior wishes, but in only one group are those wishes respected. Thus a distinction exists based on the enumerated ground of mental disability, which creates lesser legal protection for these individuals, attracting s.15's attention.

Is s.39 an ameliorative program under s.15(2) of the Charter?

Charter ss. 15(1) and 15 (2) must work together, to promote an overall "vision of substantive equality."¹⁶ Upon finding a distinction, attention shifts to s.15(2), asking if the differential treatment "has as its object the amelioration of conditions of disadvantaged individuals or groups", allowing it to escape being ruled discriminatory. "Any law, program or activity" may constitute an ameliorative program so IPTA s.39 may qualify.

Is s.39 an ameliorative program under s.15(2) for redressing psychiatric patients' disadvantage? The test is: "A program does not violate the s.15 equality guarantee if the government can demonstrate that: (1) the program has an ameliorative or remedial purpose; and (2) the program targets a disadvantaged group identified by the enumerated or analogous grounds."¹⁷ This requires determining s.39's objectives, whether they are ameliorative, and whether any amelioration favours disadvantaged groups.

Some may argue that s.39 has an ameliorative purpose. The "Thank-You Theory" of psychiatric treatment¹⁸ claims many patients lack insight and may later be grateful for treatment. Psychiatrist John E. Gray (2000) argues that non-consensual treatment is necessary to prevent greater patient suffering, increased patient restraint or seclusion, longer detention (i.e., 'warehousing')¹⁹, poorer prognoses for youth, negative impacts on staff, fellow patients and the therapeutic environment, greater costs²⁰ and lost treatment opportunities due to 'blocked beds.'²¹ Yet treatment refusals may be an infrequent concern hardly warranting s.39's existence: in one study only 7.2% of patients refused treatment, averaging just 13 days, while only 2% refused beyond 14 days.²²

Some, including the 'anti-psychiatry movement'²³ which has legally empowered some competent psychiatric patients to refuse unwanted treatment, counter that forced treatment is not ameliorative. Patients may have valid reasons to reject treatment, including undesirable side-effects, a preference for their own untreated thoughts and a right to make seemingly unwise choices. In addition, forced treatment may impair outcomes. Yet refusing treatment may sometimes mean an untreated patient cannot be released into the community, needing long-term hospitalization,²⁴ which some term "rotting with their rights on."²⁵

Untreated mentally ill face grave disadvantages --possible direct suffering from the illness, and negative societal attitudes—deserving amelioration. Yet IPTA s.39 may not qualify as affirmative

action, as it does not fit the typical format. Usually in affirmative action, a legal disadvantage, lack of benefit or exclusion is conferred on a relatively privileged group (e.g., white people), to confer needed advantages on a less privileged group (e.g., Aborigines).²⁶ Section 39 confers a disadvantage on a less privileged group and re-labels this as an 'advantage' to it. A similar argument failed in *R. v. Music Explosion, Ltd.*,²⁷ where a restrictive bylaw²⁸ was claimed as a s.15(2) program "for the benefit of the special needs of young persons."²⁹ The Appeal Court, however, held that such a restriction was not a *conferral of special benefits* but simply a colourable attempt to discriminate.³⁰ Thus, restricting the rights of psychiatric patients to make their own treatment decisions may not qualify as a 'special ameliorative program.' *Kapp* also stressed the importance that an ameliorative *purpose* be more than a "shield to protect a program or activity which is...discriminatory."³¹ There must be a genuine nexus between the claimed goal and the law's form and implementation:

It is insufficient to declare that the object of a program is to help a disadvantaged group if in fact the ameliorative remedy is not *directed to the cause of the disadvantage*. There must be unity ...among the elements of the program, [suggesting] that the *remedy...is rationally related to the cause of the disadvantage*.³³ (Emphasis added).

Many psychiatric patients are competent to choose their own treatment, contradicting societal myths of their global incompetence and the seeming foolishness³³ of their choices. These unchallenged societal myths reflect stereotypes and stigmatization³⁴ of difference, affecting psychiatric patients' in and beyond the hospital. They generate disadvantages³⁵ in employment, housing, financial credit, and social participation, causing increased poverty, homelessness,³⁶ addictions³⁷ and criminalization,³⁸ which in turn impede recovery.³⁹ The Kirby Report (2006) into Canada's mental healthcare left little doubt that people with mental illnesses experience disadvantage. Yet the real 'cause' of much of this disadvantage is often *not* illness itself, but false, over-generalized stereotypes that exclude patients from the community. Thus, while IPTA s.39 may reduce surface differences between mentally ill patients and others through enforced treatment, it leaves intact and even perpetuates underlying societal myths about people with mental illnesses. Since IPTA s.39 does nothing to ameliorate these myths--the major cause of patients' disadvantage-- a court may not find that s.39 constitutes affirmative action.

Does s.39 of IPTA infringe the s.15(1) Charter equality right?

Different treatment may not always constitute discrimination. Substantive inequality does not always require identical treatment between groups because, where relevant differences in group characteristics exist, "like treatment can generate serious inequality."⁴² For s.39 to constitute discrimination requires satisfying a two-part test: "(1) Does the law create a distinction based on an enumerated or analogous ground?⁴³ and, (2) does the distinction create a disadvantage by perpetuating prejudice or stereotyping?" The second question requires examining four contextual factors identified in *Law*⁴⁴ and *Kapp*: any pre-existing disadvantage affecting the group; any correspondence between the different treatment and the group's 'reality,' whether the impugned law has an ameliorative purpose (or effect); and the nature of the

interest affected. Consider two of these factors in the context of s.39.

The mentally ill have endured a long history of discrimination, marginalization, and stigmatization. As noted, the lesser legal protection accorded patients' prior wishes under s.39 perpetuates societal myths about psychiatric patients' competence,⁴⁵ infantilizing them and oversimplifying the more complex reality.⁴⁶ It continues patterns wherein the opinions of the mentally ill are deemed of lesser significance and worth, suggesting a discriminatory aspect to s.39.

The nature of the interest at stake in s.39 – the right to bodily integrity and autonomy – is profoundly intimate, fundamental, and central to an individual's sense of self. So important is it that, as noted in *Fleming v. Reid*, it is not only protected by the common law but also warrants constitutional protection under s.7 of the *Charter* as a right to security of the person, only to be denied according to the principles of fundamental justice. While the court in *Fleming* observed that the right is not absolute,⁴⁸ but is subject to overriding societal interests, it stated that bodily integrity and autonomy deserve the "highest order" of protection.⁴⁹ In this, "... few medical procedures can be more intrusive than the forcible injection of powerful mind-altering drugs...often accompanied by severe and sometimes irreversible side-effects..."⁵⁰

Overall, the *Law* and *Kapp* factors suggest that s.39's differential treatment perpetuates prejudice and denies psychiatric patients' s.15(1) 'equality under the law', suggesting that s.39 discriminates, based on mental disability.

Can s.39 of IPTA be saved by s.1 of the *Charter*?

Legislation may be saved as a "reasonable limit, prescribed by law in a free and democratic society"⁵¹: a public policy choice, reflecting overriding societal interests, under s.1 of the *Charter*. Analysis follows the four-step Oakes test below.

Is there a pressing and substantial objective? Section 39's purpose seems directed at ensuring that patients receive medical treatment and are released rather than warehoused.⁵³ Some feel this goal has been frustrated by lawyers more concerned with clients' civil liberties than with patient well-being and potential. Herschel Hardin (1993),⁵⁴ former director of the British Columbia Civil Liberties Association and father to a schizophrenia patient explains:⁵⁵

Far from respecting civil liberties, legal obstacles to treatment limit or destroy the liberty of the person...Such victims... cannot think for themselves or exercise any meaningful liberty...The opposition to involuntary committal and treatment betrays a profound misunderstanding of the principle of civil liberties. Medication can... restore [patients'] dignity, free will and the meaningful exercise of their liberties.

Thus in view of the human values at stake⁵⁶ the objective of ensuring involuntary treatment *does* seem 'pressing and substantial'.⁵⁷

Are the means taken rationally connected to the objective sought?

If s.39's objective involves ensuring treatment to optimize chances of release, the rational connection branch may also be met. A legislative attempt to redress marginalization of patients – ensuring treatment to remove stigmatizing symptoms—seems *somewhat* rationally connected to the goal, even if it cannot hope to eliminate stigma.

Anti-psychiatry's supporters may disagree. Arguably, psychiatry has a long history of State suppression of eccentric, provocative (but non-dangerous) people whose non-conformity, threatens public order, or those in power.⁵⁸ Labelling and treating mental illness may be powerful tools for silencing, suppressing minority views and enforcing conformity. Kate Millett (1990), a lawyer with bipolar disorder, also notes that psychiatry -- "the system that keeps millions in line"⁵⁹ — may have somewhat tenuous foundations:

The entire construct of the "medical model" of "mental illness"—what is it but an analogy?...whereas in physical medicine there are verifiable psychological proofs...in mental illness alleged socially unacceptable behaviour is taken as a symptom, even as proof...Diagnosis is based on impressionistic evidence: conduct, deportment, and social manner. Such evidence is frequently imputed. Furthermore, it may not even be experienced by the afflicted party but instead may be observed [only] by others...⁶⁰

Psychiatry is a field in some chaos: the scientific connection between mind and brain remains unclear⁶¹ and even explaining the biological basis of the *healthy* human mind poses challenges. Does *any* competent patient possess autonomy in a medical decision, or is such freedom illusory?⁶² Uncertainties abound:⁶³ psychiatric diagnoses may vary and feigned illness may go undetected.⁶⁴

Medications⁶⁵ also raise doubts regarding efficacy and side-effects.⁶⁶ Physical side effects among older anti-psychotic drugs include stigmatizing neurological symptoms. The older drug Haldol may risk lethal cardiac arrhythmias.⁶⁷ Such side-effects give patients valid reasons to consider refusing these older, but still used, drugs.⁶⁸ While newer ('atypical') anti-psychotics exhibit improved efficacy and lack these side-effects, they possess other effects. Although cardiac rhythms are not affected, significant weight gain,⁶⁹ metabolic changes and possible diabetes may pose cardiovascular risks to be weighed against benefits. Yet despite such doubts, s.39 may still demonstrate a sufficient rational connection to satisfy the test.

Does the impugned legislation 'minimally impair' the right infringed?

The legislature must tailor any rights intrusion, or provide exceptions to it. IPTA's requirement of the "least restrictive" treatment⁷⁰ suggests efforts to tailor s.39's intrusion.⁷¹ A "least restrictive" choice implies sometimes using physical restraints, seclusion, persuasion and incentives⁷² to gain cooperation, prevent harm and preserve the therapeutic environment. Yet if *any* psychiatric treatment refusal progressively damages brain and mind, or risks 'mental harm to others'⁷³ s.39 may subject almost *any* competent patient to unwanted medication. This seems inconsistent with tailoring. Moreover, the specific right infringed by s.39 seems inconsistent with minimal impairment. While neither rights to liberty nor bodily integrity are absolute, both are important s.7 *Charter* rights, only to be infringed in

accordance with the principles of fundamental justice. Yet they may warrant different treatment.

Liberty and security of the person differ in their sensitivity to interference. It is easier to tailor intrusions on liberty. This may be done spatially, limiting a person's movements, activities or interactions, or at the extreme, by restricting almost all activity, using seclusion, chemical or physical restraints.⁷⁴ Liberty intrusions may also be modified temporally, by duration. Security of the person,⁷⁵ however, is much more sensitive to interference, and more difficult to infringe in a tailored way. Bodily integrity either is, or is not, entirely breached by intrusions. Temporal tailoring of intrusions seems meaningless when even brief intrusions on bodily integrity, as in unwanted sexual contact, may have profound negative effects.

Bodily integrity and autonomy rights—the right to dictate what is done to one's body, brain and mind—also seem of more central value than liberty, given the importance of a person's physical 'being' to identity, self-determination and survival. Individuals express their unique personal identities through their bodies,⁷⁶ via temporary adornment,⁷⁷ or permanent body modifications,⁷⁸ communicating beliefs, affiliations and social status. A person's self-identity, memories and personality also exist in a specific body part: the brain. The body is therefore central to a person's identity and most intimate self-concept.⁷⁹

Thus, while both liberty and security of the person are important, security of the person seems both more fragile and more central to the person, warranting greater protection. The 'least intrusive' (i.e., most minimally impairing)⁸⁰ option requires infringing liberty over bodily integrity.⁸¹ Yet s. 39 adopts the opposite approach of infringing bodily integrity⁸² to promote patients' liberty, so it fails to minimally impair psychiatric patients' equality rights, clearly failing this third *Oakes*' branch.

Is there proportionality between benefits and costs of the means chosen or objective sought? For certainty, the final *Oakes* test branch will also be explored. Here, the means (s.39) allows interference with the personal autonomy of involuntary psychiatric patients, against their express, competent wishes. These patients are a dependent and isolated group, vulnerable to coercion, possibly confused by illness and sedation, who cannot easily air their views. Thus further restricting these patients' choices require caution, to preserve patient autonomy wherever possible.

Bodily integrity warrants "the highest order of protection"⁸³ in law, so proportionality requires s.39's goal to be of comparable or higher priority. Section 39 offers some benefits: it reduces violence, verbal abuse and stress to staff or other patients, and may reduce the application of more severe liberty restraints, shorten hospital stays⁸⁴ and lower costs.⁸⁵ Yet s.39's forced treatment is an overly simplistic approach to psychiatric illness that may cause harmful side-effects and impair real treatment progress.⁸⁶

Tragic as such lost potential may be, it may be a necessary sacrifice to respect patient autonomy. The power difference and information asymmetry between medical staff and patient imply a trust situation, requiring respect for patient choices. Also in a diverse, pluralistic society should the views of only one group—healthcare staff—determine the 'best interests' of all patients?⁸⁷ Patients have

many dimensions to their lives, only one of which involves their biomedical status. Biomedical assessments cannot canvas all of the values a person may treasure, which define him personally. Some patients prefer their own unique mental processes, as 'Starson' (2003) preferred his rapid thoughts, supporting his research.⁸⁸ Others enjoy the emotional highs,⁸⁹ or find meaning and livelihoods using artistic states inaccessible in treatment.

Emerging concepts such as 'Mad Pride' seek to reclaim and celebrate, rather than pathologize,⁹⁰ mental difference. The 'neurodiversity'⁹¹ movement holds that healthy human neurological function forms a continuum of (equally acceptable) ways of thinking, including conditions labelled as illness or disability.⁹² Mental differences may be a 'way of life,'⁹³ as is 'deaf culture' to some. Some argue the true location of mental 'disability' may lie within mainstream society's unconscious reactions to difference, not in the person claimed to be different.

Accordingly, is s.39's cost-benefit ratio proportional to the goal's importance? The answer will depend on the values of highest priority—those less reasonable to sacrifice. Here, freedom from interference with a patient's bodily integrity and autonomy are of higher priority than staff morale, and patients' potential and conformity with mainstream values. Thus the goal of recovering psychiatric patients' full potential, rather than warehousing them, while important, cannot support serious impositions on the sacrosanct Canadian value of security of the person. The proportionality step of the *Oakes*' test must fail, therefore. Accordingly, at trial, it seems highly likely that s.39 would fail on at least two *Oakes* test branches and could not be saved under s.1. However, what remedies a judge might impose, such as striking down s.39 or reading in certain requirements, must await an actual challenge in a court of law.

Conclusion

Non-consensual treatment of competent psychiatric patients ranks among the most controversial healthcare issues. Some regard it as a travesty for a patient not to be treated, if there is any chance of restoring healthy function. The issue seems all the more glaring with younger patients, who face a longer period of potential illness (or health), and who may forfeit opportunities to establish career paths and important social relationships due to illness. There is thus a temptation to view constitutional rights (including legal equality) as of lesser *practical* importance than a patient's mental health status.

Some may see s.39 as a compassionate response to mental illness. Yet its disregard for involuntary patients' legal rights perpetuates damaging stereotypes about patients, such as that their competent wishes are unworthy of respect. Such healthcare double standards in the treatment of physically and mentally ill patients *add to* rather than alleviate any burdens from mental illness.

This paper has asked whether IPTA s.39 could survive a s.15 *Charter* challenge. Overall, it seems it may not. While s.39 may superficially ameliorate the most *visible* disadvantages of mental illness through required treatment, it thereby reinforces our society's *invisible* barrier to inclusion: stigma. Overall, s.39 starkly denies the *Charter* legal equality guarantee, infringing a right—bodily integrity and

autonomy—considered sacrosanct in Canadian health law, which warrants stronger legal protection than liberty. Thus s.39 seems unlikely to be saved by s.1 of the *Charter*, due to failures in minimal impairment and proportionality.

Although IPTA updated many aspects of Nova Scotia's mental health legislation, s.39 is less than progressive. In contrast to the 'emergence from the shadows' heralded for mental illness this century, s.39 suggests a return to a more paternalistic era. Unchallenged, s.39 represents several steps backwards for psychiatric patients, compared with those in Canada's physical healthcare system.

References:

- Appelbaum, P.S. (1994) *Almost a Revolution: Mental Health Law and the Limits of Change* (New York: Oxford University Press).
- American Psychiatric Association, (2006) *American Psychiatric Association Practice Guidelines for the Treatment of Psychiatric Disorders: Compendium 2006*, (Arlington, VA: American Psychiatric Association).
- Bartlett, K.T. 'Feminist legal methods' (1990) 103 *Harvard Law Review* 829-888.
- Bear, M.F., Connors, B.W. and Paradiso, M.A. (2001) *Neuroscience: Exploring the Brain*, 3rd ed. (Lippincott, Williams & Wilkins: New York) at 673, 674, 679.
- Blume, H. "Neurodiversity" *The Atlantic* (30 September 1998) online at: www.theatlantic.com/doc/199809u/neurodiversity (accessed 12 March 2009).
- Cahn, C.H. 'The ethics of involuntary treatment: the [1982] position of the Canadian Psychiatric Association', (1982) 27 *Can. J. Psychiatry* 67-74.
- Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act*, 1982, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c.11. ['the Charter'].
- Canadian Mental Health Association, 'Informed consent to treatment' online at: www.cmha.ca/bins/print_page.asp?cid=5-33-174&lang=1 (accessed 3 March 2009).
- Canadian Mental Health Association, 'Stigma and Mental illness' online at www.cmha.ca (accessed 3 March 2009)
- Canadian Mental Health Association (British Columbia), 'Criminalization of Mental Illness' online at: www.cmha.bc.ca/files/2-criminalization.pdf (accessed 27 September 2009)
- Chadwick, R. and Levitt, M. 'Genetic technology: a threat to deafness' (1998) 1 *Medicine, Healthcare and Philosophy* 209-215.
- Consent to Treatment and HealthCare Directives Act*, R.S.P.E.I. 1988, c.C-17.2, ss.20 and 24
- Corbiere v. Canada (Minister of Indian and Northern Affairs)*, [1999] 2 S.C.R. 203 at para.70-72
- Crick, F. (1994) *The Astonishing Hypothesis* (Charles Scribner's Sons: New York).
- Fleming v. Reid*, [1991] 4 O.R. (3d) 74 at para. 31
- Gillett, G. 'Intention, autonomy and brain events,' (2009) 23 *Bioethics* 330-339.
- Gordon, H. 'Treatment Act divides mental health advocates' *Nova News Net* (4 November 2005) online at http://novnewsnet.ukings.ca/nova_news_3588_6825.html
- Gray, J.E., Shone, M.A. and Liddle, P.F. (2000) *Canadian Mental Health Law and Policy* (Toronto: Butterworths).
- Hermann, D.H.J. (1994) *Mental Health and Disability Law* (Eagan, MN: West Publishing).
- Hospitals Act*, R.S.N.S. 1989, c.208. s. 54A
- Incompetent Persons Act*, R.S.N.S., 1989, c.218, s.2 (b).
- Involuntary Psychiatric Treatment Act*, S.N.S., 2005, c.42 ['IPTA']
- Kesey, K. (1962) *One Flew Over the Cuckoo's Nest* (New York: Viking).
- Kirby M. J. L. and Keon, W. J. (2006) *Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada*, Final Report of the Standing Committee on Social Affairs, Science and Technology, May 2006 ['the Kirby Report']
- Kirk, T. and Bersoff, D. N. 'How many procedural safeguards does it take to get a psychiatrist to leave the light-bulb unchanged? A due process analysis of the MacArthur Treatment Competence Study,' (1996) 2 *Psychology, Public Policy, and Law* 45-
- Law v. Canada (Minister of Employment and Immigration)* [1999] 1 S.C.R. 497 at para. 51.
- Law Society of British Columbia v. Andrews* [1989] 1 S.C.R. 143 at para. 37
- McKenzie, J. I. 'The delicate dance in Canadian mental health policy: balancing equality rights, family rights and community rights,' (2008) 3 *Journal of Ethics in Mental Health* 1 -5.
- Malette v. Shulman* (1990), 72 O.R. (2d) 417, 67 D.L.R. (4th) 321 at para. 18 and 24
- Mental Health Act*, C.C.S.M., c.M110 s.28(4)(b)(ii)
- Metzger, E. and Friendman, R. "Prolongation of corrected QT interval and torsades de pointes cardiac arrhythmia associated with intravenous haloperidol in the medically ill" (1993) 13 *J. Clin. Psychopharmacol.* 85-86
- Millett, K. (1990) *The Loony-Bin Trip* (New York: Simon & Schuster).
- Pothier, D. 'Miles to go: some personal reflections on the social construction of disability,' *Dalhousie Law Journal* 526 -543.
- R. v. Kapp* [2008] S.C.J. No. 42
- R. v. Music Explosion, Ltd.*, (1990), 68 Man. R. (2d) 203 at para. 18.
- R v Oakes*, [1986] 1 S.C.R. 103 at para 69-71, 77
- R. v. Laba*, [1994] S.C.J. No. 106 at para 79-91.
- Ray, O. and Ksir, C. (2004) *Drugs, Society and Human Behaviour* 10th ed. (Boston: McGraw-Hill).
- Re M and The Queen* (1985), 21 C.C.C. (3d) 116 (Man. Q.B.).
- Re Rebic and The Queen* (1985), 20 C.C.C. (3d) 196 (B.C.S.C.), aff'd (1986), 28 C.C.C. (3d) 154 (B.C.C.A.)
- Saner, E. "It's not a disease, it's a way of life," *The Guardian* online at: www.guardian.co.uk/society/2007/aug07/health_medicineandhealth
- Schizophrenia Society of Canada, 'Schizophrenia Society disappointed with Supreme Court decision' and sample 'Letter to the Editor' for members, online at: www.schizophrenia.ca (accessed 11 June 2003).
- Slobogin, C. (2006) *Minding Justice: Laws that Deprive People with Mental Disability of Life and Liberty* (Cambridge, MA: Harvard University Press)
- Starson v Swayze*. [2003] S.C.J. No. 33 at para 76.
- Sullivan, G., Burnam A. and Koegel, P. 'Pathways to homelessness among the mentally ill,' (2000) 35 *Soc. Psychiatry Psychiatr. Epidemiol.* 444-.
- Tallis, R. "Why blame me? It was all my brain's fault: the dubious rise of neurolaw," *The Times* (24 October 2007) online: www.timesonline.co.uk/tol/comment/columnists/guest_contributors/article2726643.ehtml.
- Tisdale, J.E., Kambe, J.C., Chow, M.S. and N.S. Yeston, "Effect of haloperidol on ventricular fibrillation threshold in pigs" (1991) 69 *Pharmacol. Toxicol.* 327-9.

- Torrey, E.F. (1997) *Out of the Shadows: Confronting America's Mental Illness Crisis*, (Toronto: J. Wiley & Sons, Inc.)
- Weiner, B.A. and Wettstein, R.M. (1993) *Legal Issues in Mental Health Care* (New York: Plenum Press)
- Weisstub, D.N. (1990) *Enquiry on Mental Competency: Final Report* (Toronto: The Enquiry).
- Wildeman, S. (2008-9), 'Mental Disability Law' (course), Dalhousie University Law School.

Endnotes

- ¹ *Involuntary Psychiatric Treatment Act*, S.N.S., 2005, c.42 ['IPTA']
- ² *Incompetent Persons Act*, R.S.N.S., 1989, c.218, s.2 (b).
- ³ *Involuntary Psychiatric Treatment Act*, s.3(m): an 'involuntary patient' means "a patient who is admitted to a psychiatric facility pursuant to a declaration of involuntary admission." A psychiatrist can make a declaration of involuntary admission where he or she is of the opinion that:
- (a) the person has a mental disorder;
 - (b) the person is in need of the psychiatric treatment provided in a psychiatric facility;
 - (c) the person, as a result of the mental disorder,
 - (i) is threatening or attempting to cause serious harm to himself or herself or has recently done so, has recently caused serious harm to himself or herself, is seriously harming or is threatening serious harm towards another person or has recently done so, or
 - (ii) is likely to suffer serious physical impairment or serious mental deterioration, or both;
 - (d) the person requires psychiatric treatment in a psychiatric facility and is not suitable for inpatient admission as a voluntary patient; and
 - (e) as a result of the mental disorder, the person does not have the capacity to make admission and treatment decisions."
- ⁴ *Involuntary Psychiatric Treatment Act*, s. 39: The substitute decision-maker shall make the decision in relation to specified psychiatric treatment and other related medical treatment
- (a) In accordance with the patient's prior capable informed expressed wishes; or
 - (b) in the absence of awareness of a prior capable informed expressed wish or if following the patient's prior capable informed expressed with would endanger the physical or mental health or safety of the patient or another person, in accordance with what the substitute decision-maker believes to be in the patient's best interests.
- ⁵ *Malette v. Shulman* (1990), 72 O.R. (2d) 417, 67 D.L.R. (4th) 321 at para. 18 and 24: "Under the doctrine [of informed consent], no medical procedure may be undertaken without the patient's consent..." and: "A doctor is not free to disregard a patient's advance instructions any more than he would be free to disregard instructions given at the time of the emergency..." *Fleming v. Reid*, [1991] 4 O.R. (3d) 74 at para. 31: "The right to determine what shall, or shall not, be done with one's own body, and to be free from non-consensual medical treatment, is a right deeply rooted in our common law. This right underlies the doctrine of informed consent."
- ⁶ Hospitals Act, R.S.N.S. 1989, c.208. s. 54A states (for example): The substitute decision-maker shall make the decision in relation to specified medical treatment
- (a) in accordance with the patient's prior capable informed expressed wishes; or
 - (b) In the absence of awareness of a prior capable informed expressed wish, in accordance with what the substitute decision-maker believes to be in the patient's best interest.
- A second example, Prince Edward Island's *Consent to Treatment and HealthCare Directives Act*, R.S.P.E.I. 1988, c.C-17.2, ss.20 and 24 state:
20. (1) Every person over the age of sixteen years who is capable may execute a directive.
- (2) A directive may
- (a) stipulate treatment, procedures, or medication that the maker authorizes or refuses to consent to, or directs to be discontinued, in the circumstances set out in the directive;
 - (b) stipulate circumstances in which the maker shall be permitted to die a natural death, receiving only palliative care intended to reduce pain and suffering;
 - (c) appoint a proxy;
 - (d) specify an event or condition upon which the directive becomes effective;
 - (e) make any other direction concerning the health care or treatment of the maker.
24. (1) A decision contained in a directive shall be as effective as if made by the maker when the maker had capacity to make the decision.
- ⁷ *Fleming v. Reid*, [1991] 4 O.R. (3d) 74 at para.60. noted that the right to bodily integrity and autonomy is not absolute. Thus there may be limited circumstances where competent psychiatric patients' autonomy may validly be curtailed, for example, in emergency mental health situations, where a patient must be temporarily chemically restrained using sedative drugs. This seems reasonable since individual rights are never absolute but must be weighed against other rights, or those of other parties or the community. For instance, in physical healthcare, autonomy rights of competent patients may also be curtailed in limited circumstances, such as where a patient has been diagnosed with a serious communicable disease (e.g., multiple-drug resistant tuberculosis) that presents a serious public health risk. It should be noted that the patients affected by s.39 of IPTA are not at large in the community or able to leave the hospital at will. All are involuntarily hospitalized and thus pose no danger to public safety in the wider community.
- ⁸ IPTA s.39 is not entirely unique in Canada in its attempts to override the competent advance wishes of psychiatric patients. For example, Manitoba's *Mental Health Act*, C.C.S.M., c.M110 s.28(4)(b)(ii) accomplishes much the same end. Section 28(4) states:
- A person who makes treatment decisions on a[n incompetent] patient's behalf under subsection (1) shall do so
- (a) in accordance with the patient's wishes, if the person knows that the patient expressed such wishes when apparently mentally competent; or
 - (b) in accordance with what the person believes to be the patient's best interests if
 - (i) the person has no knowledge of the patient's expressed wishes, or
 - (ii) following the patient's expressed wishes would endanger the physical or mental health or the safety of the patient or another person.

While this paper focus specifically on IPTA s.39, many of the arguments may be applicable to other provincial legislation that attempts to override psychiatric patients' competent wishes in this manner.

- ⁹ While IPTA is in the minority in its overriding of psychiatric patients' competent wishes, it is not entirely alone in so doing in Canada. For example, the Manitoba's *Mental Health Act* s. 28(4)(b)(ii) permits an almost identical situation, overriding the patient's expressed wishes (made while competent) with best interests where following such wishes would "endanger the physical or mental health or safety of the patient or another person." In addition, British Columbia's *Mental Health Act* s.31(1) may override competent patient wishes by *deeming* patient consent to treatment have been given, on the basis of detention; and New Brunswick's *Mental Health Act* s.8.11(2) may override competent advance directives if they are not reliable, not current, or not applicable.
- ¹⁰ *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c.11. [the *Charter*].
- ¹¹ *R. v. Kapp* [2008] S.C.J. No. 42
- ¹² *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c.11, s.15(1).
- ¹³ *Law v. Canada (Minister of Employment and Immigration)* [1999] 1 S.C.R. 497 at para. 51.
- ¹⁴ *Law Society of British Columbia v. Andrews* [1989] 1 S.C.R. 143 at para. 37
- ¹⁵ While no comparator group may be perfect, and others could perhaps have been selected, patients suffering physical illness seemed the most useful comparator group for the purposes of this paper. Ideally, in a s.15 *Charter* analysis, the comparators should be very similar in all respects except for their legal treatment, which is the focus of the comparison. Choosing the physically ill seemed to appropriately emphasize the role of illness in creating the undeservedly unequal legal situation on which this paper focuses. Alternatively, it might have been possible to compare, for instance, the mentally ill detained under s.39 with the group composed of non-mentally ill persons detained criminally. While some might think it appropriate to thereby place the emphasis on detention and loss of liberty, this appeared less useful due to the very different purposes detention may express in these two groups: in the former, protection (of patient and potentially public), and in the latter, public protection but also punishment and the expression of societal disapprobation. The additional aspect of justly deserved punishment and moral disapprobation in the latter group renders it sufficiently different from the mentally ill detained involuntarily as to make it an inappropriate comparator, because in that case there genuinely appears to be a non-discriminatory reason for any different treatment.
- ¹⁶ *R. v. Kapp* [2008] S.C.J. No. 42 at para. 16.
- ¹⁷ *R. v. Kapp* [2008] S.C.J. No. 42 at para. 41.
- ¹⁸ The "Thank-you theory" has been attributed to psychiatrist Alan Stone by T.Kirk and D.N. Bersoff, 'How many procedural safeguards does it take to get a psychiatrist to leave the light-bulb unchanged? A due process analysis of the MacArthur Treatment Competence Study,' (1996) 2 *Psychology, Public Policy, and Law* 45 at 46. Some related concepts are of note. The 'human needs perspective' on mental illness is promoted by some as an antidote to civil libertarian efforts to legally empower psychiatric patients to contest involuntary committal and resist unwanted medical

treatment. J.E. Gray, M.A. Shone and P.F. Liddle, *Canadian Mental Health Law and Policy* (Toronto: Butterworths, 2000) at 10-12. P.S. Appelbaum also discusses the 'common-sense model' in which he argues psychiatrists and judiciary in practice often ignore the law, preferring involuntary committal and treatment of patients. This, he claims, prioritizes (presumed) patient suffering over legal rights. P.S. Appelbaum, *Almost a Revolution: Mental Health Law and the Limits of Change* (New York: Oxford University Press, 1994) at 42.

- ¹⁹ There may be a belief by some that the entire *purpose* of hospitalization is to treat and discharge psychiatric patients, rather than simply detaining them long-term to protect them or the public, termed 'warehousing.' J.E. Gray, M.A. Shone and P.F. Liddle, *Canadian Mental Health Law and Policy* (Toronto: Butterworths, 2000) at 208; C. Slobogin, *Minding Justice: Laws that Deprive People with Mental Disability of Life and Liberty* (Cambridge, MA: Harvard University Press, 2006) at 222. Psychiatrist C.H. Cahn described the situation as a trade-off or *quid pro quo*, in which he claimed restriction of a patient's liberty could only be justified by giving a patient (effective, non-harmful) treatment in return. C.H. Cahn, 'The ethics of involuntary treatment: the [1982] position of the Canadian Psychiatric Association,' (1982) 27 *Can. J. Psychiatry* 67 at 70. Countering this is the view that psychiatric hospitalization is *itself* a form of treatment, or a vital part of the healing process for psychiatric patients. The hospital environment offers supportive human relationships, monitoring and interaction, improved hygiene, shelter, nutritional and educational benefits, freedom from illicit street drugs, physical abuse, hypothermia, criminal justice system involvement and other dangers, compared to the potentially isolated and impoverished circumstances of homelessness, to which a patient may have been subject prior to involuntary hospitalization.
- ²⁰ From longer hospitalizations, added nursing and administrative workloads.
- ²¹ J.E. Gray, M.A. Shone and P.F. Liddle, *Canadian Mental Health Law and Policy* (Toronto: Butterworths, 2000) at 202-7; B.A. Weiner and R.M. Wettstein, *Legal Issues in Mental Health Care* (New York: Plenum Press, 1993) at 120, 124.
- ²² T. Kirk and D.N. Bersoff, 'How many procedural safeguards does it take to get a psychiatrist to leave the light-bulb unchanged: a due process analysis of the MacArthur Treatment Competence Study,' (1996) 2 *Psychology, Public Policy, and Law* 45 at 46.
- ²³ The anti-psychiatry movement formed the basis for the novel *One Flew Over the Cuckoo's Nest*, a novel which harshly critiqued psychiatry's treatment of involuntarily committed psychiatric patients; K. Kesey, *One Flew Over the Cuckoo's Nest* (New York: Viking, 1962).
- ²⁴ There are, of course, similarities between involuntary psychiatric committal and criminal incarceration: both share "loss of liberty, separation from family and friends, stigma of being institutionalized and reliance on the state to satisfy basic needs." D.H.J. Hermann, *Mental Health and Disability Law* (Eagan, MN: West Publishing, 1994) at 193. However, there are also important differences, such as that the purpose underlying psychiatric detention is not punitive or deterrent.
- ²⁵ i.e., in full possession and awareness of their legal rights, yet *because* of these legal rights supporting treatment refusal, unable to access their seeming 'right' to their full potential in life and a place in society. D. Treffert, quoted in C. Slobogin, *Minding Justice: Laws that Deprive People with Mental Disability of Life*

and Liberty (Cambridge, MA: Harvard University Press, 2006) at 244.

- ²⁶ As noted by the Court in Law, “Legislation which seeks to ameliorate disadvantage may not offend s.15(1) of the Charter even if it excludes certain other individuals or groups...However, this is *only* the case where the group excluded...is more advantaged in a relative sense than those the legislation seeks to assist.” (Emphasis added). *Law v. Canada (Minister of Employment and Immigration)* [1999] 1 S.C.R. 497 at para. 72
- ²⁷ *R. v. Music Explosion, Ltd.*, (1990), 68 Man. R. (2d) 203 at para. 18. Yet the Court noted that in two different cases, sections of the *Criminal Code* and *Young Offenders Act* were upheld as affirmative action programs under s.15(2): *Re Rebic and The Queen* (1985), 20 C.C.C. (3d) 196 (B.C.S.C.), aff’d (1986), 28 C.C.C. (3d) 154 (B.C.C.A.) and *Re M and The Queen* (1985), 21 C.C.C. (3d) 116 (Man. Q.B.). Both cases upheld differences in incarceration periods as ameliorative of the special needs of certain classes of offenders: mentally ill offenders found not guilty by reason of insanity (then detained under a Lieutenant-Governor’s Warrant), and youth serving time while awaiting trial, respectively. In both cases, the impugned law seemed rationally related to identified unique needs of the parties affected: the need for long-term separation of dangerous mentally ill patients from society for their own and others’ safety, and the need for greater leniency with youthful offenders. In contrast, in *Music Explosion*, the impugned bylaw’s attention to younger teenagers did not seem to reflect a rational ameliorative purpose related to the youths’ abilities or special needs, appearing almost arbitrary. The circumstances of s.39’s involuntarily hospitalized but competent mentally ill treatment-refusers more closely resembles the fact pattern in *Music Explosion*, with its seemingly arbitrary restriction of these patients’ rights to have their competent advance directives obeyed.
- ²⁸ Limiting younger teenagers’ use of a musical ‘amusement device’ without parental consent.
- ²⁹ *R. v. Kapp* [2008] S.C.J. No. 42 at para. 53.
- ³⁰ *R. v. Kapp* [2008] S.C.J. No. 42 at para. 54
- ³¹ *R. v. Kapp* [2008] S.C.J. No. 42 at para. 46.
- ³² *R. v. Kapp* [2008] S.C.J. No. 42 at para. 48, quoting *Manitoba Rice Farmers v Human Rights Commission (Man.)*, [1985] M.J. No. 446
- ³³ As the court in *Fleming v. Reid* said: “This right [to refuse treatment] must be honoured... regardless of how ill-advised the patient’s decision may appear to others.” *Fleming v. Reid*, [1991] 4 O.R. (3d) 74 at para. 32-33. Also in *Starson v Swayze*, [2003] S.C.J. No. 33 at para 76, the Supreme Court stated: “The right knowingly to be foolish is not unimportant; the right voluntarily to assume risks is to be respected. The State has no business meddling with either.”
- ³⁴ Stigma involves “negative attitudes or beliefs that are held about people who are perceived as different”; since they are often semi-conscious, they are difficult to address directly. The World Health Organization (WHO) stated in 2001 that stigma was “the single most important barrier” faced by people with mental illnesses. Reported by the Canadian Mental Health Association, ‘Stigma and Mental illness’ accessed online at www.cmha.ca As one contributor noted: “We attach no blame to someone who develops a physical illness, but when it comes to mental illness, people experience discrimination on a daily basis.”
- ³⁵ While not *all* individuals with mental illness may experience disadvantage, it is not necessary that all mentally ill individuals be found to be disadvantaged to advance an argument of affirmative action. As the Court noted in *Corbiere v. Canada (Minister of Indian and Northern Affairs)*, [1999] 2 S.C.R. 203 at para.70-72: to qualify as ameliorative of disadvantage, it is not necessary for *all* individuals members of a generally ‘disadvantaged’ group to suffer disadvantage, or to the same degree; confirmed in *R. v. Kapp* [2008] S.C.J. No. 42 at para. 59.
- ³⁶ Individuals with psychiatric diagnoses are overrepresented among the homeless, totalling 20-25% of the homeless population. G. Sullivan, A. Burnam and P. Koegel, ‘Pathways to homelessness among the mentally ill,’ (2000) 35 *Soc. Psychiatry Psychiatr. Epidemiol.* 444 at 444. In contrast, individuals with schizophrenia, bipolar disorder and major depression account for only 1%, 2% and 5% of the population respectively; M.F. Bear, B.W. Connors and M.A. Paradiso, *Neuroscience: Exploring the Brain*, 3rd ed. (Lippincott, Williams & Wilkins: New York, 2001) at 673, 674, 679.
- ³⁷ More than 50% of people with psychiatric disorders also have substance abuse problems; Canadian Mental Health Association (British Columbia), ‘Criminalization of Mental Illness’ online at: www.cmha.bc.ca/files/2-criminalization.pdf
- ³⁸ One estimate is that 15-40% of inmates in Canada’s criminal justice system have a mental illness; Canadian Mental Health Association (British Columbia), ‘Criminalization of Mental Illness’ online at: www.cmha.bc.ca/files/2-criminalization.pdf
- ³⁹ The Kirby Report into Canadian mental healthcare found widespread stigma and discrimination against mentally ill people in employment, housing, social opportunities and even healthcare, with debilitating effects on lives and recovery. One contributor stated: “Some patients struggle with poverty so grinding and housing so appalling, it would challenge the sanity of even the strongest among us.” Another added: “Individual recovery from mental health [problems] is impossible when struggling with the consequences of poverty alongside stigma and discrimination.” The Hon. Michael J.L. Kirby and the Hon. Wilbert J. Keon, *Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada*, Final Report of the Standing Committee on Social Affairs, Science and Technology, May 2006 at 7, 8 [‘the Kirby Report’]
- ⁴⁰ Numerous scholars have discussed the social construction of disability (or difference) and the question of where precisely such disability (or difference) is located: in the individual claimed to be different or in a society unwilling to accept or accommodate that difference? D. Pothier, ‘Miles to go: some personal reflections on the social construction of disability’, *Dalhousie Law Journal* 526 at 530-1; R. Chadwick and M. Levitt, ‘Genetic technology: a threat to deafness’ (1998) 1 *Medicine, Healthcare and Philosophy* 209 at 210; and K.T. Bartlett ‘Feminist legal methods’ (1990) 103 *Harvard Law Review* 829 at 843. Mental illness has similarly been claimed to be a social construction located not so much in the affected individual, but in the society in which that person lives, which is unwilling to accept and accommodate their mental illness and the differences it represents.
- ⁴¹ An absurd analogy might be an attempt to eliminate racism by superficially ‘whitewashing’ people of different ethnicities without addressing and rooting out the underlying myths, fears and stereotypes fueling (often semi-conscious) racist attitudes.
- ⁴² In *Andrews*, McIntyre J. quoted that “...there is no greater inequality than the equal treatment of un-equals;” *Law Society of British Columbia v. Andrews* [1989] 1 S.C.R. 143 at para 26. The view that like treatment does not accord with true, substantive

equality was also re-iterated by the Court in *R. v. Kapp* [2008] S.C.J. No. 42 at para. 15.

⁴³ Answered affirmatively, earlier in the paper.

⁴⁴ *Law v. Canada (Minister of Employment and Immigration)* [1999] 1 S.C.R. 497 at para. 62, 69, 72, 74

⁴⁵ D.N. Weisstub, whose *Enquiry on Mental Competency: Final Report* (Toronto: The Enquiry, 1990) at 116, was cited in evidence by the Supreme Court in *Starson v Swayze*. [2003] S.C.J. No. 33 at para. 77, stated: “The tendency to conflate mental illness with lack of capacity, which occurs to an even greater extent when involuntary commitment is involved, has deep historical roots, and...attitudes and beliefs have been slow to change. For this reason, it is particularly important that autonomy and self-determination be given priority when assessing individuals in this group.” (Emphasis added).

⁴⁶ There is in general no such thing as global competence or incompetence. In some patients, competence may fluctuate over time, or be present for some decisions but not others. However, overall, many mentally ill patients are competent either all or at least part of the time for all or at least some decisions.

⁴⁷ Therefore, individuals whose s.7 Charter rights to life, liberty or security of the person are to be infringed must receive procedural fairness entitlements, such as a right to an impartial hearing, a right to counsel, etc. This applies to the administration non-consensual treatment to a patient. There may be some procedural protections for security of the person under s.39 (e.g., a Board hearing at the mental hospital, where a substitute decision-maker deliberates on the patient’s ‘best interests’). However, this may not be enough. As discussed elsewhere, s.39 of IPTA has the potential for a s.7 Charter challenge too, although this issue will not be pursued in the paper.

⁴⁸ *Fleming v. Reid*, [1991] 4 O.R. (3d) 74 at para. 60

⁴⁹ *Fleming v. Reid*, [1991] 4 O.R. (3d) 74 at para. 39

⁵⁰ *Fleming v. Reid*, [1991] 4 O.R. (3d) 74 at para. 40

⁵¹ *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act*, 1982, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c.11, s.1.

⁵² *R v Oakes*, [1986] 1 S.C.R. 103 at para 69-71, 77; and *R. v. Laba*, [1994] S.C.J. No. 106 at para 79-91.

⁵³ This conclusion is based on several factors: the s.2 subordination of patient self-determination rights (respected only “where possible”) to treatment; the overriding effect of s.39 on prior wishes (opposing the usual trends in informed consent); the Act’s title (the *Involuntary Psychiatric Treatment Act*); and the admission requirement under s.17(e) that, involuntary psychiatric patients lack competence.

⁵⁴ E.F. Torrey, *Out of the Shadows: Confronting America’s Mental Illness Crisis*, (Toronto: J. Wiley & Sons, Inc., 1997) at 162.

⁵⁵ Others echo this view. The Schizophrenia Society of Canada has argued that competent patients’ Charter liberty rights are violated by allowing them to remain untreated; Schizophrenia Society of Canada, ‘Schizophrenia Society disappointed with Supreme Court decision’ and sample ‘Letter to the Editor’ for members’ use, online at: www.schizophrenia.ca (dated 11 June 2003). I am indebted to Professor Sheila Wildeman for drawing my attention to this article in her course ‘Mental Disability Law’ at Dalhousie University Law School. In this distorted view of liberty, untreated psychiatric patients are claimed to have no meaningful liberty; E.F. Torrey, *Out of the Shadows: Confronting America’s Mental Illness Crisis*, (Toronto: J. Wiley & Sons, Inc., 1997) at 142.

⁵⁶ Including possible patient suffering, loss of liberty and exclusion due to stigma and involuntary committal, and lost human potential.

⁵⁷ The urgent societal goals of reducing homelessness, poverty, addictions and criminalization of the mentally ill may also be indirectly assisted, if treatment lets patients gain insight, acquire healthy lifestyle patterns and establish career, educational and social networks for life in the community.

⁵⁸ E.F. Torrey, *Out of the Shadows: Confronting America’s Mental Illness Crisis*, (Toronto: J. Wiley & Sons, Inc., 1997) at 172-3

⁵⁹ K. Millett, *The Loony-Bin Trip* (New York: Simon & Schuster, 1990) at 313.

⁶⁰ K. Millett, *The Loony-Bin Trip* (New York: Simon & Schuster, 1990) at 311.

⁶¹ According to current mainstream scientific consensus, the ‘mind’ is a product of interactions between the neurons of the brain and other cells. F. Crick, *The Astonishing Hypothesis* (Charles Scribner’s Sons: New York, 1994) at 7.

⁶² Numerous authors have questioned whether human beings in general can be said to possess meaningful free will, autonomy and free choice in our decisions; F. Crick, *The Astonishing Hypothesis* (Charles Scribner’s Sons: New York, 1994) at 10, 171, 267-8; R. Tallis, “Why blame me? It was all my brain’s fault: the dubious rise of neurolaw,” *The Times* (24 October 2007) online: www.timesonline.co.uk/tol/comment/columnists/guest_contributors/article2726643.ehtml. In the specific context of healthcare decisions made by competent patients, Grant Gillett has explored the meaningfulness of informed consent in light of mental factors that appear to undermine truly free choice in healthcare (e.g., framing effects and other unconscious irrational forces directing decisions). He concludes that the deliberation process is not just a facade, and that competent patients do in fact possess meaningful freedom in their medical decisions. This autonomy is exemplified by patients’ decision-making within (or in opposition to) the knowledge scaffolding provided by an informed mentor (the healthcare provider or others); G. Gillett, ‘Intention, autonomy and brain events,’ (2009) 23 *Bioethics* 330 at 336-7.

⁶³ While the lack of scientific understanding of psychiatric treatments may seem concerning, in physical illness, after safety assessments, certain medical treatments or drugs may be routinely used, as Aspirin’s active ingredients once were, without a full understanding of their mechanism of function.

⁶⁴ J.E. Gray, M.A. Shone and P.F. Liddle, *Canadian Mental Health Law and Policy* (Toronto: Butterworths, 2000) at 41.

⁶⁵ Once termed neuroleptics, the older-style (first-generation) anti-psychotic medications included drugs such as haloperidol (Haldol), used to treat psychotic patients with various diagnoses. There are now also newer ‘atypical’ (or second-generation) anti-psychotic drugs, such as olanzepine (Zyprex). O. Ray and C. Ksir, *Drugs, Society and Human Behaviour* 10th ed. (Boston: McGraw-Hill, 2004) at 225-7. However, the older first-generation drugs still appear to be in use, as discussed infra.

⁶⁶ The older generation of anti-psychotics worked by blocking dopamine receptors, causing a similar clinical picture to Parkinson’s disease, where a deficiency of dopamine and the dopamine receptors is caused by reduced dopamine production in the brain. Thus as a result of the older anti-psychotic drugs, some 20% of patients suffer Parkinsons-like motor side-effects, including for 2% of patients, tardive dyskinesia, a motor disorder featuring writhing facial movements, drooling, etc. The chance of Parkinsons-like side effects may be reduced either by

administering a second (anti-cholinergic) drug to block motor side-effects, by carefully selecting an (older-style) anti-psychotic drug, or by using atypical anti-psychotic drugs, although the latter possess other concerning side effects. O. Ray and C. Ksir, *Drugs, Society and Human Behaviour* 10th ed. (Boston: McGraw-Hill, 2004) at 227-8.

⁶⁷ American Psychiatric Association (APA), American Psychiatric Association Practice Guidelines for the Treatment of Psychiatric Disorders: Compendium 2006, (Arlington, VA: American Psychiatric Association, 2006) at 85; E. Metzger and R. Friendman, "Prolongation of corrected QT interval and *torsades de pointes* cardiac arrhythmia associated with intravenous haloperidol in the medically ill" (1993) 13 *J. Clin. Psychopharmacol.* 85-86; J.E. Tisdale, J.C. Kambe, M.S. Chow and N.S. Yeston, "Effect of haloperidol on ventricular fibrillation threshold in pigs" (1991) 69 *Pharmacol. Toxicol.* 327-9.

⁶⁸ However, the APA Practice Guidelines for 2006 identified haloperidol as still the "anti-psychotic medication of first choice," *American Psychiatric Association Practice Guidelines for the Treatment of Psychiatric Disorders: Compendium 2006*, (Arlington, VA: American Psychiatric Association, 2006) at 85.

⁶⁹ J.I. McKenzie, "The delicate dance in Canadian mental health policy: balancing equality rights, family rights and community rights," (2008) 3 *Journal of Ethics in Mental Health* 1 at 1.

⁷⁰ *Involuntary Psychiatric Treatment Act*, S.N.S., 2005, c.42, s. 2(c)

⁷¹ In addition, the s.39 override only applies to *some* mentally ill patients at certain times: those who risk harm to self or others.

⁷² For example, outdoor grounds privileges.

⁷³ Including an unjustified fear of untreated patients)

⁷⁴ Some argue that impositions on one's physical autonomy (via forced psychiatric treatment) restrict not only physical liberty but mental liberty as well. C. Slobogin, *Minding Justice: Laws that Deprive People with Mental Disability of Life and Liberty* (Cambridge, MA: Harvard University Press, 2006) at 222.

⁷⁵ 'Security of the person' will be used interchangeably here with the common law rights to bodily integrity and autonomy.

⁷⁶ Including gender, age, racial and ethnic characteristics.

⁷⁷ For instance, clothing, hairstyling, jewellery and cosmetics.

⁷⁸ Such as diet, exercise, surgical augmentation, and skin piercing or tattooing

⁷⁹ Accordingly, *Fleming* noted that few intrusions are more extreme than the legislatively enforced administration of mind-altering drugs, affecting this intimate body part.

⁸⁰ As noted, the s.7 right to security of the person is *only* to be restricted in accordance with the principles of fundamental justice. Yet s.39 of the IPTA appears to restrict security of the person in discriminatory manner, which cannot be in accordance with the principles of fundamental justice. Fundamental justice and discriminatory treatment are diametrically opposed in effect and motive. Thus s.39 seems unlikely to *minimally* impair the s.15 equality right because not only does s.39 *completely* impair a patient's right to bodily integrity, but it does so on the basis of values *diametrically opposed* to the principles of fundamental justice,

⁸¹ The mode of administration of unwanted medication is *not* relevant to whether or not a violation of bodily integrity and autonomy has occurred. Gray suggests that since *injections* of medications are now rarely used in modern Canadian psychiatry, this is acceptable because no force is being used against the patient (presumably implying there is no violation of bodily integrity); J.E. Gray, M.A. Shone and P.F. Liddle, *Canadian*

Mental Health Law and Policy (Toronto: Butterworths, 2000) at 196. However, this is a misconception: whether the unwanted drug therapy is oral or by injection, the effect remains the same: the drugs enter the person's body and transit the blood brain barrier, potentially affecting the competent patient's most intimate thoughts in an unwanted manner. Thus, regardless of the route of administration, the patient's right to bodily integrity has been violated, and to the same degree.

⁸² For example, no competent skin cancer patient, regardless of how life-threatening or treatable their disease, is required to undergo treatment, on the justification that the patient and his potential can be saved, preventing family distress and later costly warehousing. The competent treatment refusal by the *physically* ill is a well-recognized right at law and will ordinarily be respected to avoid legal liability for battery. Comparable respect for competent wishes of the *mentally* ill is required in psychiatric care, in the interests of legal equality.

⁸³ *Fleming v. Reid*, [1991] 4 O.R. (3d) 74 at para. 39.

⁸⁴ Untreated patients' stays may average twice as long, generating higher costs. J.E. Gray, M.A. Shone and P.F. Liddle, *Canadian Mental Health Law and Policy* (Toronto: Butterworths, 2000) at 204. Some treatment-refusers are hospitalized for much longer—ordered to spend a 12-month period in hospital, 'Professor Starson' had been hospitalized for years by his trial date in 2003; Schizophrenia Society of Canada, 'Schizophrenia Society disappointed with Supreme Court decision', online at: www.schizophrenia.ca (dated 11 June 2003). Some never return to the community nor fulfil their potential, although medication could make this possible in months.

⁸⁵ Gray argues that warehousing a treatment-refuser for two years might cost \$330,000, while a one-month treatment costs only \$15,000, followed by release. J.E. Gray, M.A. Shone and P.F. Liddle, *Canadian Mental Health Law and Policy* (Toronto: Butterworths, 2000) at 206. Yet his estimate omits the need for post-release community supports and medications. Hence the actual cost asymmetry remains unclear.

⁸⁶ Professor Sheila Wildeman describes IPTA's involuntary treatment as a "combative approach to psychiatric therapy" that "polarizes the therapeutic relationship" and is counterproductive to meaningful treatment; H. Gordon, 'Treatment Act divides mental health advocates' *Nova News Net* (4 November 2005) online at http://novnewsnet.ukings.ca/nova_news_3588_6825.html Studies show that treating patients against their will generally results in poorer prognoses; C. Slobogin, *Minding Justice: Laws that Deprive People with Mental Disability of Life and Liberty* (Harvard University Press: Cambridge, MA, 2006) at 245.

⁸⁷ The Canadian Medical Health Association states: "It cannot be assumed that medical treatment is the only or best option for individuals [with mental illnesses]." Canadian Mental Health Association, 'Informed consent to treatment' online at: www.cmha.ca/bins/print_page.asp?cid=5-33-174&lang=1 (accessed 3 March 2009).

⁸⁸ *Starson v Swayze*. [2003] S.C.J. No. 33 at para. 46.

⁸⁹ E.F. Torrey, *Out of the Shadows: Confronting America's Mental Illness Crisis*, (Toronto: J. Wiley & Sons, Inc., 1997) at 156.

⁹⁰ Again, I am grateful to Professor Sheila Wildeman and her course 'Mental Disability Law' at Dalhousie University Law School, for drawing my attention to this emerging trend, described in an undated *Toronto Star* article by H. Henderson, entitled 'Mad Pride', accessed online at: www.mindfreedom.org/mindfreedom/

madpride/Toronto_d.shtml (accessed 30 January 2004).

- ⁹¹ H. Blume, "Neurodiversity" *The Atlantic* (30 September 1998) online at: www.theatlantic.com/doc/199809u/neurodiversity
- ⁹² Maintaining and encouraging mental differences – neurodiversity-- may be as important as preserving biodiversity, to ensure humanity's future adaptability and survival: "Who can say what form of [neurological] wiring will prove best?" H. Blume, "Neurodiversity" *The Atlantic* (30 September 1998) online at: www.theatlantic.com/doc/199809u/neurodiversity
- ⁹³ E. Saner, "It's not a disease, it's a way of life," *The Guardian* online at: www.guardian.co.uk/society/2007/aug07/health.medicinandhealth

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The Ethics of Applied Research with Individuals with Addictions

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ABSTRACT

Myriad ethical issues are inherent in applied research involving individuals with addictions. Formal guidance from governing bodies for research with this specific vulnerable population is needed; however, it is presently all but absent. The current paper highlights the interrelated issues of dual relationships, incentives/inducements, and informed consent that occur when this research is conducted. Given the varied nature of addiction in terms of severity and likelihood of relapse, a focus on the unique risk for each participant is recommended. It is advised that applied researchers be cognizant of these important ethical issues, develop protocols, and ensure that research assistants have appropriate training.

Key words: research ethics; applied research; ethics; incentives; dual relationships; applied research with individuals with addictions; addictions research ethics.

Ethical issues are inevitable when conducting applied research with individuals with addictions. The quandaries discussed in this paper pertain to dual relationships with clinician-researchers, the use of incentives/inducements, and the ability of the client to provide informed consent. First, a discussion of available ethical guidance is provided.

The Ethical Climate – Standards and Practices

Ethical research practices in Canada are guided by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TPS: CIHR et al, 1998). This policy provides direction with respect to many aspects of research with human participants (e.g., minimal risk, informed consent, confidentiality, and conflicts of interest). Still, these guidelines do not adequately inform practices in the arena of addictions research, especially with respect to dual relationships and the use of incentives. With respect to incentives, Research Ethics Boards (REB) are instructed by the TPS to consider the economic situation of potential participants and to caution against a payment structure that might unduly induce individuals to join or remain with a study. Similarly, the Canadian Code of Ethics for Psychologists (Canadian Psychological Association, 2000), while commenting on the issues, does not provide enough direction. The standards for the *Avoidance of conflict of interest* indicate that one should:

III.31: Not offer rewards sufficient to motivate an individual or group to participate in an activity that has possible or known risks to themselves or others. (Canadian Psychological Association, 2000, p. 26)

III.33: Avoid dual or multiple relationships (e.g., with clients, research participants, employees, supervisees, students, or trainees)

and other situations that might present a conflict of interest or that that might reduce their ability to be objective and unbiased in their determinations of what might be in the best interests of others. (Canadian Psychological Association, 2000, p. 26)

With respect to attaining consent, also relevant are statements I.27 (Take all reasonable steps to ensure that consent is not given under conditions of coercion, undue pressure, or undue reward) and I.28 (Do not proceed with any research activity, if consent is given under any condition of coercion, undue pressure, or undue reward). Again, these statements provide a framework, but they do not provide the direction needed in terms of providing incentives and managing dual relationships with addictions clients.

With respect to program evaluation, the Canadian Evaluation Society (CES) has recently (April 3, 2008) published its ethical guidelines and, with these, a comparison to the guidelines outlined by evaluation associations in other countries (CES, 2008). Still, these guidelines make no reference to issues of payments to participants or dual relationships. Further, although CES is the professional association for evaluators in Canada, there are currently no standards in place that govern practice as an evaluator, nor is there any type of accreditation as a professional evaluator (although this process is underway). Further, the educational backgrounds of individuals working in the field of evaluation are quite disparate. As such, it would behoove professional evaluators and others involved in applied research to avail of additional training in research ethics in order to supplement the available guidance from their regulatory body or association. Such training may involve accessing free online tutorials, such as those available through the National Institutes of Health (<http://www.nih.gov/>) or the Interagency Panel on Research Ethics (www.pre.ethics.gc.ca), or reviewing the ethical guidance provided by such governing bodies as the Office of Human Research Protections in the United States (<http://www.hhs.gov/ohrp/>) or similar governing bodies in other jurisdictions.

Clearly, specific guidelines for practice are lacking and further evidence-based ethical direction is necessary to protect participants and ensure quality research (Anderson & Dubois, 2007). Of course, REBs may provide specific guidance regarding these issues; however, the applied research and applied researcher for which this paper is intended may not always be affiliated with an institution which has an REB. The following sections address some of the primary considerations for such guidelines.

The Ethical Problems: Dual Relationships – The Clinician-Researcher

A clinician-researcher is an individual who provides direct clinical services and conducts research (see Yanos & Ziedonis, 2006). Within these roles, a number of dual relationships are prevalent in applied research with substance users.¹ Evans and Hearn (1997, citing Pope, 1991; Sonne, 1994; Valentich & Gripton, 1992; Younggren & Skorka, 1992) suggested that “a dual relationship in professional practice occurs when a practitioner is in another significantly different professional or non-professional relationship with one or more of his or her clients” (p.53). With respect to

a clinician also acting as a researcher, Evans and Hearn (1997) suggested only that there is a potential for a dual relationship. Of course, such potential is realized when the clinician asks the client to participate in a research project.

When considering the concept of professional boundaries, Gutheil and Gabbard (1993) discussed a distinction between boundary crossing and boundary violation. The authors suggest that boundary crossing occurs when roles have been changed wherein the professional helper-client relationship may have moved in ways that reflect a friendship, or an alternative relationship not akin to the original professional roles and practices. The authors define boundary violations as occurring when exploitation of the client exists. The position in the present paper is that the situation in which a clinician participates in the recruitment of a research participant exemplifies a boundary crossing and should thus be avoided as it extends the limitations of the helper-client relationship.

Within the concept of dual relationships, a discussion around power imbalances is also warranted. It is the power differential that contributes to the influence that the clinician has over the client (Evans & Hearn, 1997), and we must question whether this power differential is contributing to the client’s decision to participate in a research study in which he/she would not have otherwise participated. Table 1 presents types of dual relationships that are present in applied research and illustrates the power imbalance through the recruitment questions that may be asked of clients. In each of these situations, it is evident that the client may experience some pressure to participate. One cannot be certain that the client would have participated without such influence, so the clinician should take into careful consideration his/her potential influence and its impact on the client.

**TABLE 1:
RECRUITMENT QUESTIONS POSED TO ADDICTON CLIENTS**

<i>Recruiter</i>	<i>Recruitment Question Posed to Addictions Client</i>
Clinician-Researcher	Will you participate in my research study?
Clinician	Will you participate in my colleague’s research
Researcher	I was given your name by your clinician. Will you participate in my research?
Program Manager/Staff	Will you participate in the evaluation of the program in which you are currently enrolled?

The conflicts that are presented within the dual roles of the clinician-researcher in applied research are commonly summarized into financial conflicts of interest and those arising from the opposing agendas inherent in each role, namely, beneficence on the part of the clinician (e.g., acting in the best interest of the client) and scientific autonomy on the part of the researcher (e.g., conducting scientific research using the appropriate rigour) (Yanos & Ziedonis, 2006). Clinicians often have good reason to participate in research involving human participants. Reasons may be related to professional promotion and reputation, as well as partnerships with

third parties, such as pharmaceutical companies. Moreover, Yanos and Ziedonis (2006) present the argument that within applied research those with direct clinical exposure have the advantageous position of understanding the most relevant research that would contribute to issues 'on the ground'.

Thus, the direct and subtle ways in which clinicians influence the recruitment of clients as research participants challenge a position that suggests that clinicians completely avoid any role in the recruitment of research participants. Rather, it is suggested that clinician-researchers maintain extreme caution when these roles cross. Yanos and Ziedonis (2006) present an effective approach for clinician-researchers to integrate their dual roles. Specifically, the authors suggest that clinician-researchers develop an 'integrated identity' toward dealing with conflicts of interest such as dual relationships. The approach entails that clinician-researchers be aware of themselves and their ethical responsibility to the individual client and take steps to ensure that relationships with participants are formed in ways that minimizes the chance of therapeutic misconception. The authors also make the point that although self-awareness and education may still leave room for bias leading to exploitation and or poor science, these key steps are effective in putting forth the appropriate context for the clinician-researcher to use sound ethical judgment.

In the case where this ethical judgment leads to a conclusion that recruiting participants may cause irreversible harm to the existing relationship, then the clinician should avoid any role in the recruitment of participants for a research study. This may include engaging in a discussion of research projects, distributing research information, and permitting a recruitment poster in his/her office. In each of these cases, the client may perceive that the clinician views participation favourably and is therefore, if even minimally, influencing participation. As such, clients are participating with the underlying expectation that they will be pleasing their clinician because of "prosocial" behaviour. In many cases, however, this can not be avoided as the research cannot proceed without the clinician bridging the gap between a researcher and the research participant. Moreover, the benefit of the research may extend beyond any potential harm which is created through a boundary crossing. At the very least, it is important for these issues to be considered when research protocols are being developed and implemented.

The Ethical Problems: Dual Relationships – The Qualitative Researcher

Dual relationships and boundary crossings may also occur in the context of a qualitative research interview (Bourdeau, 2000). Qualitative research, as compared to quantitative research, relies heavily on interview methodology and may involve lengthy sessions (e.g., 2 hours) crafted to facilitate maximum disclosure. Bourdeau (2000) reviewed literature that suggested many similarities between the qualitative researcher-participant relationship and the clinician-client relationship. Although the relationship between clinician and client is somewhat unique, the time that a researcher engages with a client during a qualitative interview also has the potential to test boundaries. For example, if the qualitative researcher does not remain attentive to maintaining

his or her boundaries, he or she may over-disclose personal issues when in dialogue with a client in an effort to enable a client to relate to a research question or bring meaning to a research question.

It is the position of the authors that the nature of the disclosures made in interviews with individuals with addictions necessitates that qualitative researchers make every effort to limit the potential for boundary crossings; specifically, the qualitative researcher should avoid assuming roles that resemble those of a clinician. As the qualitative interviewer employs many of the same interviewing skills (e.g., reflection, probing, reframing, summarization) as the clinician in an effort to achieve similar goals (e.g., rapport, insight into client emotions, thoughts, and motivations, and identification of problems) there is a high potential for roles to become blurred. Moreover, the fact that qualitative researcher training is often minimal, it cannot be assumed that competence will be exercised in dealing with the complex diversification of emotions that may surface during the course of an interview. Further, if the research employs a longitudinal design, the potential for dual relationships and boundary crossings is larger and thus requires more skill to avoid. In summary, research interviews with individuals with addictions could result in dual relationships because of a possible power-differential, the possibility of a lengthy interaction, and a potential for non-immediate termination of the researcher-participant relationship, especially in the case of longitudinal studies.

The Ethical Problems: Incentives and Inducements

The ethical issues surrounding dual relationships are exacerbated when incentives are considered. Unfortunately, however, very little has been published regarding the ethics of paying substance users to participate in research. This is of particular concern given this is a population for which payment for participation may trigger relapse (Seddon, 2005). Seddon (2005) reviewed research suggesting that financial incentives (including food vouchers) place individuals with addictions at risk because they are likely to use this compensation to fund the addiction. Similarly, Shaner et al (1995), in an evaluation of 105 individuals with cocaine dependence, noted a strong temporal association between support payments to drug users and substance abuse relapse. This suggests that even payment to individuals in addiction recovery may be creating undue harm. Indeed, many clients in treatment for substance abuse problems consider money a precipitating factor with respect to relapse. Moreover, as noted by Fry, Hall, Ritter, and Jenkinson (2006), we must especially attend to the undue influence of incentives on individuals experiencing withdrawal symptoms, intoxication, or related psychosis.

Still, if incentives were so detrimental to individuals with addictions, one would expect larger incentives to have a greater negative impact. Yet, Festinger et al (2005), in a well-devised controlled study on the matter, found that neither the method (cash or gift certificate) nor the amount (\$10, \$40, or \$70) of payment had an impact on perceptions of coercion or subsequent rates of drug use. Payment amount was, however, associated with increased rates of participation. Still, as with the general population, incentives are not the only reason that individuals with addictions participate

in research (Fry et al., 2006). Fry et al noted that individuals with addictions participate in research for a variety of reasons: “citizenship, altruism, personal satisfaction, drug user activism, and to obtain information” (p. 24). Thus, this research suggests that incentives are beneficial for recruiting participants (Fry et al., 2006; Ritter et al., 2003) and maintaining longitudinal samples (e.g., Festinger et al., 2005). In summary, payment may result in relapse for some (Seddon, 2005), which is a definitive risk to participant wellbeing. Ultimately, individuals with addictions have the right to receive the same benefit from research as is received by other research participants (Fry et al., 2006).

It is evident that payment acts as an incentive; however, the issue of inducement is somewhat less clear. Of relevance here is the economic situation of this target group. Many substance users are recipients of social benefits, and therefore, have limited resources. As noted, REBs are asked to consider the economic situation of participants when examining financial incentives (CIHR et al., 1998). This consideration is nowhere more relevant than with marginalized mental health consumers. As such, financial incentives are more likely to act as an inducement with this population than with the general population. As Marson, Savage, and Phillips (2006) noted in a review of literature on ethical concerns related to the financial capacity of individuals with serious mental illness, “a monetary payment of \$50 may represent a full month’s personal spending money for the person with severe mental illness, but only a modest recompense for his or her typical adult counterpart” (p. 89). It is troubling then that a survey conducted by Ripley, Macrina, and Markowitz (2006) demonstrated that REBs examining clinical research proposals did not, in fact, consider participant income as important in determining the appropriateness of different payments. Nonetheless, REBs need to be aware of the link between incentives and drug use for individuals with addictions, and pay particular attention to the economic situation of the participants. If relapse is likely, then it is not ethical to facilitate this relapse.

It follows that REBs and researchers should not work under the naïve assumption that the addictions population is somehow a homogenous group that shares the common thread of substance dependence. There are marked differences across substances in terms of behaviour and impact on reasoning. As such, it is speculated that the impact of incentives and dual relationships will vary across individuals, depending on the drug being used and the severity of the addiction. Therefore, to adequately determine and manage the risk to participants, a thorough screening of potential participants and their motives is warranted. A better understanding of risk for each specific participant will undoubtedly have an impact on the informed consent process. Given the mixed findings in the reviewed literature, it is clear that we do not yet know enough about the effect of incentives on relapse and other negative outcomes. So, until which time as a larger and more conclusive body of evidence is developed, it seems prudent to proceed with caution and inform individuals with substance abuse problems about these potential harms.

The Ethical Problems: Informed Consent

The condition of informed consent requires that: 1) the individual

is given enough information to make the decision of consent, 2) the individual understands the information, 3) the individual has the capacity to consent, and 4) the consent is voluntary (Faden et al., as cited in Loue & Ioan, 2007). The preceding discussion of inducements and relapse risks draws into question whether or not individuals with addictions are capable of meeting the requirements of informed consent. Fry et al. (2006) noted that “the main ethical questions about subject payments relate to their potential impact upon voluntary consent (i.e., inducement or influence), and the related issue of how prospective participants evaluate the personal risks, harms and benefits from research.” (p.23). It does not appear then, based on the reviewed literature, that individuals with addictions are currently being offered adequate risk information to permit consent. At the very least, participants should be provided with additional information during the consent process. Applied research conducted by the first and third authors has included the following statement in the consent form: “Some evidence suggests that participating in research for financial compensation is associated with an increased risk of relapse.”

Research Quality

Finally, we must consider the purpose and quality of the research that is being conducted with individuals with addictions. We must consider that applied research with individuals with addictions has important public health implications and therefore obtaining a representative sample is essential. With respect to the evaluation of programs that facilitate recovery, it is essential to ensure participation of the clients being served. It is often the case that these programs may be piloted with a limited number of individuals and therefore methods to increase participation rates are important. The experiences of these individuals speak to the value of the program/intervention and have direct effects on program continuance and expansion. As noted in a review by Fisher (2004), certainly, the validity of such studies is questionable if participation rates are minimal.

Another important issue with respect to the quality of research with individuals with addictions relates to the longitudinal nature of much applied research. In making the case for the value of a program/intervention, it is essential to demonstrate the long-term benefits of these programs. Therefore, including incentives is key to ensuring that participants maintain contact with researchers and that they notify the researchers when changes of address occur. This is especially relevant for mental health and addictions consumers who are likely to be transient and suffer relapses. Fry et al (2006) reviewed research that supported the contention that incentives improve recruitment and retention. Still, as noted, consumers should be informed of the risks associated with such incentives.

Conclusions and Recommendations

The prior discussion has highlighted some of the ethical issues relating to research with individuals with addictions. It is clear that attention to these ethical issues, while growing, is still

extremely limited. REBs, professional associations, and the clinical and research professionals in the field are in a position to provide leadership and guidance in this area. In the case of vulnerable populations, such as individuals with addictions, evidence-based decision-making is necessary (Anderson & DuBois, 2007). It is clear that dual relationships exist (Evans & Hearn, 1997), that incentives increase participation and are linked to drug use (Seddon, 2005), and that participants may not fully understand the risks associated with participation and are therefore not meeting the requirements of informed consent (Fry et al., 2006). Therefore, REBs should require that researchers demonstrate an understanding of these issues and have in place steps to minimize the risk of relapse.

However, in the absence of formal guidance, the onus is placed on the applied researcher to ensure that participants and research assistants are informed of the potential risks. Research assistants who will be interviewing substance users should be trained to recognize dual relationships and to be aware of the power differential that exists with clients/participants and the potential hazards involved with paying participants (e.g., traveling with money to and from interviews). Further, protocols should be developed for situations wherein the participant may be experiencing withdrawal symptoms, intoxication, or related psychosis. Protocols should cover, for example, appropriate meeting places/times, methods of payment, emergency contact information, and training in recognizing adverse symptoms. This would help ensure the safety of the participant and the researcher. REBs should require that such training and protocols be in place prior to study commencement.

Researchers should also be conscious of the fact that many clinicians working with individuals with addictions have not received ethics training and may not be aware of appropriate research ethics or the intricacies of related dual relationships. Therefore, providing direction to clinicians (for example, on not recruiting participants) may be necessary. Likewise, clinicians should be aware that many individuals who conduct applied research, such as program evaluation, have not received adequate training in research ethics and may also not fully understand the problems associated with dual relationships. These problems may be partially addressed if all individuals who are involved in collecting data from clients be advised to take one of the available online ethics courses. It is important to note that many of the projects which are the focus of this paper do not undergo REB review as they are considered quality assurance or because they are being conducted regarding a program or treatment facility that is not university affiliated. As such, the onus rests with the applied researcher/clinician to consider and address these education gaps.

Further, as noted, a more detailed screening of participants is necessary in order to minimize risk. This screening should inform the researcher about the availability of financial resources, severity of addiction, sources of emotional support, and motives for participation. The researcher should not permit the participation of individuals for whom payment is a primary motive and/or the purchase of drugs with this payment seems likely. However, it is also important to consider that research participation could be seen as a means to earn money without resorting to crime; thus, a possible form of harm reduction. An alternative approach may be to build research participation into the program design and funding, thereby requiring that participants of programming be

participants in related evaluation research. Beyond these methods, applied researchers should lobby professional associations and REBs to attend to, and provide further guidance, on this matter.

As a final note, the reader is also cautioned that, in a mental health setting, it is difficult to disentangle the addictions population from other clinical populations. As such, attention to the ethical issues relevant to research with forensic clients, clients with developmental disabilities (Fisher, 2003), geriatric clients (Moye & Marson, 2007), and clients with severe mental illnesses (Marson, Savage, & Phillips, 2006) is important. Concurrent and dual diagnoses are prevalent and, therefore, the applied researcher must ensure sound ethical practice when dealing with these vulnerable populations. In the absence of action from other groups, the applied researcher should be cognizant of ethical practice with individuals with addictions and the outlined nuances of dual relationships, incentives, and informed consent.

References:

- Anderson, E. E., & DuBois, J. M. (2007). The need for evidence-based research ethics: A review of the substance abuse literature. *Drug and Alcohol Dependence*, 86, 95-105.
- Bourdeau, B. (2000, March). Dual relationships in qualitative research. *The Qualitative Report* [On-line serial], 4(3/4). Available: <http://www.nova.edu/ssss/QR/QR4-3/bourdeau.html>.
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, 1998 (with 2000, 2002, 2005 amendments).
- Canadian Psychological Association (2000). *Canadian Code of Ethics for Psychologists - 3rd Edition*.
- Evans, D. R., & Hearn, M. T. (1997). Sexual and non-sexual dual relationships: Managing the boundaries. In D. R. Evans (Ed.), *The law, standards of practice, and ethics in practice of psychology* (pp. 53-83). Toronto, ON: Edmond Montgomery.
- Festinger, D. S., Marlowe, D. B., Croft, J. R., Dugosh, K. L., Mastro, N. K., Lee, P. A., DeMatteo, D. S., & Patapis, N. S. (2005). Do research payments precipitate drug use or coerce participation? *Drug and Alcohol Dependence*, 78(3), 275-81.
- Fisher, C. B. (2003). Goodness-of-fit ethic for informed consent to research involving adults with mental retardation and developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 9, 27-31.
- Fisher, C. B. (2004). Ethics in drug abuse and related HIV risk research. *Applied Developmental Science*, 8, 91-103.
- Fry, C. L., Hall, W., Ritter, A., & Jenkinson, R. (2006). The ethics of paying drug users who participate in research: A review and practical recommendations. *Journal of Empirical Research on Human Ethics*, XX, 21-36.
- Gottlieb, M. C. (1993). Avoiding exploitive dual relationships: A decision-making model. *Psychotherapy*, 30, 41-48.
- Gutheil, T.G., & Gabbord, G.O. (1993). The concept of boundaries in clinical practice: theoretical and risk-management dimensions. *American Journal of Psychiatry*, 150, 188-196.
- Grady, C. (2005). Payment of clinical research participants. *Journal of Clinical Investigation*, 115, 1681-1687.
- Graham, K. (2008). Fiddling while Rome burns? Balancing rigour with the need for practical knowledge. *Addiction*, 103, 414-415.

- Loue, S., & Ioan, B. (2007). Legal and ethical issues in heroin diagnosis, treatment, and research. *The Journal of Legal Medicine*, 28, 193-221.
- Magura, S., Staines, G. L., Blankertz, & Madison, E. M. (2004). The effectiveness of vocational services for substance users in treatment. *Substance Use Misuse*, 39, 2165-2213.
- Malley, P., Gallagher, R., & Brown, S. M. (1992). Ethical problems in university and college counseling centers: A delphi study. *Journal of College Student Development*, 33, 238-244.
- Marson, D. C., Savage, D., & Phillips, J. (2006). Financial capacity in persons with schizophrenia and serious mental illness: Clinical and research ethics aspects. *Schizophrenia Bulletin*, 31(1), 81-91.
- Moye, J., & Marson, D. C. (2007). Assessment of decision-making capacity in older adults: An emerging area of practice and research. *Psychological Sciences*, 62B, 3-11.
- Ripley, E. B. D., Macrina, F. L., & Markowitz, M. (2006). Paying clinical research participants: One Institution's research ethics committees' perspective. *Journal of Empirical Research on Human Ethics*, XX, 37-44.
- Ritter, A., Fry, C., & Swan, A. (2003). The ethics of reimbursing injecting drug users for public health research interviews: what price are we prepared to pay? *International Journal of Drug Policy*, 14, 1-3.
- Seddon, T. (2005). Paying drug users to take part in research: Justice, human rights and business perspectives on the use of incentive payments. *Addiction Research and Theory*, 13(2), 101-109.
- Shaner, A., Eckman, T., Roberts, L., Wilkens, J., Tucker, D., Tsuang, J., & Mintz, J. (1995). Disability income, cocaine use, and repeated hospitalization among schizophrenic cocaine abusers: a government-sponsored revolving door? *New England Journal of Medicine*, 333, 777-783.
- Yanos, P. T., & Ziedonis, D. M. (2006). The patient-oriented clinician-researcher: Advantages of being a double agent. *Psychiatric Services*, 57, 249-253.

Endnotes

- ¹ Note that issues of dual relationships are important for all areas of applied research in mental health settings, not just for substance users.

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Mental Health Research Through Clinical Innovation or Quality Improvement – A Reflection on the Ethical Aspects

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ABSTRACT

When clinical services aspire to quality improvement, creative and innovative approaches to old problems are needed to drive such change. Whilst new efforts should be applauded, information on this topic can be somewhat grey from an ethical and research point of view. Within the mental health profession there is currently an expectation to routinely evaluate care and disseminate findings. The notion of service enhancements under the guise of routine practice is an interesting and untested ethical issue. Should clinical innovation continue to enjoy such impunity as patient autonomy is often compromised as they are often compelled to accept treatment under the coercion of mental health legislation? We believe that it should not. All involvement in any form of research is voluntary, thus patients should also have the right to decline participation in quality projects if they wish to do so.

Key words: quality research; mental health; ethics; consent; risk assessment; consumer.

Progress in the art and science of mental health care depends upon innovation in clinical settings. In the research setting, the oversight of ethics committees and scientific peer review enables such innovation to occur in a manner that avoids much of the adverse consequences of the past. Such consequences emerge from ethical lapses or poor and unsafe scientific method (Roberts, 1998).

When clinical services aspire to quality improvement, creative and innovative approaches to old problems are needed to drive such change. Whilst the barriers to quality improvement usually arise indirectly from resource restrictions, bureaucratic inertia or systemic resistance, very little consideration has been given to the need for the kind of oversight considered imperative for safe and ethical research. Should clinical innovation continue to enjoy

such impunity? We believe that it should not.

In contemporary mental health care settings, both new and old approaches to care are stimulating change. The drive for change derives, in large part, from the allure of new treatments or new research findings, however this is frequently balanced by the realization that change for change sake is not always for the better. Moreover, in teaching hospitals both clinical and academic staff seek to develop research hubs of specialty within their service. This process of change often attracts additional resources to a clinical service, enhances institutional esprit de corps and stimulates research and publication.

Approaches to Limiting Risk

Which of the preconditions to ethical conduct of scientific research should be expected of such clinical innovation? In the first instance, the moral reckoning that followed the “doctors trial” at the Nuremberg War crimes trials in 1945 emphasized the centrality of informed consent to any research involving the interests of patients (Lifton, 1986). In New South Wales, the use of “Deep Sleep Therapy” at Chelmsford hospital was a tragic example of clinical innovation which led to significant harm. In this instance, a dangerous treatment was implemented in the name of innovation without any process of informed consent, peer review or ethical oversight and dozens of patients died or were seriously harmed. Community outrage in the aftermath of this tragedy led to profound changes to mental health laws and clinical governance in Australian healthcare institutions (Lawrence, 1991; Lupton, 1993).

Consent to innovative treatment programs is intrinsically problematic in mental health settings as patient autonomy is often compromised. The capacity for research subjects suffering serious mental illness episodes to consent to research participation has been discussed elsewhere (Appelbaum & Roth, 1982) – in many instances potential recipients of the new treatment are compelled to accept it under the coercion of mental health legislation—such as the out-dated practice of surgical sterilization of psychiatric inpatients in the United States during the first half of the 1990s (Grob, 1980). Moreover, acute psychiatric settings engender a culture of submission in both their design and operation; the presence of symbols of coercion such as seclusion rooms, locked doors and security infrastructure perpetuate the exercise of power typical of the asylums described by Goffman (1961) and Foucault (2006).

The second precondition to ethical research is the expectation of scientific rigour. Such enquiries are to be conducted in a methodologically sound way and likely to produce further knowledge that is beneficial (American Psychiatric Association’s Task Force on Research Ethics, 2006). Ethical and scientifically rigorous research is never the pretext for the self-serving imposition of idiosyncratic views about mental illness or its treatment. Clinical research innovation should only occur on the basis of a coherent, evidence-based argument justifying its potential benefits balanced with the demonstrable risks (Miller & Joffe, 2009).

The involvement of consumers and their carers in the development

and operation of mental health services has been a characteristic of the field in the last few decades (Horsfall, Cleary, Walter, & Malins, 2007; Lammers & Happell, 2004). Since the early 1990’s the presence of a consumer ‘voice’ has become a necessary step in policy development and implementation in mental health care in liberal Western democracies. Despite this, it seems that academic enterprises clad in “quality improvement” or “service development” garbs can often by-pass this by not seeking the views of the service users.

Towards Better Mental Health Research

The reality of mental health care is one of limited resources and seemingly limitless demand. As such, resources may be diverted from established models of care to academically driven service developments, creating further pressure on existing services. Moreover, staff are often expected to accommodate additional demands upon their time including, for example, the expectation of their arranging and coordinating appointments or the collection of data for research, rather than clinical purposes. Additionally, if limited health resources as spent on investigations to gather data of questionable clinical significance (as against academic necessity), this also adds to the ‘footprint’ of such services. Some medical tests can be justified because they are a requirement for admission to a psychiatric hospital (Zun, Hernandez, Thompson, & Downey, 2004), while others seem to be more beneficial to the academic-clinician than the patient as they have poor clinical utility for the individual.

One of the essential features of ethical research is clear communication of the potential benefits of a study to participants. This is a necessary step in obtaining informed consent. More significantly, making potential research subjects in clinical care settings aware of their right to refuse to participate in these programs is problematic in that such patients may fear that their clinical care may be affected. In settings of involuntary psychiatric treatment, such consent may be provided under the auspices of the law, which overrides the patient’s right to refuse any form of therapeutic intervention.

Studies based upon the acquisition of a database of biological material for later genetic testing or other future biological analysis place clinical research subjects in a dilemma. In these situations patients are required to endure potentially invasive procedures for no clinical benefit with the added anxiety aroused from the uncertainty around the future use of their tissue samples. Moreover, these patients may be concerned that the results of the analysis of their tissue samples may have a clinical significance which may not be readily available to them at a future time (Merlo, Vahakangas, & Knudsen, 2008). Moreover, clinical improvement can also include non-biological innovations that that impact on patient ethics that involve non-routine procedures.

So how can clinical innovation and academic progress not be stifled by such concerns? Whilst ethics committees, whose focus and remit are research projects, cannot and should not be tasked with an oversight role in clinical innovation, they do provide a potential model of such a process. In the first instance, any data collected

from a clinical service that is to be used for any publication or teaching purposes should be subject to the same conditions as any funded research – consent, confidentiality, peer review of methods and subject safety. Second, the primary task of service innovation should be improved patient care, not the progression of a particular academic agenda. Third, broad consultation from all relevant stakeholders from consumers and their advocates to government departments is a requirement of any such process. The likely impact of such service innovations on the existing services should be evident from such a process.

Clinical settings provide fertile ground for the generation of valuable knowledge about mental health care and the marriage of academic and clinical concern is vital to progress in the field. Much academic misconduct and ethically questionable practice occurs as a result of a failure of oversight and broad reflection of the implications of different processes (Spece & Bernstein, 2007; Steneck & Bulger, 2007). Rather than stifle progress, the kind of concerns we have highlighted should facilitate the important contribution that academic-clinical innovation should offer.

References:

American Psychiatric Association's Task Force on Research Ethics (2006). Ethical principles and practices for research involving human participants with mental illness. *Psychiatric Services*, 57, 552-557.

Appelbaum, P.S., & Roth, L.H. (1982). Competency to consent to research: a psychiatric overview. *Archives of General Psychiatry*, 39, 951-958.

Foucalt, M. (2006). *Psychiatric Power - Lectures at the College de France 1973-74*. Houndmills: Palgrave Macmillan.

Goffman, E. (1961). *Asylums: Essays on the Social Situation of Mental Health Patients and Other Inmates*. New York: Doubleday.

Grob, G.N. (1980). Abuse in American mental hospitals in historical perspective: myth and reality. *International Journal of Law & Psychiatry*, 3, 295-310.

Horsfall, J., Cleary, M., Walter, G., & Malins, G. (2007). Challenging conventional practice: placing consumers at the centre of the research enterprise. *Issues in Mental Health Nursing*, 28, 1201-1213.

Lammers, J., & Happell, B. (2004). Research involving mental health consumers and carers: a reference group approach. *International Journal of Mental Health Nursing*, 13, 262-266.

Lawrence, J.M. (1991). Inquiries into psychiatry: Chelmsford and Townsville. *Medical Journal of Australia*, 155, 652-654.

Lifton, R. (1986). *The Nazi Doctors*. New York: Basic Books.

Lupton, D. (1993). Back to bedlam? Chelmsford and the press. *Australian and New Zealand Journal of Psychiatry*, 27, 140-148.

Merlo, D.F., Vahakangas, K., & Knudsen, L.E. (2008). Scientific integrity: critical issues in environmental health research. *Environmental Health*, 7 Suppl 1, S9.

Miller, F.G., & Joffe, S. (2009). Limits to research risks. *Journal of Medical Ethics*, 35, 445-449.

Roberts, L.W. (1998). The ethical basis of psychiatric research: conceptual issues and empirical findings. *Comprehensive Psychiatry*, 39, 99-110.

Spece, R.G., & Bernstein, C. (2007). What is scientific misconduct, who has to (dis)prove it, and to what level of certainty? *Medicine & Law*, 26, 493-510.

Steneck, N.H., & Bulger, R.E. (2007). The history, purpose, and future of instruction in the responsible conduct of research. *Academic Medicine*, 82, 829-834.

Zun, L.S., Hernandez, R., Thompson, R., & Downey, L. (2004). Comparison of EPs' and psychiatrists' laboratory assessment of psychiatric patients. *American Journal of Emergency Medicine*, 22, 175-180.

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Incest Survivors and “Borderline Personality Disorder”

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ABSTRACT

This essay is about the common experiences of survivors of incest trauma and the psychiatric label of “borderline personality disorder” which harms their interests by keeping attention away from much needed societal changes. I draw a parallel with the survivors of a severe storm, seeking to illustrate the severe difficulties of incest survivors in a society that stigmatizes and marginalizes them. Because of negative thinking about incest survivors and their personalities and the societal minimization of incest as a serious trauma, the aftermath of incest is, in important respects, different from and more layered than the aftermath of a natural catastrophe.

Introduction

A few weeks ago I was feeling a need to reconnect with a Survivors of Incest Anonymous (SIA) support group. I had trouble finding the location of the meeting as the place is a faceless white building, in between a pet store and a large brick seniors’ center. When I finally found it, I was directed with a handwritten scribbled sign hanging lopsided on the door telling people to go to the back. After some steps in the wrong direction into the back of the pet store I stumbled up some broken door steps and fell into a comfortable, cozy home environment. A very slight woman with pretty turquoise eye shadow greeted me with a quick, relaxed smile and hug and I went into the kitchen to make myself a cup of tea. Other members had arrived and were chatting and laughing. Then the meeting began, with the usual introductions and lead up to an open floor and time for more introverted, individual sharing. I listened attentively to each woman refer to the usual topics at SIA meetings: denial and lack of support of relatives; unsupportive job environments which allowed no room for gloomy and cheerless faces emerging from a sleep full of the usual nightmares; dominating boyfriends or husbands who women admitted were so much like their original abusers but who they found it impossible to separate from; unemployment and financial dependency on complicit mothers and siblings; inept and humiliating responses of police voyeuristically enjoying hearing about “sexy” forbidden “relationships” between adult men and young girls; and psychiatric mistreatment with a barrage of labels. Hearing the women’s stories made me feel very much at home and I snuggled up with a giant teddy bear and sipped my hot tea.

My compassion and love for incest survivors magnified but so did my anger about the injustices we had faced and continued to face. For example, why, I asked, did we have to be anonymous? What was there to be ashamed and secretive about? Could we not in large letters paint the words “Support Group for Incest Survivors” on the front of the building/our house? We had done nothing wrong, and had continued on courageously despite the severe lack of support and the ugliness surrounding us. We should be wearing medals of honour and an amount of ribbons totalling the years of our lives.

“Borderline Personality Disorder”

In mental health practice it is still very common that when women present histories of chronic sexual trauma they are given the label of “borderline personality disorder”, despite the numerous feminist critiques of the term in scholarly literature which maintain the label over-problematizes personalities.¹

Here I am adding that the label gives no consideration to the fact that a person’s persisting difficulties are exacerbated by a society that is not structured around being welcoming and supportive toward survivors of childhood trauma with their particular struggles. Thus the label “borderline personality disorder” serves to blame individuals for their persistent challenges, in referring to emotions and behaviour as irrational that are actually understandable in relation to the social context of survivors, such as anger and despair, frequent changes in work and relationships, and self-harming behaviour. We live in a society which is both highly individualistic and family-centered, where individuals must depend on their families and cannot rely on the kindness of strangers. If a person is from a very abusive family, or with no or very few non-abusive family members, one is lacking a very fundamental support system and thus will have significant obstacles that others with more functional units will not understand.

It is unconscionable for mental health professionals and theorists to continue to engage with this unethical label in any shape or form. What confident and self-loving person would accept thinking of himself/herself as having something inherently wrong with his/her most basic self? People like incest survivors are so used to being insulted and mistreated that they think they must deserve this psychiatric insult. One woman at an SIA meeting said she had been given three psychiatric diagnoses, including “borderline personality disorder.” She said, “I’m so bad. I’m such a bad person. I am so mixed up.” That she is bad and faulty and not someone

deserving of love is exactly what the label “borderline personality disorder” is telling her, thus affirming her very low self-esteem.

A few months ago I taught a course in health care ethics in an MHA program with health professionals; several of them work in the mental health field and I brought up the topic of borderline personality disorder. I was appalled by how quickly and easily some of the students showed their disgust of “the borderlines.” Activists on behalf of people with other kinds of disabilities such as people with cognitive disabilities and people with physical disabilities have been more warmly received in their challenges to pejorative thought and language; we would not expect to find an article in a scholarly journal entitled “A critical exploration of people with Mongolism” or “Treating Cripples.”²

Proper respect toward survivors of childhood incest trauma is long overdue. After hearing survivors of incest talk about their very negative experiences and poor health outcomes with psychiatrists upon being labelled with “borderline personality disorder,” some members of SIA, including myself, decided to form a non-profit organization called “Matron Saints of Incest Survivors” which provides empowering educational resources and peer counselling, and does community outreach.

Social Context of Incest Survivors

Incest trauma is no more shaming and also no less serious than trauma related to natural catastrophes. But there are several differences in the aftermaths. One difference is that survivors of natural catastrophes are not heavily stigmatized and shunned or oversexualized by others in society, as when survivors are seen as having had consensual “relationships” with their abusers. Despite having experiences of post-traumatic stress and other serious challenges if the society is highly individualistic, survivors of a natural catastrophe can more easily distance themselves from the natural catastrophe. By contrast, incest survivors, with fewer avenues of validation, healing and support, are left circling the trauma and will have more trouble moving on. For example, when people talk about surviving a natural catastrophe, others may look uncomfortable but it is unlikely that they will question the reliability of their memory or bring up “false memory syndrome,” behaviour that is commonly experienced by incest survivors when they refer to the incest trauma. Further, survivors of a natural catastrophe will not usually be treated poorly by a health professional simply because they are survivors of a natural catastrophe whereas incest survivors often encounter difficulties finding a general health care provider when they mention a history of sexual trauma.

Imagine you are in a storm and there is no shelter and no one to assist you. You must fend for yourself and try to build your own shelter. You use your own wits and also reach out for help and use the telephone and call some help lines. The people on the telephone, the helpers, tell you you are not in a serious storm as you are not so far away from where they are standing where it is very sunny and comfortable. In fact these people have never experienced a severe storm, though they have read about it in books, and have only experienced rain showers themselves. They tell you the storm is now over and that you need to talk about the storm, take some pills, and work hard on controlling your emotions. Your emotions are too stormy, they say; you need to become more stable. And of course your emotions are stormy because from your perspective

the storm is not over, and there are continuing serious challenges, and you are simply reacting to the waxings and wanings of the storm. When a branch flies and hits you on the head you cry out in great pain and anger because there is no one to comfort you. There is nothing wrong with your survival instincts and you know you must make a safe shelter for yourself; you make a raft out of the branches of fallen trees. When your raft breaks because you were so exhausted from your relentless struggles that you forgot to attend to something important, you become very depressed. When the storm subsides for a while you start to feel relaxed and even elated and look wild-eyed (“manic”), as you are so thankful and grateful for a moment of peace, but you know that the storm will soon show its mean red eye again and you are not safe from harm. You keep in contact with the helpers because you think they are better than nothing, though they say there must be something wrong with you since all you can come up with is a raft and nothing more stable and enduring. Some of them say the problem is not just in your personality but in your neurology and genes too. Sometimes you feel so exhausted and alone trying to survive in a reality that the helpers won’t recognize, you feel suicidal. You tell the helpers you are feeling angry toward them. They say you seem to be acting out a fear of abandonment; you should try to control that too. You try to make friends with others in the storm but many of them are in the same panicked state to survive and you are poor company for each other. You consider forming an intimate relationship with someone but you know during a storm is no time for this. The helpers say you have a problem with avoiding relationships. Sometimes you cut yourself with your jackknife to relieve some emotional pain.

Finally the storm abates and stops. You can make a good life for yourself, build a home, not just a raft. You are grateful to be alive. For those who know nothing of severe storms you seem peculiar; they find your conversation questions and your manner odd. You seem from a foreign country and you are.

I look forward to the day when incest survivors can enjoy the same sexually neutral respect that has been accorded to survivors of other catastrophes. Some of my closest friends are refugees, and it’s because we understand well what it means to be deprived of a safe home.

Notes:

1. See especially Herman, J.L. 1992. *Trauma and Recovery*. New York: Basic Books. Herman argues that the label should be replaced with “complex post-traumatic stress disorder.” I explore her views in my article “Rethinking ‘Multiple Personality Disorder’: Recovering Moral Agency” Nicki, A. 2008. *Journal of Social Alternatives*. Volume 27: 4: 2008.
2. This is not to argue, however, that people with cognitive and physical disabilities are not often subject to dehumanizing language and treatment. I am simply trying to raise the status of incest survivor to the level where perjorative language directed at them will be a matter of controversy like the phrase “People with Mongolism” directed at people with cognitive challenges.

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Ethical Issues in a National Mental Health Arts and Film Festival

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ABSTRACT

The Scottish Mental Health Arts and Film Festival has seen hundreds of arts, public and community groups co-produce over 300 events to over 25,000 audience members. Integral to this arts-based approach, in contrast to social marketing or public education models, is the notion that mental health is an essentially contested concept whereby meanings are negotiated and debate encouraged. With emerging evidence that the festival is an effective way of engaging people intellectually and emotionally, we explore ethical issues, challenges and paradoxes that have emerged as the festival has developed. Consideration is given to issues of power, purpose, opportunity costs, reach, impact, programming risks, and participation from those with experience of mental ill-health. Throughout, we explore practical implications for funding, managing, programming, marketing and evaluation of this and similar endeavours.

Key words: arts; film; festival, stigma; discrimination.

This paper seeks to begin a conversation about the ethical issues associated with organizing, delivering and evaluating an arts festival about mental health. In doing so we would acknowledge the thoughtful paper by Krahn (2009) that considers some of the ethical and practical issues in organizing a mental health film series. The potential scope of this territory is extensive,

and this paper does not aim to provide a comprehensive overview of the ethical issues involved. Nor will we be reporting back on the extensive festival evaluations that are being undertaken. Instead we aim to describe and explore some of the challenges, tensions and paradoxes that emerge 'in practice', practice that has been inspired by the ideas and work of Byrne (2009). We hope to generate questions that will provoke and encourage others to respond. In doing so, the authors draw upon our differing experiences of directing and evaluating the Scottish mental health arts and film festival (smhaff). We will briefly outline the development and purposes of the festival and then consider some of the ethical issues in relation to the scope of the festival, its identity, issues of leadership and power, the cost of the festival, its reach and impact on audiences and the involvement of people who use mental health services.

The Festival

The Scottish Mental Health Arts and Film Festival has become a major national cultural event and one of the largest festivals of its kind. Over 300 events have attracted audiences of 25,000 people. Media coverage has been extensive and positive in the press, radio and television, with an emphasis upon high profile artists that appear at the festival. The events are increasingly the culmination of year round collaborations between artists, artistic organisations, community development groups, mental health groups and practitioners and include theatre, film, concerts, exhibitions, dance, comedy, literature and fusion events. Partners

now range from the BBC and national arts bodies through to small community groups. The festival has evolved over 3 years towards a collective model which sees hundreds of partners working locally or nationally and includes a collaborative funding and management model, co-curation between arts, public and community groups, and regional planning networks spanning numerous sectors of civil society. The festival's stated vision is to achieve social change towards mental health through the arts by: 1) Challenging perceptions of meaning, stigma and inequalities in mental health 2) Making connections between community, public, arts, academic and voluntary organisations. 3) Developing audiences and reaching those who are often missed 4) Encouraging participation in the creative process by those who have experienced mental health issues, but also the wider community as a well-being initiative 5) Creating great arts events. It is formally supported by the Scottish Government who lead the national mental health improvement plan 'Towards a Mentally Flourishing Scotland' (Scottish Government, 2009).

Scope

The initial idea for the festival was a weekend of film designed to challenge stigma associated with mental health problems. Stigma and discrimination towards people experiencing mental health issues remains stubbornly entrenched despite a wide range of national and international campaigns that use public education, mental health literacy and social marketing approaches (Corrigan & Penn, 1999; Thornicroft, 2006). The limitations of these positivistic approaches have led to a reconsideration of the potential of the arts. The multi-faceted role of the arts has been explored in relation to recovery from mental health problems (Crawford & Patterson, 2007; Spandler et al, 2007). Added to the benefits of participation in the creative arts on individuals' mental health, there is potential for using the arts for communicating ideas and effecting social and personal change in mental health (McCarthy et al, 2004). The main premise for the festival is that the arts have the ability to change public attitudes to reduce the stigma against people with mental illness (Chung et al, 2006; Twardzicki 2008).

Identity, power and partnerships

The approach taken within the festival is to have a broad planning and funding group comprising a diverse range of partners and funders that share the costs and are part of a decision making process. This avoids being too dependent upon one funder and the problems this would create in terms of being restricted to being 'on message' for this particular funder. The range of partners funding and organising the festival hold different philosophical and political positions in relation to mental health and the arts. These include professional groups including psychiatrists, a range of organisations within the service user movement, government agencies and policy makers, social marketers, voluntary and community groups and arts organisations. These positions are informed by both organisational and personal identities. This results in debates and tensions about concepts of mental health and the purposes of the arts in society. Consequently the festival as a whole may be viewed very differently by partners in terms

of its identity and nature and its purposes. The festival can and has been seen as:

- a human rights initiative
- an anti-stigma initiative
- a social marketing tool
- an artistic platform
- an opportunity for members of the public to meet people with mental health problems

This raises ethical issues in relation to the leadership and management of the festival. Is one perspective dominating? Are compromises diluting the focus and value of the festival? Are partners clear about what they are signing up to and what others might try to promote? It may be possible to fulfill a diverse range of organisational aims but this has to be carefully considered. One implication is that potential partners may not join as their positions may not be reconcilable with the concerns of a broader community of practice. For example, the remit of the festival is not to say *how* mental health problems should be treated and therefore accepting funding from pharmaceutical companies might be unacceptable to some partners. For a different reason, certain arts bodies might argue that all work should be artist-led rather than co-created with mental health partners and may exclude themselves from the process for this reason. A community of practice (Wenger, 1998) that is more democratic or equitable creates a process whereby contradictory ideas and intentions can be identified and managed. It has the potential to lead to meaningful festival events shaped by a broad range of partners, in contrast to a model in which a festival is commissioned to a single organisation and thereby dominated by one perspective, which is unlikely to engage the wide range of perspectives, which such a complex and contested issue as mental health needs (Faulkner & Thomas, 2002).

Cost

One ethical question to emerge from the development of a mental health festival is, '*Can we justify limited resources in the public and voluntary sector being spent upon such a festival?*' Mental health problems are seen globally as one of the major health issues and are an increasing public health burden (WHO, 2001). Given that mental health is consistently an under-funded area of health and the pressures on health budgets in the context of recession, it can be argued that an arts festival cannot be justified. The ethical question is '*Could this resource be better used to provide frontline services?*' In addition, it could also be argued, '*Can the resource be more effectively used in other public health approaches?*' We would argue that mental health services are not an appropriate comparator, partly as the festival aims to create extensive opportunities for people who use services and promote recovery and positive personal identity. In addition, the direct funding and in-kind pro bono money received would not be combined into a central fund and donated to mental health services. Opportunity costs essentially relate to the moderate cost of administering the festival. In relation to public education, the festival offers excellent

economic value being low cost and having extensive reach both directly to audiences/public and through media reporting. Even excluding the economic value from the PR and media coverage and excluding the range of visitors to exhibitions, outreach and education events, the cost per attendee at an event with debate is approximately £5. These figures are a fraction of the costs of national training courses on mental health and national mental health campaigns. The reason that this is possible is that the festival engages hundreds of organisations, who often don't see mental health as their core business, in events. This process is successful in leveraging in huge additional direct and in-kind finance to the area of mental health that other approaches do not. Moreover, it has the potential to make mental health a mainstream issue, which has resulted in the development of formalized multi-agency networks in almost 20 regions of Scotland linking arts, media, public and community organisations.

Reach

A challenge for the festival is to reach the widest possible range of the community. One potential criticism is that a festival is only likely to reach those who are already well informed about and well intentioned towards mental health issues, such as people who use mental health services and their families and friends, and those who work in mental health.

However, even where a significant portion of the audience and participants have an interest in mental health issues there is still a lot of value in the scope to consolidate and build a community of interest that can challenge stigma and discrimination. The process of practitioners, those that use services, academics and others debating issues through the arts and panel discussions, offers the scope to construct new understanding and insights and challenge the dominant discourses and promote equity (Pilgrim, 2005). In addition, if one of the primary aims of the festival is to challenge stigma, then it seems entirely appropriate that those affected by stigma have the opportunity to come together. There is a tendency among mental health service users to internalise the negative views that they perceive as coming from others, to such a degree that it devalues their sense of self-worth and creates a feeling of 'otherness' relative to the general public (Green et al, 2003). Bagely and King (2005) suggest that a major focus of stigma work should be exploring, and coming to understand service-users' experiences of stigma and use this to inform interventions and campaigns. Moreover, if a central theme of the festival is to challenge stigma then you can argue there is a need to challenge stigma amongst this community of interest, given that service users have reported friends, family and mental health professionals as being sources of stigma (Wahl, 1999).

Another potential criticism is that an arts festival will only be relevant to middle and higher income earners within society. Internationally, there appears to be a relationship between socio-economic standing, and the tendency to pursue artistic and cultural activities. McCarthy et al (2004), argue that the individuals with an interest in the arts will typically be well-educated and hold sizable stocks of cultural and social capital. Thus, there may be a danger that any potential benefits afforded by attending an arts festival may be absorbed primarily by a middle-class subsection of society at the expense of reaching wider communities. Individuals

who earn higher salaries and higher educational qualifications, attend, and participate in, more artistic events than those who earn lower salaries (Hill Strategies Research Inc, 2003; TNS, 2008; NEA, 2009; Timmins, 2009), although this does vary according to art form. This has particular implications for the future of an arts festival as an anti-stigma intervention; if an arts festival cannot reach wider society then its potential for effecting social change must be considered severely compromised.

Equally, there is evidence that mental health awareness campaigns rarely reach communities that are at risk of marginalisation, such as minority ethnic communities (Tilbury et al, 2004). A central question is whether the festival corresponds to this pattern. A strength of arts events in this context is that they have the capacity to be flexible, and to work with and within the explanatory frameworks of diverse cultures and communities – indeed one driver for establishing the festival emerged from community conversation and dialogue with ethnic minority communities about overcoming the deficiencies of existing approaches (Knifton et al, 2009). And in practice, the evidence from the festival is that the events seem to be particularly effective in engaging ethnic minority communities, and low income communities (Quinn et al). One explanation for this is that we have evolved a co-programming model where community development organisations are central to the development of events and the marketing process. This is resource intensive but seen as an ethical imperative (the festival has almost 20 regional and equality/diversity planning groups). Events are often in different languages and ethical programming necessarily involves a broad range of partners from different ethnic minority groups and low-income communities.

In building the ethical case for a mental health festival we have outlined a festival that is collectively managed, cost effective, and reaches a wide range of society. At this point, it is important to consider the impact of the festival upon audiences.

Impact

Of course impact needs to be considered from a variety of perspectives, but in terms of audience impact (the core stated concern of many stakeholders) this is very complex. It depends upon the broad concepts that are being used in events; there is scope for considerable variation in what different people will take away from events. Traditional social marketing and public education would argue that the safest, most ethical approach would be to focus upon the content of the art/film and present only those that have clear and positive messages and that post event discussions and information should contextualise these with key messages. However, approaches that focus only upon education/information not only exclude a contribution of a range of perspectives, but they are not particularly effective (Corrigan et al, 2007).

However, there is a strong ethical case for avoiding screening suicide and self harm, specifically the problem of graphic depictions of the methods of self harm and suicide, which have the potential to influence vulnerable people within the audience (Byrne, 2003).

There are also other artistic representations which evidence

suggests have the potential to ‘worsen’ attitudes. Gaebel and Baumann (2003) report an attempt to challenge stigmatised attitudes towards people with schizophrenia amongst a sample of 200 participants. Here, participants were shown a film (*‘White Noise’*) that acutely portrays a character’s subjective experiences of paranoid hallucinatory schizophrenia, and attempts to maximise the viewers’ involvement with such experiences. Although the majority of viewers reported an enhanced understanding of schizophrenia following the screening - as well as a greater capacity to empathise with individuals who might be suffering from schizophrenia – the film also appeared to reinforce negative stereotypes concerning people with schizophrenia, and increased social distancing. Gaebel and Bauman (2003) suggest that the nature of the film may have made participants feel too ‘close’ to the protagonist and his plight, which sparked the negative reaction. This impact has been seen with one film in the festival, *The Devil and Daniel Johnson*, which led to dangerousness perceptions worsening amongst the audience (Quinn et al). This documentary is a provocative piece that portrays its subject as unpredictable and remaining unwell with schizophrenia, despite continuing as a highly accomplished musician. Importantly, this film also induced strongly positive responses indicating that evaluating arts events is very complex and demonstrating the need for thoughtful programming, and careful evaluation.

Films that explore more positive themes, such as recovery and rehabilitation, may be more effective in engendering more positive reactions and breaking down stigma. Emerging evidence from the festival also suggests that meaningful involvement in events from people who have experience of mental health problems, or who are from communities that experience marginalization, are crucial to impact (Quinn et al).

The key ethical dilemma here is about the balance between certainty and risk – a continual safe programme may lose the attention of the public and media, and lose the chance to create new insights and create real debate. But on the other hand, this has to be set against the risk that challenging programming might increase stigma and possibly alienate partners who want to stay ‘on message’. The festival has an international film competition, judged by a range of stakeholders, which has consistently identified and rewarded films that are challenging but do not show self harm, suicide or overtly negative portrayals of people with mental illness.

This brings us back to the actors...

Support

If, as the emerging evidence indicates, the involvement of people who have experienced mental health problems is central to the success of events whose intention is to address stigma, then is this at a cost? It is imperative that a festival has a strong enough contribution from mental health service user groups to ensure that events reflect peoples’ lived experiences, and that people are not being used as puppets of policy makers, social marketers and others. One way of assessing this is to consider to what extent events challenge dominant models and perspectives of mental health. One approach that has evolved in the festival to address this is a devolving of ownership of programming. Our challenge is not

only to create an artistic programme but an artistic platform for a multitude of voices, perspectives and conversations – the balance is achieving and presenting coherence in this collective model. More generally, one can argue that the entertainment aspects of the arts cannot be minimized. Even if well-intentioned, are we entertaining people at the expense of the range of people that experience mental health problems? Green et al (2003) argue that whilst campaigns that stress the prevalence of stigmatisation toward the people with mental illness may be effective in changing the attitudes of the general public, they may have a negative impact on service users.

At an individual level, involvement by people who identify as having mental health issues remains sensitive. Ethical dilemmas in sharing personal narratives are considerable. An ethical imperative is to ensure that involvement is not coercive - there may be formal or subtle pressure to share your narrative. Also, we know very little about the long-term impact on the narrator. Support must be available when people share their experiences with hundreds or thousands of people in arts events or post performance panels, that they are aware of potential consequences - that they can deal with potential hostility. There should be adequate support and safeguards before, during and after events to allow people to withdraw without feeling that they are letting others down.

There is a particular challenge around the issue of informed consent, for example what if people change their minds after it has entered the public domain? Film has particular issues. When experiences and narratives are captured on film this can remain in the public domain forever (or at least it can be difficult to take back). There can be a tension between the documentary filmmaker who wants raw, dramatic footage and the service user who does not want to be depicted as unwell, unstable or dangerous. With film, documentary subject frequently becomes object, and the service user’s story if mistold is forever available for public viewing (Byrne, 2009). The process of sharing your personal narrative on an ongoing basis creates a potential paradox. Personal narratives have the potential to be empowering and transformative (Gergen & Gergen, 2003) but equally to reinforce negative identities. Whilst reducing stigma amongst the audience, you may be reinforcing your negative self-identity based upon your label as part of a stigmatised minority group.

However, the contribution of people who use services drives the festival. As long as consent is informed and people feel supported and can opt out at any time, these risks have to be considered against the immense potential for positive impact, for both the person and the audience, captured well in quotes from an ongoing study on the festival:

- *As a person suffering from mental health problems, being a part of this has given me confidence*
- *Members of our group have gained pride, confidence and had a wonderful experience*
- *It has given me a wide insight into the effects and causes of mental illness*
- *It made me appreciate myself and others for who they are*

Yet, it is also useful to consider the multiple, temporal and fluid nature of identities that all narrators have (e.g. loving parent, creative writer etc). This raises questions of whether it is most useful for narrators to be identified and introduced as 'service users' as their primary identity. It raises the issue of whether we can work towards a different approach to narratives and arts, where the narrative focus is upon mental health as part of the human condition, and where perhaps the audience also engages in dialogue about their own mental health identities.

We are aware that this paper is just the beginning of a dialogue in which only some of the ethical dimensions of the festival have been tentatively explored. We are aware that we have not touched upon a number of areas such as the ethical dimensions of charitable fundraising or profit making from a festival, or the representations of mental health problems as positive states. However, what we highlight is the importance of incorporating different voices into shaping the festival and the need to develop the dialogue to inform the ethical dimensions of planning, implementing and evaluating the festival.

References:

- Bagely, C., & King, M. (2005) Exploration of three stigma scales in 83 users of mental health services: Implications for campaigns to reduce stigma. *Journal of Mental Health*, 14, 343-355
- Byrne, P. (2003) Psychiatry and the Media. *Advances in Psychiatric Treatment*, 9, 35-42
- Byrne, P. (2009) Why psychiatrists should watch films (or what has cinema ever done for psychiatry?) *Advances in Psychiatric Treatment* 15, 286-96.
- Chung, B., Corbett, C.E., Boulter, B. et al.(2006). Talking Wellness: A description of a community-academic partnered project to engage an African American community around depression through the use of poetry, film and photography. *Ethnicity and Disease*, 16, 67-77
- Corrigan, P.W., & Penn, D.L. (1999) Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*, 54, 9, 65-76
- Corrigan, P.W., Larson, J., Molly, S., Nathaniel, N., & Watson, A.C. (2007) Will filmed presentations of education and contact diminish mental illness stigma? *Community Mental Health Journal*, 43, 2, 171-81
- Crawford, M.J., & Patterson, S. (2007) Arts therapies for people with schizophrenia: an emerging evidence base. *Evidence-Based Mental Health*, 10, 69-70
- Faulkner, A., & Thomas, P. (2002) User-led research and evidence based medicine. *The British Journal of Psychiatry*, 180, 1-3
- Gaebel, W., & Baumann, A. (2003) Interventions to reduce the stigma associated with severe mental illness: Experiences from the open doors program in Germany. *Canadian Journal of Psychiatry*, 38, 657-662
- Gergen, K.J., & Gergen, M.M. (2003) *Social Construction : A Reader*. California: SAGE
- Green, G., Hayes, C., Dickinson, D., Whittaker, A., & Gilheany, B. (2003) A mental health service users perspective to stigmatization. *Journal of Mental Health*, 12, 223 - 234
- Hill Strategies Research Inc (2003) Performing arts attendance in Canada and the provinces. *Research Series on the Arts*, V1, N1. Canada: Canada Council for the Arts.
- Knifton, L., Gervais, M., Newbigging, K., Mirza, N., Quinn, N., & Hunkins-Hutchison, E. (in-press) Community conversation: addressing mental health stigma with ethnic minority communities. *Social Psychiatry and Psychiatric Epidemiology* (in-press, Epub July 2009)
- Krahn, H. (2009) Building a mental health ethics film series, building mental health ethics literacy. *Journal of Ethics in Mental Health*, 4,1.
- McCarthy, K.F., Ondaatje, E.H., Zakaras, L., & Brooks, A. (2004) *Gifts of the muse: Reframing the debate about the benefits of the arts*. Santa Monica, CA: RAND.
- NEA National Endowment for the Arts (2009) *Arts participation 2008: Highlights from a national survey*. Washington: National Endowment for the Arts.
- Pilgrim, D. (2005) *Key Concepts in Mental Health*. London, SAGE.
- Quinn, N., Shulman, A., Byrne, P., & Knifton, L. The arts can change stigma: Impact of a national mental health arts and film festival. Manuscript submitted for publication
- Timmins, S. (2009) *The 2008 Omnibus Survey*. The Arts Council of Wales.
- TNS Travel and Tourism (2008) *Taking part in Scotland 2008*. Edinburgh :Scottish Arts Council.
- Scottish Government (2009) *Towards a Mentally Flourishing Scotland*. Scotland: Scottish Government.
- Spandler, H., Secker, J., Kent, L., Hacking, S. & Shenton, J. (2007) Catching life: the contribution of arts initiatives to recovery approaches in mental health. *Journal of Psychiatric and Mental Health Nursing*, 14, 791-799.
- Thornicroft, G. (2006) *Shunned: Discrimination against people with mental illness*. Oxford University Press.
- Tilbury, F., Slee, R., Clark, S., O' Ferrall, I., Rapley, M., & Kokanovic, R. (2004) Listening to diverse voices: understandings and experiences of, and interventions for, depression among East African migrants. *Synergy- Multicultural Mental Health Australia*. www.mmha.org.au/mmha-products/synergy/2004_No2/Listeningtodiversevoices/
- Twardzicki, M. (2008). Challenging stigma around mental illness and promoting social inclusion using the performing arts. *The Journal of the Royal Society for the Promotion of Health*, 128, 68-72
- Wahl, O.F. (1999) Mental health consumers' experience of stigma. *Schizophrenia Bulletin*, 25, 467-478
- Wenger E (1998) *Communities of Practice: Learning, Meaning and Identity*. New York, Cambridge University Press.
- World Health Organisation (2001) *The World Health Report 2001. Mental health: new understanding, new hope*. Geneva: WHO.

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Building Understanding of Schizophrenia: An Extended Commentary on The Soloist

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ABSTRACT

In the previous issue of this journal I detailed a programme for building mental health ethics literacy with a regular column dedicated to critical discussions of mental health ethics issues in film. The first section of this commentary provides background on the problems of stigma attached to schizophrenia and how film can be used to fight stigma by providing a point of para-personal contact between the general public and narrative accounts of persons living with schizophrenia. The next section provides a critical review of *The Soloist*, a recent feature film that tells the true story (based on a book of the same title (Lopez, 2008)) of how journalist Steve Lopez befriended and wrote a series of columns in the *Los Angeles Times* about Nathaniel Ayers, a talented musician living with schizophrenia on the streets of Skid Row. The last section explains some of the prevalent socio-economic disadvantages faced by persons living with schizophrenia and concludes with the hope that this movie will be taken up critically to build a greater sense of social responsibility for those in our society living with schizophrenia.

Key words: Ethics; film; homeless persons; mental health; schizophrenia; stigma; treatment refusal.

Mental health and stigma—the case of schizophrenia

Persons living with mental illness face a double challenge. They must live with the symptoms of the disease(s) and the attendant effects this has on their ability to work, live independently, or achieve a satisfactory quality of life. Additionally, they must live with common negative stereotypes of their condition—often based on ignorance, misunderstanding, and misinformation (Schizophrenia Society of Canada, 2009)—in the form of public stigmas (Rüsch et al., 2005). The National Institutes of Mental Health (1986) has even gone so far as to say that stigma is the most debilitating aspect of mental illness.

On a widespread level, for persons with mental health conditions stigma has been linked to decreased self-esteem, loss of social and employment opportunities, distorted experiences in the workplace and criminal justice system, as well as disparities in access to

health care and social services (Esterberg et al., 2008; Compton & Kotwicki, 2007). Indeed, stigma is like an oppressive web that feeds discrimination. One relatively recent study (Corrigan et al., 2004b) even found a “significant association between stigmatizing attitudes about mental illness and allocation of resources to mental health services” (reported in Ritterfeld & Jin, 2006:248).

Schizophrenia is one of the most stigmatized mental health conditions (Thornicroft et al., 2009; Harrison et al., 1994:815; Griffiths et al., 2006; Mann & Himelein, 2004). Research investigating the relationship between socioeconomic factors and community integration of persons with schizophrenia reports that this population claims to face a number of impediments resulting in increased social marginalization that are not due to the disorder itself; these include social rejection, poverty, unemployment, and a lack of financial resources and employment supports (Davidson & Stayner, 1997; Chernomas et al., 2000; Mallik et al., 1998; El-Mallakh, 2007:56). The forces of exclusion that work to disallow persons with this condition from being “let in” to full participation in civic and social life call for redress that is both forceful and tactful, pragmatic and imaginative. As B.D. Kelly notes: “The lessons of history are not promising (Shorter, 1997), but the constant search for ways to improve the lives of society’s disadvantaged is a fundamental characteristic of civilized society—and the process can usefully start by recognizing the adverse effects of society itself” (Kelly, 2005:727).

Lack of understanding is a common source of stigma for schizophrenia. A dearth of information or misinformation amongst the general public leaves little to guard against misrepresentations and stereotypes fostered in various media portrayals of schizophrenia (Ritterfeld & Jin, 2006). A 1999 study showed that 61% of a representative sample of Americans believe persons living with schizophrenia to be predisposed to violence (Link et al., 1999; cf. Schizophrenia Society of Canada, 2009).ⁱ As to beliefs concerning the causes of the disorder, 91% of this sample attributed it to stress, 45% to the educational style of the family of origin, 33% to “bad character”, and 17% to divine retribution. In this regard, relevant content analyses of media portrayals have shown mental illness being attributed to immoral character or traumatic experiences in early childhood (Hyler, 1988). As Ritterfeld and Jen (2006) note, none of these attributions are true.ⁱⁱ

Society’s negative reactions as well as common prejudices about schizophrenia are accepted and then internalized by many persons living with schizophrenia, eroding their self-confidence and thus adding a layer of self-stigma (Link et al., 2001). The literature

has shown a resultant tendency, amongst those affected, to social isolation and concealment of their illness, perhaps as defence measures against rejection in the social sphere (González-Torres et al., 2007:20). In turn, social distancing from others—often grounded in a combination of misunderstanding and fear—feeds the cycle of isolation (Lauber et al., 2004). As González-Torres et al. observe: “[t]he ensuing reactions of isolation and concealment and the loss of self-esteem may contribute to reduce these patients’ opportunities in all areas of life” (2007:20; see Corrigan et al., 2004a). Sometimes these lost opportunities also include a chance for recovery as part of treatment. After all, “people [for the most part] will not receive care if they do not seek it” (Schizophrenia Society of Canada, 2009:13).ⁱⁱⁱ

Fighting stigma through film as a means of para-personal contact

In general, studies have shown that familiarity with mental illness significantly influences others’ attitudes towards people with mental illness. The more experience and the more knowledge people have of mental illness, the less likely they are to: i) be influenced by forces that stigmatize mental health conditions (Link & Cullen, 1983), and ii) desire social distance from persons with said conditions (Angermeyer et al., 2004; Corrigan et al., 2001; Esterberg et al., 2008:91). Recent work by Corrigan and others indicates that protest, education, and contact are prevalent methods of combating the stigma of schizophrenia (Corrigan et al., 2004a) with contact being the most effective (Schulze et al., 2003; cf. Reinke et al., 2004; cf. Holmes et al., 1999).

Direct, personal contact between members of the general public and persons living with schizophrenia is not readily feasible as a common stigma-fighting strategy (Gaertner et al., 1996), especially given the lines of distrust and fear that foster social distance and isolationism (as mentioned above). However, films have the capacity to put viewers in contact with “a surrogate reality without having to take part in it” (Horsley, 2009:2). Indeed, contact through narrative media can provide the opportunity for para-personal^{iv} experiences, and like actual contact, be instrumental for reducing misinformed prejudice and stereotypes of mental illnesses, including schizophrenia (Ritterfeld & Jin, 2006:249).

The Soloist

A story about building contact and a relationship with one person living with schizophrenia

Enlisting the interest of the broader community to build understanding, compassion and empathetic response—in other words, addressing the issue of moral motivation that might overcome stigmas—is always a challenge. According to Mary Alberti, Executive Director of the Schizophrenia Society of Ontario, “*The Soloist* demonstrates how empathy and understanding can impact the lives of those with schizophrenia and how this relationship can change the way we understand, relate to and support individuals living with this illness” (Anonymous, 2009b). Based on a true story, the film explores the growth of a relationship between Los Angeles Times reporter Steve Lopez and Nathaniel

Anthony Ayers, a one-time Juilliard student who, owing (at least *in part*) to the effects of having schizophrenia, ends up a homeless street musician. Lopez writes regular human-interest columns that weave together the arc of Ayers’ biography, introducing his readers to some of the realities of living with schizophrenia and living on Skid Row, the largest homeless district in the United States.^v

What begins as a column turns into an attempted rescue mission (Johnson, 2009). Portrayed as a pretty “decent” albeit somewhat selfish person, Lopez definitely knows his own interest is motivated by the potential of Ayers’ story. Even so, he also wants what he thinks is good for Ayers: to come in off the streets, live in an apartment, connect with the professional classical music scene in L.A., and accept medical treatment (Ogle, 2009). But as Levitin notes, “Ayers’s own suspicions (some of them well-justified) and fierce independence thwart attempts to ‘mainstream’ him” (Levitin, 2008). Ayers refuses to accept psychiatric treatment and remains schizophrenic as well as homeless since he is loathe to live in the confines of LAMP, a Los Angeles mental health housing agency and shelter that provides him with a space to practice on a donated cello (Khankhoje, 2009). Through a masterful performance by Jamie Foxx, sometimes with nothing more than a glancing frown, we see in the character of Nathaniel Ayers a person with schizophrenia who in spite of his various challenges has a strong sense of self-possession and is deeply resistant to having his life usurped (Zacharek, 2009). Lopez plays a mentor figure, but he is reticent to accept Ayers’ regard for him as something of a saviour. Lopez knows that this sort of dependence is risky: pursuing a closer relationship with Ayers could compromise his professional objectivity as a journalist (Rainer, 2009). What is more, Lopez is conflicted: though he feels compelled to invest more and more in Ayers as a friend, he also holds to the view that what Ayers “really needs” is medication and psychiatric treatment. Lopez is also just plain afraid of assuming more responsibility than he is prepared to take on. A large part of the drama of the film is generated by this tension within Lopez as he struggles with Ayers and his role in Ayers’ life (Vineberg, 2009).

“Actually, ‘*The Soloist*’ is a triumphant movie about failure,” writes Zacharek. “But the redemption that director Joe Wright and his actors go for ... is the thorny kind, the sort that means acknowledging limitations instead of blithely believing you can break through them” (Zacharek, 2009). Accordingly, one of the messages of the film—and especially the book (Lopez, 2008)—is that working with persons with schizophrenia is involving and requires the emotional investment and commitment needed to build trust. Presciently, at the outset of the book, Lopez writes: “I know if this one [i.e. “story”] ever pans out, it’s going to take time” (Lopez, 2008:5). This statement could be read as indicative not only of the process of “pulling out” and writing up Ayers’ story—it also reads as a statement about what will be required of Lopez to achieve a relationship with Ayers. Again, the Lopez of the movie feels much of the force of the Lopez of the book who writes of his relationship with Ayers as follows:

I feel jerked around, I feel sympathetic, I feel abused. It’s almost harder to see Ayers on the good days than the bad, because you let yourself be deceived into thinking he’s going to stay that way. And then the switch goes off and he’s fighting himself and blaming it on everyone around him. I see now how someone really sick can burn through your patience, if not your sense of compassion. (Lopez, 2008:110)

The movie, though realistic, is not cynical about the possibilities of reaching through the divide between the world of Ayers and the world of Lopez. Indeed, the masterful acting of both Robert Downey Jr. and Jamie Foxx make those scenes of shared joy through music (as the point of contact for these two) as equally believable as the scenes that detail the personal struggles and pain of these two characters. Relating to someone with schizophrenia in this case is seen as involving, sometimes exasperating, but genuinely rewarding too.

Questions of treatment

The film is also to be applauded for problematizing the acute-care model approach to mental healthcare—a model of mental healthcare that emphasizes intervention at the point of crisis with the goal of returning the patient to “normal” functioning (Sharfstein, 2005). This model has been shown to undervalue the importance of psychotherapy and sustaining relationships for meeting the health needs of persons with schizophrenia (Beal, 1999; Sharfstein, 2005). Through the perspective of Lopez, the movie provokes us to consider: i) why we might feel the need to see medication as a shortcut answer to treatment for persons living with schizophrenia; and ii) why we might feel the need to compel persons to accept medical treatment supposedly “for their own good”. Lopez learns over the course of the film that even just to start recovery—to get Ayers “in the door” to treatment services—requires time, a trusting relationship with the patient/consumer, and a will on the consumer’s part to accept treatment. Otherwise the road to recovery is impossible.

In the end, Ayers’ mental state and how to treat it is not resolved (Anonymous, 2009a). As such, Lopez is challenged to let go of his desire to have Ayers go on medication and be cured (Shaffer, 2009). Instead, he learns that “[t]he first order of business is to establish the makings of a relationship that extends beyond the illness” (Lopez, 2008:55). As such, *The Soloist* shows some personal gains for Ayers that are life-oriented rather than medically-calibrated. These gains are mostly tied to his developing friendship with Lopez. Relating to Lopez affords Ayers opportunities to reconnect with his passion for classical music in ways that had not been possible for him since the onset of the illness that forced him to abandon his professional training at Juilliard. As André Picard aptly points out, the movie shows that “recovery from schizophrenia involves much more than recovery from the illness itself. For many of those who have experienced this serious illness, it also means ‘recovery’ from discrimination, missed opportunities and lost dreams” (Picard, 2009).

Some criticisms of the narrative

The Soloist is not without its limitations and faults. For instance, it enlists a problematic though common trope linking genius to madness. In this regard, Rainer points to the fact that the movie would appear to “want it both ways”: there is a realism in portraying Ayers as delusional, but it would also seem that the “source” of this delusional quality is also what “fuses him with a higher level of feeling than the mundane sanity of scribblers like Lopez”

(Rainer, 2009). Resembling the movie *Shine*, Ayers is touted as a prodigy, waylaid by schizophrenia, but able to achieve heightened musical appreciation through his special, almost heavenly gift, making it seem as if mental illness is both the cruel price and yet also the “key” to artistic insight and understanding. This risks romanticizing mental illness. As Rainer explains: “Ayers is served up to us as a man whose musical passion is inseparable from his schizophrenia. This is why the film is so curiously downbeat about treatments that might have helped Ayers. He may be in pain, the film appears to be saying, but at least he owns his pain” (Rainer, 2009). Very obviously this is a problematic message if it validates a reticence to seek treatment on these grounds, abetting false beliefs that treatment is likely to compromise one’s chances for greater artistic insight and emotional capacity (Marano, 2008).

The Soloist also utilizes a problematic Hollywood narrative structure (e.g. *Rain Man*) in which a person with a mental disability is the redemption of an “outwardly successful but incomplete hero” (Gritten, 2009). Most obviously, it is condescending to trade the common stereotype of persons with mental health conditions as burdens on society for this view of them as a gift that alerts us to values unseen or unappreciated in the former perspective. Doing so, in effect, qualifies the worth of persons with mental health conditions according to their use to us as a means of redemption for our lives; it falls short of due regard for them as equals deserving of respect like any other persons. In taking up Nathaniel Ayers as a subject for the film (and book), Lopez admits there’s something interesting about a “Juilliard alum” who ended up not only playing but living on the streets. This should give us pause to analyze the character of our curiosity in, and amazement at, Ayers’ story.

Morgenstern asks why Ayers needs to be touted as a musical genius “right up there with Rostropovich” rather than a merely notable talent^{vi} (Morgenstern, 2009). Why is it that there seems to be so much more public interest in a movie like *A Beautiful Mind* than for other movies about schizophrenia like *Canvas*, *Clean*, *Shaven* and *Keane*? The latter films feature protagonists who are schizophrenic but who are not set up as extraordinary achievers. Comparatively, in *The Soloist* or *A Beautiful Mind* we are given examples of protagonists who, though living with schizophrenia, succeed at pursuits (classical music and math, respectively) that are already valued very highly in our culture. In viewing their victories either because of or in spite of—I would rather say—their mental health conditions, we (as the general audience) are really only finding a point of contact in their lives which safely maps onto points of similarity to our own “esteemed”—or at least aspirational—values.^{vii} Finding similarities to provide points of contact between members of different groups in and of itself is not wrong, and in fact is a common mechanism for building empathy. But often this move in popular film involves the concomitant tendency to look past important differences of marginalized persons like those with mental health conditions (or disabilities). For these persons to be seen, to be heard, and to be generally acknowledged, requires of those who make up the status quo to extend themselves a lot more than an empathetic response based on what amounts substantively to just a reaffirmation of our own neurotypical, conventionally-abled selves. Para-personal contact with persons with mental health conditions may be genuinely possible through film, but what is being described here is a process that fails to provide genuine contact, and might even fuel the illusion of it. By repeatedly showing persons with mental health

conditions (or disabilities) as aspiring to paths that closely align with conventional values in our culture, audiences can take away from their theatre experience a self-satisfied or unchallenged sense that being or becoming tolerant of persons with mental illness (or disabilities) in our society really doesn't require much substantial change on our part (i.e., as members of the general audience).

In *The Soloist* we mostly experience Ayers' story through the perspective of Lopez as narrator (Murray, 2009). Lopez is a novice with persons with mental health issues. The result is that we get an outside perspective on Ayers and a lot of attention to the inside of Lopez's life who, not surprisingly, occupies centre stage — as the white, neurotypical, middle-to-upper class male — most of the time.^{viii} As Matt Pais asks, "Why is 'The Soloist' so centered on Steve's ambivalence about being the only person looking after Nathaniel, rather than about Nathaniel's alienation and the social function of Steve's stories?" (Pais, 2009).

Important attention to context and setting

Fortunately, director Joe Wright's agenda for the film is broader than the dramatic narrative of the Lopez-Ayers friendship (Gritten, 2009). Wright presents the movie in a way that makes plain that Ayers' story as a homeless person with a mental health condition is the story of just one individual in a context where there are many other individuals who share his plight (Johnson, 2009; Dargis, 2009). Though the narrator, Lopez, gives us an outsider's perspective, the film itself was shot on location in Skid Row and Wright employed several hundred extras from the local population that appear pretty much unadorned in the movie. Time and again the film cuts away from Lopez's interior musings to drift amid the anonymous and largely invisible individuals who *live* without any home other than the bleak streets of Skid Row. With refreshing deference, Wright halts the dramatic friendship storyline to make space for speaking parts from clients of LAMP—a Los Angeles mental health housing agency and shelter—to tell their stories themselves^x (Denby, 2009; Gritten, 2009). As Johnson notes: "They can be fascinating and fantastically engaging people, and the film accepts them 'as-is' without any obvious effort to exploit them or turn their eccentricities into feel-good quirkiness" (Johnson, 2009).

What is more, the film is a study in the practice of listening.^x As Atkinson notes, "sometimes the soundtrack just falls away as Jamie Foxx's Ayers tries to hear only the music, and even Robert Downey Jr.'s Lopez has instances, as when he locks himself in his car at night, away from the din of the crack-cranked homeless outside, where silence is revelatory" (Atkinson, 2009). Downey Jr. as Lopez is a fast talker, but his experience with Ayers is an education in listening to much more than just the music of this talented musician and seeing much more than just a "good story" in this homeless person. "The real strength of *The Soloist*", as Johnson explains, "is not its soft heartedness but its hard eye, and the willingness to look and not look away from the unfortunate, however uncomfortable, unpleasant, and uneasy looking might make us feel" (Johnson, 2009).

Some common disadvantaging conditions of living with schizophrenia

Part of the "hard eye" of this movie is its ambition to press its viewers to look at some of the social and environmental determinants of mental health. In this regard, Ayers' plight does track certain representative elements of persons living with schizophrenia, even though it must be stressed that homelessness is not an invariable accompaniment of schizophrenia^{xi} (Kelly, 2005; Hankonen et al., 1999; Anonymous, 2009b) Despite evidence of significant biological underpinnings to schizophrenia, there is also growing evidence that socio-economic factors "play a large role in shaping the presentation, management and outcome of the illness" (Kelly, 2005:726). El-Mallakh notes that persons with schizophrenia are at risk for health disparities linked to economic factors (El-Mallakh, 2007:50). According to Eaton and Muntaner (1999), being diagnosed with schizophrenia is "strongly associated" with low socioeconomic status given the challenges it poses for both obtaining employment and advanced levels of education and training that are important for securing employment. Corrigan and colleagues also found that stigma of serious mental illnesses, including schizophrenia, "interferes with the ability to find employment" (Corrigan et al., 2006). Horsfall has linked the experience of marginalization, diminished standard of living, and social exclusion to lack of education and/or employment (Horsfall, 2003). Material deprivation and diminished financial resources often lead to homelessness or residence in deteriorating, polluted, high-crime neighbourhoods (Horsfall, 2003) that make for additional risks for poor health (Hofrichter, 2003; El-Mallakh, 2007:50). As Kelly notes, the adverse effects of these socio-economic determinants, along with enduring stigma about mental illness (Byrne, 1999), constitute a form of structural violence that acts to impair access to psychiatric care and social services and to amplify the effects of schizophrenia in the lives of sufferers. As a result of these over-arching social and economic circumstances, individuals with schizophrenia are systematically excluded from full participation in civic and social life, and are constrained to live lives that are shaped, in large part, by stigma, isolation, homelessness and the denial of basic human rights. (Kelly, 2005:726)

Being more socially responsible towards persons living with schizophrenia

In trying to bring in Ayers off the streets with the hopes that doing so will give Nathaniel a chance to better pursue his interests in music, secure a home, and eventually get treatment for his schizophrenia, Lopez encounters a common truth about homelessness and schizophrenia: namely, "there are no quick fixes or simple solutions. Good intentions are not good enough" (Johnson, 2009). Presumably, the forces of exclusion that work to disallow persons with schizophrenia from being "let in" and then accepting full participation in civic and social life call forth redress that will require widespread social change. Part of exercising the public's imagination and creating a stronger sense of social responsibility means building structures for hope that are still realistic. The all-too-common extreme public pressure

to succeed at overcoming mental illness—often fuelled by forces of stigma and discrimination—can itself be very defeating for those with mental illnesses, especially those with serious mental illnesses like schizophrenia (Davidson et al., 2001). *The Soloist*, despite its imperfections and weaknesses, is to be respected for its imaginative attempt to re-direct public focus and concern for: i) the person over and above his or her condition of schizophrenia; and ii) the context of challenges that can make living with this illness all the more difficult. It is also a movie that when taken up critically can perhaps work to lessen some of the pernicious public pressures owing to stigmas of schizophrenia. Finally, by grinding a bit of a political axe concerning the realities of homelessness, *The Soloist* may again, when taken up critically, also serve to put public pressure for change on fronts that call forth not just personal but also collective response.

References:

- Angermeyer, M. C., Matschinger, H., & Corrigan, P. W. (2004). Familiarity With Mental Illness and Social Distance From People With Schizophrenia and Major Depression: Testing a Model Using Data From a Representative Population Survey. *Schizophrenia Research*, 69, 175-182.
- Anonymous (2009a). 'Soloist' Thrives on Duo of Stellar Actors. *USA Today* (April 24, 2009). Retrieved November 28, 2009a, from: <http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=aph&AN=J0E195296105509&site=ehost-live>
- Anonymous (2009b). Robert Downey Jr. and Jamie Foxx Deliver a Wake-Up Call in *The Soloist* About the Complexities of Living With Schizophrenia. Canada News Wire, Ottawa, ON. Retrieved November 28, 2009b, from: <http://proquest.umi.com.ezproxy.library.dal.ca/pqdlink?Ver=1&Exp=11-27-2014&FMT=7&DI D=1686062441&RQT=309#indexing>
- Anonymous (2009c). Causes of Schizophrenia: Genetics, Environment, and Dopamine. *PsychiatricDisorders.com*. Retrieved January 25, 2010c, from: <http://www.psychiatric-disorders.com/articles/schizophrenia/schizophrenia-causes.php>
- Anonymous (2009d). Schizophrenia Facts and Statistics. *Schizophrenia.com*. Retrieved December 9, 2009c, from: <http://www.schizophrenia.com/szfacts.htm>
- Anonymous (2009e). "para-". *Merriam-Webster Dictionary* (online). Retrieved January 25, 2010e, from: <http://www.merriam-webster.com/dictionary/para>
- Anonymous (2009f). "para-, prefix¹". *Oxford English Dictionary* (online). Retrieved January 25 2010f, from <http://dictionary.oed.com/cgi/entry/50170860>
- Atkinson, M. (2009). *The Soloist. Sight & Sound*, 19, 76.
- Beal, G. (1999). The Constitution of Community: How Individuals Diagnosed With Schizophrenia and Their Friends Achieved Community. *Psychiatry*, 62, 173-186.
- Byrne, P. (1999). Stigma of Mental Illness – Changing Minds, Changing Behaviour. *British Journal of Psychiatry*, 174, 1-2.
- Chernomas, W. M., Clarke, D. E., & Chisholm, F. A. (2000). Perspectives of Women Living With Schizophrenia. *Psychiatric Services*, 51, 1517-1521.
- Compton, M. T. & Kotwicky, R. J. (2007). *Responding to Individuals With Mental Illnesses*. Sudbury, MA: Jones and Bartlett Publishers.
- Cormier, Bill. (2007). Breaking Down Barriers Via the Airwaves; Weekly Radio Show Gives Mentally Ill in Argentina a Place 'to Recover Their Dignity'. *The Washington Post*, A15 (January 14, 2007). Retrieved January 25, 2010, from <http://pqasb.pqarchiver.com/washingtonpost/access/1193938371.html?FMT=ABS&FMTS=ABS:FT&date=Jan+14%2C+2007&author=Bill+Cormier&desc=Breaking+Down+Barriers+Via+the+Airwaves%3B+Weekly+Radio+Show+Gives+Mentally+Ill+in+Argentina+a+Place+to+Recover+Their+Dignity%27>
- Corrigan, P. W., Green, A., Lundin, R., Kubiak, M. A., & Penn, D. L. (2001). Familiarity With and Social Distance From People Who Have Serious Mental Illness. *Psychiatric Services*, 52, 953-958.
- Corrigan, P. W., Larson, J. E., Watson, A. C., Boyle, M., & Barr, L. (2006). Solutions to Discrimination in Work and Housing Identified by People With Mental Illness. *Journal of Nervous and Mental Disease*, 194, 716-718.
- Corrigan, P. W., Markowitz, F. E., & Watson, A. C. (2004a). Structural Levels of Mental Illness Stigma and Discrimination. *Schizophrenia Bulletin*, 30, 481-491.
- Corrigan, P. W., Watson, A. C., Warpinski, A. C., & Gracia, G. (2004b). Stigmatizing Attitudes About Mental Illness and Allocation of Resources to Mental Health Services. *Community Mental Health Journal*, 40, 297-307.
- Dargis, M. (2009). Struggle and Rescue, a Duet in Sharps and Minors. *The New York Times*. Retrieved November 28, 2009, from: <http://movies.nytimes.com/2009/04/24/movies/24solo.html>
- Davidson, L., Stayner, D. A., Nickou, C., Styron, T. H., Rowe, M., & Chinman, M. L. (2001). "Simply to Be Let in": Inclusion As a Basis for Recovery. *Psychiatric Rehabilitation Journal*, 24, 375-388.
- Davidson, L. & Stayner, D. (1997). Loss, Loneliness, and the Desire for Love: Perspectives on the Social Lives of People With Schizophrenia. *Psychiatric Rehabilitation Journal*, 20, 3-12.
- Denby, David (2009, April 27). EXTRA! EXTRA! "*The Soloist*" and "*State of Play*". *The New Yorker*, 85.
- Eaton, W. W. & Muntaner, C. (1999). Socioeconomic Stratification and Mental Disorder. In A. V. Horwitz & T. L. Scheid (Eds.), *A Handbook for the Study of Mental Health: Social Contexts, Theories, and Systems* (pp. 259-283). Cambridge: Cambridge University Press.
- El-Mallakh, P. (2007). Doing My Best: Poverty and Self-Care Among Individuals With Schizophrenia and Diabetes Mellitus. *Archives of Psychiatric Nursing*, 21, 49-60.
- Esterberg, M. L., Compton, M. T., McGee, R., Shim, R., & Hochman, K. (2008). Knowledge About Schizophrenia and Social Distance Toward Individuals With Schizophrenia: a Survey Among Predominantly Low-Income, Urban, African American Community Members. *Journal of Psychiatric Practice*, 14, 86-93.
- Gaertner, S. L., Rust, M. C., Dovidio, J. F., Bachman, B. A., & Anastasio, P. A. (1996). The Contact Hypothesis: the Role of Common Ingroup Identity on Reducing Intergroup Bias Among Majority and Minority Group Members. In J. L. Nye & A. M. Brower (Eds.), *What's Social About Social Cognition?* (pp. 230-260). Thousand Oaks, CA: Sage.
- González-Torres, M. A., Oraa, R., Arístegui, M., Fernández-Rivas, A., & Guimon, J. (2007). Stigma and Discrimination Towards People With Schizophrenia and Their Family Members. A Qualitative Study With Focus Groups. *Social Psychiatry and Psychiatric Epidemiology*, 42, 14-23.

- Griffiths, K. M., Nakane, Y., Christensen, H., Yoshioka, K., Jorm, A. F., & Nakane, H. (2006). Stigma in Response to Mental Disorders: a Comparison of Australia and Japan. *BMC Psychiatry*, 6, 21.
- Grinfeld, M. (1998). From Poster Child to Wanted Poster. *Psychiatric Times*, 15, 1-3.
- Gritten, D. (2009). *The Soloist*, Review. Telegraph.co.uk. Retrieved November 28, 2009, from: <http://www.telegraph.co.uk/culture/film/filmreviews/6227806/The-Soloist-review.html>
- Hankonen, T., Saarinen, S., & Salokangas, R. K. R. (1999). Deinstitutionalization and Schizophrenia in Finland II: Discharged Patients and Their Psychosocial Functioning. *Schizophrenia Bulletin*, 25, 543-551.
- Harrison, G., Mason, P., Glazebrook, C., Medley, I., Croudace, T., & Docherty, S. (1994). Residence of Incident Cohort of Psychotic Patients After 13 Years of Follow Up. *British Medical Journal*, 308, 813-816.
- Hofrichter, R. (2003). *Health and Social Justice: a Reader on the Politics, Ideology, and Inequity in the Distribution of Disease*. (1st ed.) San Francisco: Jossey-Bass.
- Holmes, E. P., Corrigan, P. W., Williams, P., Canar, J., & Kubiak, M. A. (1999). Changing Attitudes About Schizophrenia. *Schizophrenia Bulletin*, 25, 447-456.
- Horsfall, J. (2003). Consumers/Service Users: Is Nursing Listening? *Issues in Mental Health Nursing*, 24, 381-396.
- Horsley, J. (2009). *The Secret Life of Movies: Schizophrenic and Shamanic Journeys in American Cinema*. Jefferson, NC: McFarland & Co.
- Hyler, S. E. (1988). DSM-III at the Cinema: Madness in the Movies. *Comprehensive Psychiatry*, 29, 195-206.
- Johnson, S. M. (2009). *The Soloist* (2009). In the Dark – Giving Movies a Stern Talking-to Since 1992. Retrieved November 28, 2009, from: http://sydminthedark.blogspot.com/2009_04_01_archive.html
- Kelly, B. D. (2005). Structural Violence and Schizophrenia. *Social Science & Medicine*, 61, 721-730.
- Khankhoje, M. (2009). *The Soloist*. Montreal Serai. Retrieved December 1, 2009, from: <http://www.montrealserei.com/wp/2009/09/26/the-soloist/>
- Lamp Community (2009). www.lampcommunity.org. Retrieved November 23, 2009, from: <http://www.lampcommunity.org/index.php>
- Lauber, C., Nordt, C., Falcato, L., & Rossler, W. (2004). Factors Influencing Social Distance Toward People With Mental Illness. *Community Mental Health Journal*, 40, 265-274.
- Levitin, D. J. (2008). Notes From Underground: a Newspaper Columnist Recounts His Unlikely Friendship With a Homeless Musician. *Washington Post* (Sunday, 20 July 2008). Retrieved November 28, 2009, from: <http://www.washingtonpost.com/wp-dyn/content/story/2008/07/18/ST2008071801691.html>
- Link, B. G. & Cullen, F. T. (1983). Reconsidering the Social Rejection of Ex-Mental Patients: Levels of Attitudinal Response. *American Journal of Community Psychology*, 11, 261-273.
- Link, B. G., Phelan, J. C., Bresnahan, M., Stueve, A., & Pescosolido, B. A. (1999). Public Conceptions of Mental Illness: Labels, Causes, Dangerousness, and Social Distance. *American Journal of Public Health*, 89, 1328-1333.
- Link, B. G., Struening, E. L., Neese-Todd, S., Asmussen, S., & Phelan, J. C. (2001). The Consequences of Stigma for the Self-Esteem of People With Mental Illnesses. *Psychiatric Services*, 52, 1621-1626.
- Lopez, S. (2008). *The Soloist: a Lost Dream, an Unlikely Friendship, and the Redemptive Power of Music*. New York, NY: G.P. Putnam's Sons.
- Mallik, K., Reeves, R. J., & Dellario, D. J. (1998). Barriers to Community Integration for People With Severe and Persistent Psychiatric Disabilities. *Psychiatric Rehabilitation Journal*, 22, 175-180.
- Mann, C. E. & Himelein, M. J. (2004). Factors Associated With Stigmatization of Persons With Mental Illness. *Psychiatric Services*, 55, 185-187.
- Marano, H. E. (2008). Genius and Madness. *Psychology Today*. Retrieved December 10, 2009, from: <http://www.psychologytoday.com/articles/200705/genius-and-madness>
- Mental Health Policy Research Group. (1998). *Mental Illness and Pathways Into Homelessness: Proceedings and Recommendations*. Toronto, ON: Canadian Mental Health Association.
- Miller, P. (2009). *The Soloist* Movie Review. News Blaze. Retrieved January 22, 2010, from: <http://newsblaze.com/story/20090417113719mill.nb/topstory.html>
- Morgenstern, J. (2009). 'Soloist': Beautifully Played, Bittersweet Notes. *Wall Street Journal – Eastern Edition*, 253, W3.
- Murray, R. (2009). 'The Soloist' – Movie Review. About.com. Retrieved November 18, 2009, from: <http://movies.about.com/od/thesoloist/fr/movie-review.htm>
- National Institutes of Mental Health (1986). Combating the Stigma of Mental Illness (revised edition). United States Department of Health and Human Services. Retrieved December 10, 2009, from: http://www.eric.ed.gov/ERICDocs/data/ericdocs2sql/content_storage_01/0000019b/80/1c/45/e7.pdf
- Ogle, C. (2009). Review – The Soloist: Downey and Foxx Make a Fine Duet. *The Miami Herald*. Retrieved November 29, 2009, from: <http://www.miamiherald.com/1054/story/1013467.html>
- Pais, M. (2009). 'The Soloist' Review. A True Story that Doesn't Focus on What's Most Important. Metromix New York. Retrieved January 22, 2010 from: http://newyork.metromix.com/movies/movie_review/the-soloist-review/1113374/content
- Picard, Andre (2009, May 7). *The Soloist* Actually Gets It Right – To a Point. *The Globe and Mail*, L17.
- Rainer, P. (2009). Review: 'The Soloist'. *Christian Science Monitor*, 17.
- Reinke, R. R., Corrigan, P. W., Leonhard, C., Lundin, R. K., & Kubiak, M. A. (2004). Examining Two Aspects of Contact on the Stigma of Mental Illness. *Journal of Social and Clinical Psychology*, 23, 377-389.
- Ritterfeld, U. & Jin, S. A. (2006). Addressing Media Stigma for People Experiencing Mental Illness Using an Entertainment-Education Strategy. *Journal of Health Psychology*, 11, 247-267.
- Rüsch, N., Angermeyer, M. C., & Corrigan, P. W. (2005). Mental Illness Stigma: Concepts, Consequences, and Initiatives to Reduce Stigma. *European Psychiatry*, 20, 529-539.
- Schizophrenia Society of Canada (2009). Schizophrenia in Canada: a National Report. www.schizophrenia.ca. Retrieved November 29, 2009, from: http://www.schizophrenia.sk.ca/wp-content/uploads/2009/03/schizophrenia-report_final_english2009.pdf
- Schulze, B., Richter-Werling, M., Matschinger, H., & Angermeyer, M. C. (2003). Crazy? So What! Effects of a School Project on Students' Attitudes Towards People With Schizophrenia. *Acta Psychiatrica Scandinavica*, 107, 142-150.
- Shaffer, R. L. (2009). *The Soloist* DVD Review: Fascination Drama Hits All the Right Notes. IGN.com. Retrieved November 28, 2009, from: <http://dvd.ign.com/articles/101/1011010p1.html>
- Sharfstein, S. S. (2005). The Healing Power of Relationships. *Psychiatry*, 68, 212-213.
- Shorter, E. (1997). *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac*. New York: John Wiley & Sons.

- Stevens, D. (2009). Cello Shots. *Slate*. Retrieved November 26, 2009, from: <http://www.slate.com/id/2216788/>
- Thornicroft, G., Brohan, E., Rose, D., Sartorius, N., & Leese, M. (2009). Global Pattern of Experienced and Anticipated Discrimination Against People With Schizophrenia: a Cross-Sectional Survey. *Lancet*, 373, 408-415.
- Torrey, E. F. (2006). *Surviving Schizophrenia: a Manual for Families, Patients, and Providers*. (5th ed.) New York, NY: Collins.
- Vineberg, S. (2009). The Soloist. *Christian Century*, 126, 43.
- Vonkorff, M., Nestadt, G., Romanoski, A., Anthony, J., Eaton, W., Merchant, A. et al. (1985). Prevalence of Treated and Untreated Dsm-iii Schizophrenia - Results of A 2-Stage Community Survey. *Journal of Nervous and Mental Disease*, 173, 577-581.
- Zacharek, S. (2009). *The Soloist*. Salon.com. Retrieved November 28, 2009, from: <http://www.salon.com/ent/movies/review/2009/04/24/soloist/index.html>

Endnotes

- ⁱ Lack of understanding and negative attitudes towards persons with schizophrenia are also a Canadian problem. A 2008 Leger Marketing Survey of adult Canadians showed that 32% of those polled thought that people with schizophrenia tend to be violent, 16% said they were not comfortable talking about schizophrenia, and 32% felt uncomfortable being in the presence of someone with schizophrenia (Schizophrenia Society of Canada, 2009).
- ⁱⁱ According to PsychiatricDisorders.com: “The causes of schizophrenia are unknown: while several possible causes exist, no single cause explains all cases of schizophrenia. Genetics, birth defects, environmental triggers, and imbalances of the neurotransmitter dopamine are all considered possible causes of schizophrenia” (Anonymous, 2009c).
- ⁱⁱⁱ “Recent American studies report that approximately half of all individuals with severe mental illnesses have received no treatment for their illnesses in the previous 12 months” (Anonymous, 2009d). See also Vonkorff et al., 1985.
- ^{iv} According to Merriam-Webster Dictionary (online), the prefix “para” can mean “1. beside: alongside of; 2 a. Closely related to; b. Involving substitution” (Anonymous, 2009e). The Oxford English Dictionary (online), defines the prefix “para” as that which is “analogous or parallel to, but separate from or going beyond, what is denoted by the root word”, in this case, the “personal” (Anonymous, 2009f).
- ^v “Close to 74,000 people are homeless in Los Angeles—more than in New York, Chicago, and San Francisco combined. Los Angeles’ Skid Row, a 52-block area east of the downtown business district, has the highest concentration of homelessness in the United States. More than half of the homeless men and women in this area are chronically homeless, meaning they struggle with a mental or physical disability and have been living on the street for years” (Lamp Community, 2009).
- ^{vi} Another worry is that *The Soloist* simply rehearses a convention in popular film by which persons with mental health conditions (or disabilities) become noteworthy either because of their fall from “greatness” (gauged according to conventional standards) or because of their achievement of “greatness” (gauged by conventional standards). Either way, the stories are unlikely to be representative of what most persons living with the condition in question are like or are able to reasonably aspire to. The sense of appreciation for persons with mental health conditions (or disabilities) engendered by this common approach in popular film risks being built on empathy for the “greatness” (gauged by conventional standards) from which these characters may have fallen, or the “greatness” (gauged by conventional standards) these characters manage to achieve notwithstanding their condition. What is lacking here is an attempt to take on the challenge of trying to build an empathy that transcends to those who might not care to pursue “greatness” gauged by conventional standards, or for whom the pursuit of such would be impracticable or senseless to attempt.
- ^{vii} Explaining audience appeal of movies about extraordinary persons with mental health conditions (or disabilities) is obviously multi-factorial and subject to various interpretations. Another (more sanguine) view would have it that we admire what is extraordinary about these individuals and in doing so this gives us a way to look past the illness and stereotype – the collective “other”, so to speak – and to see an exceptional individual there. In a culture that—oftentimes, only ostensibly—prizes individualism, this could count as a way to acknowledge the person instead of just seeing the disease or disability. I thank L. Syd Johnson for bringing this point to my attention.
- ^{viii} Dana Stevens holds that when Ayers’ worship turns into resentment, “questions about racial and class guilt are raised, then left unexplored” (Stevens, 2009). For a critique of the film’s handling of issues of race and class see “The Soloist Movie Review” by Prairie Miller (2009).
- ^{ix} Moe Armstrong, an advocate living with schizophrenia and director of consumer and family affairs for the Vinfen Corporation (an organization that provides consumer services through the Massachusetts Department of Mental Health) said in an interview that “mental health is an expert-driven field, and that experts are the ones who talk about the mentally ill. Ultimately, individuals with mental illnesses must speak out and have a greater impact on the way they are depicted to the public. He added that at times he resents efforts to use celebrity spokespeople as examples of mental health success stories. ‘Everyone’s pain is real,’ he said” (Grinfield, 1998:2).
- ^x See *Radio La Colifata* FM 100.1 (online) which broadcasts commentary by consumers from within Jose Borda Neuropsychiatric Hospital in Buenos Aires. It began over fifteen years ago “to help patients communicate with their peers, to carry their voices beyond the hospital walls and to break down public misconceptions and prejudices ...” (Cormier, 2007).
- ^{xi} Approximately 6% of persons with schizophrenia in the US are homeless or live in shelters and another 6% live in jails or prisons (Torrey, 2006). A Canadian study found a 6% lifetime prevalence of schizophrenia among Toronto’s homeless population (Mental Health Policy Research Group, 1998).

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BOOK REVIEW

Burdened Virtues: Virtue Ethics for Liberatory Struggles

by Lisa Tessman PhD

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The fourth sentence in this book is: “My concern is with the *selves* who endure and resist oppression and, in particular, with the way in which the devastating conditions confronted by these selves both limit and burden their moral goodness” (3). The second last sentence in the book is: “The choice to go on living, to insist upon life --with its sufferings and its joys -- is an existential choice of great significance under oppression, and this choice captures something crucial about eudaimonism” (168). The intervening 165 pages offer a tenacious examination of the relevance of Aristotelian virtue ethics theory today for people facing dilemmas impacted significantly by troubling social norms and systems.

The book was initially appealing for three reasons. First, analyses of mental health and addictions-related problems often turn to legal rights, protected freedoms, and utilitarian calculus to help determine ethically defensible responses. Virtue theory is used infrequently. Second, although Aristotle’s virtue theory focused on the symbiosis between individual character, communal prosperity and *eudaimonia* (i.e., flourishing as a human being), *eudaimonia* was envisioned for only some (e.g., not for those who were enslaved). Third, societal discrimination and stigmatization of people living with a mental health or addiction concern and their families continue today. I hoped Tessman’s work could render Aristotle’s theory more inclusive and could explain whether someone who worries about his character and acting with integrity—and who is neither an “un-seeing” idealist nor a “all-is-lost” cynic—either can live with seemingly intractable oppressive practices or can resist time after time after time.

Moral harm of the self unifies the first three chapters. Chapter one, “Regretting the Self One is,” works with four types of luck, individual control, agency, and responsibility to help refine differences between producing good outcomes, *acting* virtuously, and *being* virtuous and help challenge today’s popular embrace of unlimited personal transformation. Admittedly the chapter is difficult and inclusion of some practical examples would have helped. Nonetheless the nuanced distinctions are pivotal for increased accuracy in understanding and judging people’s character.

But what if a person has been morally wounded? In Chapter two, “The Damage of Moral Damage,” Tessman shares her ongoing worries about the stereotypic political debates in the U.S.A. wherein conservatives tend to blame oppressed people for their vicious actions (e.g., violence, substance use, criminal activities) while liberals tend to excuse them. Eschewing such simplification and polarization, the author explains the differences between holding an oppressed person responsible for her character flaws versus blaming her for them. Understanding these differences can help avoid added oppression of someone who is oppressed already as well as avoid expecting too little of her.

Although chapter two opens with a seemingly surprising statement that people in dominant positions are more morally damaged than those in subordinate positions, arguments supporting this claim make up the third chapter. Tessman wonders whether Aristotle’s claim that a good life relies on living virtuously is outdated in Western society today. This chapter’s content and questions were gripping, in part because of my own privileged circumstances plus my work in healthcare ethics. The author laments the persistent indifference of the privileged (who I take to be those belonging to the upper and middle classes) to the unrelenting hardships and disadvantages of others. Her recommended corrective begins with developing the virtue of sensitivity to the plight of others.

The next three chapters shift to the idea that virtues themselves can be burdened. In other words, being virtuous has personal costs and this challenges Aristotle’s claim that virtues are an important contributor to flourishing. As chapter three ends by advocating sensitivity, chapter four explores how a sensitive person copes with the fact of unremitting and extensive suffering in the world. Reminiscent of MC Escher’s art that interweaves possibility with impossibility, Tessman insightfully and candidly discusses ways a person can avoid cynicism or martyrdom and remain involved.

Chapters five and six tackle the costs of liberatory struggles wherein a person of character fights systemic or structural oppression. In specific, the traits of anger and courage are scrutinized by comparing how they are often extolled for resistance efforts with how a resister’s character or quality of life can be harmed. Just

BOOK REVIEW

as she wonders when is anger and courage a vice versus a virtue, Tessman also wonders when is loyalty to one's "group," be it of resisters or oppressed people, a vice versus a virtue. Both chapters probe well beyond generalized or romanticized views about battling injustice to show why having virtues and being virtuous are very complex and why one can feel ambivalent about the fact of having a character.

The concluding chapter offers ways to help identify virtues in four different situations. This was a pleasant change from the previous chapters' density although including a few examples to more clearly illuminate and contrast the situations would have been appreciated. Given that I tend to be practically minded, reading this chapter first may have made the others easier to follow.

In summary, I plan to re-read this book for three reasons. First, it brings Aristotle's virtue theory into contemporary times to understand people's characters -- their virtues and vices -- as well as how to appropriately evaluate them and how to appropriately evaluate the systems of which they are part. So too, for understanding and evaluating one's own character. Second, Tessman also engages pertinent liberal and feminist viewpoints to help ensure that virtue ethics theory is sound enough to withstand important political critiques. Third, Tessman's work content is not just agent-centred. It purposively focuses on agents who must live in or work within unjust situations. Since healthcare dilemmas are often about injustice, discrimination, power, or marginalization as well as about those directly involved, this book will be useful to those working in healthcare, be they clinicians, ethics specialists, or community advocates. In the Nichomachean Ethics, Aristotle extols *phronesis* or practical wisdom. The insights, candor, reflections, and hope that make up Burdened Virtues should help its readers meet Aristotle's ethical standards for good character and right action.

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