

What is New with the JEMH?

1. Publication Schedule:

Rather than publish three issues per year we have decided to publish two longer issues in November and April. Recognizing that electronic publishing is not restricted by page limits in the same manner as paper publishing, it was felt that a July release was not an ideal time given summer vacations and institutional lulls.

2. Student Award Program:

We are pleased to announce that we will be providing a cash award once a year to a student in an undergraduate, graduate, residency, post-doctoral or fellowship program who submits an article that is selected by the Editorial Committee for publication. Our goal is to encourage academic interest and writing in the area of mental health ethics. Watch for more details in our next issue.

3. Guest Editors:

From time to time distinguished guest editors will be invited to develop a collection of articles with their chosen colleagues on a theme that represents their shared area of expertise. In this issue, we are very grateful to Walter Glannon for serving as our first guest editor on the theme of neurodiversity.

4. New Options for the "In My Life" Section:

In an effort to encourage submissions by people living with mental illness, as well as by the people who love and care for them, we are creating some options that we hope will make the process easier. We will: i) accept written submissions in the usual manner, and we will actively provide some writing and editing assistance if requested; ii) accept electronic audio files (tape recordings) that we will transcribe, or that we might publish as an audio file within our regular issue.

Our hope is to eliminate writing skill or literacy barriers as much as possible so that stories related to ethical struggles may be effectively shared.

5. Word Limits:

We have had a number of authors request that we consider exceptions to our 3,000 word limit. In response, we have adopted the following position: "The editors may from time to time publish articles in excess of 3,000 words if it is felt that the integrity of the thesis, content or flow would be impaired by strict adherence to the 3,000 word limit. These rare instances will be considered on a case by case basis".

6. Indexing Update:

The JEMH is now indexed on CINAHL and Sociological Abstracts. Many databases require publication of at least 3 issues before indexing will be considered. With this, our third issue, we hope to be indexed widely in the near future.

7. Conferences:

Our 2007 Lakefield conference was a sold-out success and the presenters' Powerpoint and audio files are now available on our website. We plan to continue to host conferences both in Ontario and in partnership with other organizations or institutions around the world.

Our warmest thanks to our readers, conference attendees, and editors for all of your helpful feedback. The journal continues to evolve and we look forward to developing some excellent new features over time.

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Special Theme for this Issue: “Neurodiversity”

Psychiatric and neurological disorders affect roughly 400 million people globally. In June 2004, the Journal of the American Medical Association published the results from the world’s largest survey on mental health. From one to five percent of the populations of most countries surveyed have some form of mental illness. More recently, results from a US study on mental illness published in June 2005 showed that about half of all Americans will have conditions that meet criteria of the Diagnostic and Statistical Manual of Mental Disorders over the course of their lifetime. Yet many neurological and psychiatric conditions are not well understood by the general public. Indeed, some of these conditions are not well understood by many mental health professionals.

‘Neurodiversity’ usually appears in discussions of autism spectrum disorders and the view that individuals with these disorders have at least as much mental ability as disability. Their neurological and psychological traits form a unique and valued identity, which forces us to reconsider accepted models of “normal” and “abnormal” states of mind. Construed more broadly, however, neurodiversity can describe a wider range of conditions consisting of complex sets of traits and symptoms influenced by biological and environmental factors. These conditions may pose a challenge for clinicians in explaining their etiology and establishing a diagnosis. They often also involve questions about whether or how they should be treated. The authors of the four papers in this thematic issue of the Journal of Ethics in Mental Health recognize the scope of neurodiversity and explore its clinical, ethical, personal, and social implications.

I point out that many people have a constellation of both normal and pathological mental traits in “Neurodiversity.” I describe cases of individuals with mental traits associated with exceptional intellectual or artistic ability, despite being diagnosed with a neurological or psychiatric

disorder. These cases raise the question of whether mental traits that deviate from accepted standards of normal neurological and mental function should be characterized as differences or disabilities. They also raise the question of whether it is always in an individual’s best interests to be treated for a disordered mind.

In “Autism, Neurodiversity, and Equality Beyond the ‘Normal,’” Andrew Fenton and Tim Krahn present neurodiversity as a part of the struggle for the civil rights of people with neurological or neurodevelopmental disorders. They argue that the goal of “neuro-equality” requires a critical examination of current nosology that pathologizes the phenotypes associated with these disorders. It also requires a critique of the social institutions that set standards for what counts as properly functioning cognitive capacities. In their discussion of certain forms of autism spectrum disorders, Fenton and Krahn show that an appeal to functional and neurological diversity can help to achieve neuro-equality.

In “Neglecting the Social System: Clinical Neuroimaging and the Biological Reductionism of Addiction,” Daniel Buchman explains how addictions arise from the interaction of genetic, environmental, and social influences. Heavy reliance on neuroimaging to display brain activity underlying addiction is a form of biological reductionism that ignores the effect of these influences on the brain’s response to addictive substances. Buchman emphasizes that brain plasticity does not occur in a biological vacuum. Biological reductionism will only further marginalize and harm people with addictions. In particular, recognition of the influence of social factors on brain function could lead to more effective pharmacological and psychosocial interventions that could help to prevent or control drug abuse.

“Locked in Syndrome, PVS and Ethics at the End of Life” is a poignant account of Nick Chisholm’s experience with locked-in syndrome (LIS) by Chisholm and neurosurgeon and bioethicist Grant Gillett. Fully conscious and aware of his surroundings but trapped inside his body as a result of a brain injury, Chisholm describes how his condition altered his phenomenological experience as a being in the world with others. This case also shows how subtle indicators critical to diagnosing the condition may be missed by medical professionals. Unlike patients in a persistent or permanent vegetative state (PVS), a patient in an LIS can be reconnected to the world. Because of this and other differences in the neurological status of LIS and PVS patients, clinicians have different duties of care to these two groups.

Gillett emphasizes two related duties of care that should be discharged to all individuals with neurological and psychiatric disorders: “Attention to and recognition of the patient as the creator of and living being at the centre of the story of his or her own life.” This can promote better understanding and more effective treatment of these disorders. It can also help to reduce the marginalization and stigma associated with mental illness.

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Neurodiversity

A Neurodiversity Theme Article

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ABSTRACT

The neurological and psychological traits that regulate our thought and behavior fall along a spectrum that extends from the normal to the pathological, from traits that enable us to perform mental and physical functions to traits that interfere with these functions. Yet many people have a constellation of both normal and pathological mental traits. Some even have traits associated with exceptional intellectual or artistic ability despite being diagnosed as having a neurological or psychiatric disorder. These cases raise medical, ethical and legal questions about which conditions should be diagnosed as mental disorders or pathologies, and whether it is always in one's best interests to be treated for these conditions.

Introduction:

In the American Journal of Psychiatry, an advertisement for the selective serotonin reuptake inhibitor (SSRI) sertraline (Zoloft) shows a young woman wearing a hat whose rim covers her eyes. The caption reads: "Is she just shy? Or is it Social Anxiety Disorder?" The suggestion is that our cognitive and affective traits fall along a neuropsychiatric spectrum that extends from normal to pathological. Traits falling at the pathological end of the spectrum are often manifestations of an underlying neurobiological dysfunction that is diagnosed as a psychiatric or neurological disorder. Treatment for these conditions is indicated when it can restore patients to normal mental and physical functioning. In psychiatry, this may include interventions such as cognitive-behavioral therapy (CBT), psychopharmacology or a combination of these treatment modalities (Bloch, Chodoff and Green, 1999). Severe cases may be treated with electrical stimulation of the affected brain regions. In neurology, therapeutic interventions include pharmacology, surgery or deep-brain electrical stimulation.

In some cases, however, cognitive and affective traits may fall slightly outside the broad middle region of the spectrum, where the constellation of one's psychological properties is neither clearly normal nor pathological. Moreover, there may be considerable variation among people with the same generic neuropsychiatric disorder. Individuals with severe depression who experience psychosis and suicidal ideation fall at the pathological end of the spectrum. In contrast, individuals with a mild form of depression such as dysthymia may experience only a feeling of melancholy and fall just outside the middle of the spectrum.

Some neuropsychiatric conditions have both pathological and salutary characteristics. An individual with such a condition may display poor social skills and impairment in such cognitive functions as planning, inferential reasoning and decision-making. At the same time, this same individual may display exceptional mathematical ability or artistic creativity (Fitzgerald, 2003; Frith and Hill, 2003). This ability or creativity might include insight into problems or dimensions of the natural world not ordinarily open to the general population. Autism spectrum disorders are perhaps the best example of a neuropsychiatric condition that may involve both mental ability and mental disability, especially in the moderate form of the disorder--Asperger's syndrome (DSM-IV-TR, 200, 75 ff.). For those who have this combination of mental traits, exceptional mathematical or artistic talent are recognized and valued as natural gifts. Yet these gifts cannot be separated from what others would describe as cognitive and affective disabilities that are also associated with the condition. Mental ability and disability are inseparable components of a set of psychological properties that make these people the unique individuals they are.

These are examples of "neurodiversity," which recognizes that many people have a combination of neurological and psychological abilities and disabilities (Baker, 2006). This mix is generated and sustained by the different ways in which their brains are wired. It celebrates differences in the unique cognitive and affective capacities of people who fall along different stages of the neuropsychiatric spectrum. This phenomenon forces us to ask what counts as a mental disorder, and whether certain mental traits that deviate from those of the general population should be characterized as differences rather than disabilities. It also forces us to consider

the extent to which pathological traits can be balanced by salutary traits, and whether and on what grounds individuals with a combination of these traits should be treated. But how do we decide whether a person's general set of mental traits is normal or abnormal and thus indicative of an illness or pathology? What is the link between a brain disorder and outstanding mental attributes? Would it be in the best interests of an individual with such a disorder to intervene with CBT, psychopharmacology or other therapy? Or would their interests be better served by leaving the condition and its symptoms untreated? Could any gain from the restoration of some mental attributes outweigh or compensate for the loss of other mental attributes as a result of these interventions?

To respond to these questions, I will present cases of different individuals with distinct conditions and traits falling at different points along the neuropsychiatric spectrum. These cases will test our intuitions about what constitutes normal or pathological thought and behavior, and whether it is appropriate to always intervene with treatment for these conditions.

A Spectrum of Mental Traits

Very generally, normal mental functioning consists in the cognitive and affective ability to interact with other people and to perform a range of ordinary cognitive tasks of daily life. These abilities fall in a broad middle range of the neuropsychiatric spectrum. Different people may possess these abilities to varying degrees. But the idea of a broad middle range of mental traits is an intuitively acceptable measure that can be used as a basis on which to classify conditions as illnesses or pathologies. This measure may also indicate which conditions warrant therapeutic intervention.

Consider autism spectrum disorders (ASD). Individuals with these disorders often have difficulty commuting and interacting with others in social contexts. Some also have cognitive impairment in concept formation and inferential reasoning. They can focus on the details of parts but not on the general patterns of wholes. Although autism is characterized as a psychopathology, the ability to see parts of details normally denied to conscious awareness could explain some forms of genius. Autism spectrum disorders fall along a neuropsychiatric spectrum that may include severe mental impairment at one end and creative genius at the other.

Although the neural mechanisms of autism are still not completely understood, the inability of many autistic individuals to interact socially with other people or to draw inferences from parts to wholes appears to be traceable to abnormalities in pathways between the limbic area of the brain and the prefrontal cortex. Post mortem studies of the brain of individuals who had autism have shown a decreased number of neurons in limbic regions such as the amygdala and hippocampus, as well as in the anterior cingulate (Volkmar and Pauls, 2003). Like schizophrenia, autism involves abnormalities in dopaminergic and serotonergic systems and probably arises from mutations in multiple genes. Autism may also involve dysfunctional mirror neuron systems. These systems are distributed through the insula and other brain regions. Mirror neurons regulate the ability to understand others' intentions and to grasp the social meaning of their behavior. This occurs through direct simulation rather than cognition (Rizzolatti and Craighero,

2004). While it is not known whether there is a direct causal link between these brain abnormalities and any outstanding mental attributes in ASD, there does appear to be a correlation between the two. Autism spectrum and certain other neuropsychiatric disorders usually develop from birth or very early in life. In this regard, the mental traits that characterize the condition are an essential part of the identities of those who have it.

Indeed, many people with ASD would insist that their mental traits make them a distinctive culture, a culture to which they are proud to belong and which they would not want to change in any respect. Individuals with traits falling at or near the extreme end of the autistic spectrum do not respond well to CBT or pharmacotherapy. In mild to moderate forms of these disorders, even if some traits considered borderline pathological could be treated, one would have to consider the consequences of the treatment if it eliminated the source of considerable mental ability and one's identity. At the same time, this would have to be weighed against the fact that children with moderate ASD may face problems as they approach adolescence, when social interactions become more complicated.

It is believed that the Indian mathematician Srinivasa Ramanujan (1887-1920) and the Austrian philosopher Ludwig Wittgenstein (1889-1951) had some form of Asperger's (Stewart, 1991; Monk, 1990). Ramanujan's work has profoundly influenced number theory in mathematics. Wittgenstein arguably has had an even greater influence on the philosophy of language and the philosophy of mind. If their exceptional ability was inseparable from cognitive and affective traits symptomatic of a mental disorder, then we should consider the possible loss of mathematical or philosophical genius as a consequence of any treatment that might have been given to them for the suspected syndrome. Individuals with ASD who are intellectually gifted may not be as rare as one might think. It is estimated that the incidence of savant ability in children with autism may be as high as 10 percent. In the United States, autism spectrum disorders may affect as many as two to six per 1,000 children.

If an abnormal mental trait or set of traits is offset by a mental trait indicative of exceptional cognitive ability in the same individual, then one can question whether the individual's collective set of mental traits warrants the label of "syndrome" or "disorder." At the very least, these considerations suggest that any label of "disease," "disorder," or "syndrome" should be given in qualified form. They also suggest that "normal" should be construed more broadly to include traits distributed over a fairly large area of the neuropsychiatric spectrum. Some might argue that it is preferable to trace these mixed sets of mental traits to their biological basis and give them a medical diagnosis. Presumably, this would avoid the social stigma and moral diagnosis of these traits as deviant or bizarre and would in turn avoid the psychological harm that could result from internalizing these attributions. Yet a medical diagnosis would not obviously be any better at avoiding psychological harm to these individuals than the absence of one. A medical diagnosis could indicate that the condition should receive medical treatment, which some people with conditions falling along the autistic spectrum might be reluctant to accept. It could reinforce the idea that they have a mental disorder. For these individuals, the idea of having mental traits that are simply different from the traits of others might be preferable to having a diagnosis.

I will now discuss neurological and psychiatric disorders in which there are radical swings between normal and abnormal mental states and behavior at distinct times. Three principal questions motivate the discussion of these cases: (1) On what basis should a condition be diagnosed as a mental disorder or psychopathology? (2) Would treatment for these conditions be in a person's best interests? (3) How does the condition affect the properties of psychological unity, continuity, agency, and embodiment that constitute the self? If an individual identifies with a particular set of psychological properties that constitute his or her self, and cognitive-behavioral or psychopharmacological interventions alter these properties, then these interventions can alter the self (Ramachandran, 2003; Damasio, 1999, 2003; Kircher and David, 2004). Yet some individuals with conditions diagnosed as psychopathologies may identify with the self that is constituted by the very same properties symptomatic of these psychopathologies. These may be selves with which these individuals are quite happy and would not want to change. At the same time, the cognitive or affective impairments symptomatic of these conditions may pose a risk of harm to the individuals who have them.

Thus there may be trade-offs between benefit and harm in these cases. Psychiatrists, neurologists, and other medical professionals need to weigh the benefit of treating to restore normal mental functions and certain traits against the risk of causing the loss of other traits with which the individual identifies and which make life meaningful for him or her.

Epilepsy, Bipolar Disorder and Creativity

Many artists throughout history have identified with the creativity associated with temporal lobe epilepsy, the manic phase of bipolar disorder and other disorders of the brain and mind. Studies by Norman Geschwind and other researchers have shown that the hypergraphia of prolific writers such as Dostoevsky, as well as the creativity of artists such as Van Gogh and composers like Schumann, may be attributed to hyperactivity in certain brain circuits (Geschwind and Waxman, 1975; Geschwind, 1979). Temporal lobe epilepsy has also been associated with a heightened sense of spirituality or mystical visions (Jackson and Fulford, 1997; Rho, Sankar and Cavazos, 2004). The exceptional mental ability that some individuals have as a result of these disorders is something they are reluctant to give up.

Despite any experience of rapture associated with a heightened sense of spirituality or with creative writing, untreated epilepsy poses the risk of uncontrolled seizures and extensive damage to many brain regions. It does this by disturbing the balance between excitatory and inhibitory neural circuits in the brain, resulting in hyperactive excitatory circuits. In severe cases, epilepsy can lead to coma and death. In bipolar disorder, the potential harmful consequences of both manic (impaired reasoning, impulsive judgment) and depressive (suicidal ideation) phases of this condition are so significant that failure to intervene with lithium or other equally effective drugs would be difficult to justify. When a person's artistic creativity or other cognitive and affective talents are associated with a neuropsychiatric disorder and psychopathology, he may insist that life for him would be worse if regulating the disorder came

at the expense of his creativity. But if such a person is under the care of a physician, the patient's decision to refuse treatment for this reason could be overridden by the physician. This could be justified if the physician judged that the disorder posed a significant risk of harm to the patient or to others, and that the patient was incapable of understanding these risks.

The compulsion to write that is symptomatic of hypergraphia could prevent one from attending to more immediate and important matters, such as attending to the needs of one's family. During a manic phase or an epileptic seizure causing a mystical vision, someone might believe that he had a choice between retaining his symptoms and controlling or eliminating them through treatment. Yet the compulsive nature of hypergraphia or other creative urges suggest that he would not have the cognitive control to rationally consider the long-term consequences of not seeking treatment. He would lack or have an inadequate degree of competence and decisional capacity, and any choice in the matter might not really be his to make.

There are important differences between conditions such as temporal lobe epilepsy or bipolar disorder, on the one hand, and autism spectrum disorders, on the other. In the second type of disorder, there is a marked contrast between exceptional mental ability and mental disability, both of which are functions of an underlying neurological or psychiatric disorder. In cases where one has symptoms like those of Dostoevsky, the contrast is between an exceptional ability associated with a neurological or psychiatric disorder and normal neurological and mental functioning.

Even bipolar disorder involves considerable variability along its own spectrum. Bipolar II, III, and IV include episodes of depressed mood as well as hypomania and hyperthymia, which fall on the moderate to mild end of the bipolar spectrum (DSM-IV-TR, 200, 350 ff.). Unlike the extreme swings between mania and depression in more severe cyclothymic Bipolar I disorder, hypomania involves more constant and less labile mental states of exuberant mood and heightened concentration. Hyperthymia involves a state of elevated mood. Cases of hyperthymia and hypomania may constitute only a small percentage of the total number of diagnosed cases of bipolar disorder. But they suggest that symptoms characterized as part of a mental disorder may overlap with the normal range of cognitive and affective mental functions.

One might argue that, for creative individuals with bipolar disorder, lithium would not diminish one's intellectual or artistic creativity. On the contrary, it would enhance this ability by enabling one to be more organized, focused, and productive. Treatment may not always be in the best interests of people with bipolar disorder, however. In moderate forms of this condition, an affected individual may rationally decide that any benefits from pharmacological intervention would not be worth the cost of losing certain abilities.

This issue figured prominently in a case reviewed by the Supreme Court of Canada in 2003, *Starson v. Swayze* (Supreme Court of Canada, 32, 2003). Scott Starson was an engineer and computer programmer who also had a gift for physics. Diagnosed with bipolar disorder, he was found not criminally responsible for making death threats. He was detained in a psychiatric hospital, where he received various psychotropic medications for his mental condi-

tion. Starson argued that the drugs prevented him from thinking at his full capacity and that he had a right to refuse them. He claimed that the drugs made him worse off than he was before he was put on them. But a psychiatrist (Ian Swayze) responsible for his care argued that Starson lacked the mental capacity to know what was in his best interests and to understand the need for the prescribed medications. If true, this would have justified treating him against his will.

The Ontario Consent and Capacity Board confirmed Swayze's finding of incapacity. But the Board's decision was overturned by the Superior Court on judicial review. Swayze then appealed, yet the Supreme Court dismissed the appeal. On the basis of his testimony and behavior, the Court ruled that Starson was not incapacitated but was capable of knowing what was in his best interests. He was capable of making decisions about psychotropic treatment for his condition. Starson was deemed competent enough to know the difference between the consequences of having or forgoing treatment. For these reasons, his capacity to make decisions about his treatment and his right to refuse it were upheld.

All of these cases raise more general ethical questions. Do psychiatrists, neurologists and other medical professionals have an obligation only to restore normal brain and mental functions in patients with various forms of psychopathology? Or do they also have an obligation to restore the patient's normal self, the highly functional set of mental traits the person had before brain trauma or the onset of a neuropsychiatric disorder underlying the psychopathology? Strictly speaking, they would be obligated only to try to achieve the first goal, since only that goal is included among the principal goals of medicine. These include promotion of health, prevention and cure of disease, and relief of symptoms, pain and suffering (Jonsen, Siegler and Winslade, 2006, 15). In most cases, achieving the first goal will entail achieving the second. One will be a by-product of the other. But the neurological integrity of the brain may not always map so easily on to the psychological integrity of the self in every case. Symptoms of a psychiatric condition may not always justify attempts to treat them and restore the cognitive or affective traits of a patient's self to what many would consider a normal state.

Conclusion

The neurological and psychological traits that regulate our thought and behavior fall along a neuropsychiatric spectrum that extends from normal to pathological. Yet the same person may have some traits that tend toward the normal end of the spectrum and other traits that tend toward the pathological end. Indeed, many people may possess a complex constellation of positive and negative mental traits that makes it difficult to separate them. This phenomenon suggests that "normal" should be construed more broadly in assessing a person's neurological and psychological properties. Autism spectrum disorders, especially moderate forms such as Asperger's syndrome, are unique in that people with a general set of traits that are definitively or borderline pathological may also have traits involving exceptional cognitive ability. This ability may be present even in people with moderately severe to severe mental disabilities.

The cases I have discussed involve combined salutary and pathological mental traits, or both mental ability and disability. As the Starson case illustrates, this combination may result in conflict between the interests of patients and those of clinicians. Patients may refuse treatments that are medically indicated for diagnosed psychiatric or neurological disorders. With the autonomy of the competent client as the default position, the general implication is that clinicians should treat abnormal traits and behaviors only when they pose a credible risk of harm to the client or others. This does not suggest any radical alteration of psychiatry and neurology. On the contrary, it shows that this position is consistent with other areas of medical practice.

There is a more socially significant implication of neurodiversity. Blurring the boundaries between normal and abnormal traits along a segment of the neuropsychiatric spectrum may reduce the negative perception of people with mental illness. It would make it more difficult to marginalize them. This in turn might help to reduce the stigma attached to mental illness and minimize harm to those affected by both illness and social attitudes toward it.

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Autism, Neurodiversity and Equality Beyond the 'Normal'

A Special Theme Issue Article

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ABSTRACT

"Neurodiversity" is associated with the struggle for the civil rights of all those diagnosed with neurological or neurodevelopmental disorders. Two basic approaches in the struggle for what might be described as "neuro-equality" are taken up in the literature: (i) There is a challenge to current nosology that pathologizes all of the phenotypes associated with neurological or neurodevelopmental disorders (e.g. Autism Spectrum Disorder (ASD)); (ii) there is a challenge to those extant social institutions that either expressly or inadvertently model a social hierarchy where the interests or needs of individuals are ranked relative to what is regarded as properly functioning cognitive capacities. In this paper, we explore some of the reasons justifying (i) which make it an important tool for achieving greater neuro-equality, while still recognizing its limitations for achieving this goal. Particularly, we explore how an appeal to functionality and neurological diversity can support a re-seeing of at least certain forms of ASD.

Introduction:

Though it was first associated with those diagnosed as autistic – particularly those diagnosed with high functioning autism (HFA) – "neurodiversity" is now associated with the struggle for the civil rights of all those diagnosed with neurological or neurodevelopmental disorders (Ward & Meyer, 1999; Nadesan, 2005:203-210). The current scope of the term includes not only lower functioning autistics (LFAs) but also those diagnosed with such neurological or neurodevelopmental disorders as attention deficit-hyperactivity disorder, bipolar disorder, developmental

dyspraxia, dyslexia, epilepsy, and Tourette's syndrome. The neurodiverse, as they call themselves, contest the default pathologizing of differences in brain circuitry that are revealed in behavioral deviances from the standard norm (Harmon, 2004b). Autistic individuals, or the neurodiverse more generally, seek, among other things, better social support mechanisms, greater understanding from those around them or those who treat them, and a recognition that, though they are neurologically, cognitively and behaviorally different, they do not necessarily suffer from being neurodiverse nor do they need to be cured (Sinclair, 1993; Trivedi, 2005).

Two basic approaches in the struggle for "neuro-equality" (understood to require equal opportunities, treatment and regard for those who are neurologically different) are taken up in the literature: (i) there is a challenge to current nosology that pathologizes all of the phenotypes associated with neurological disorders (e.g. ASD) (Edelson, 1995; American Psychiatric Association, 1994); (ii) there is a challenge to those extant social institutions that either expressly or inadvertently model a social hierarchy where the interests or needs of individuals are ranked relative to what is regarded as properly functioning cognitive capacities. Though these approaches are sometimes used in tandem and thought to be compatible, they are not necessarily so. (i) challenges widely held but inaccurate views of what constitutes functional human cognition—inaccurate views that pathologize certain phenotypes that are properly regarded as non-maladaptive cognitive variations in *Homo sapiens* (*sapiens*). (ii), on the other hand, is firmly grounded in motivations of an egalitarian nature that seek to re-weight the interests of minorities so that they receive just consideration with the analogous interests of those currently privileged by extant social institutions. An appeal to expected variation associated with (i) still implies that certain human phenotypes – some of which are expressed by those who qualify as neurodiverse – are maladaptive and so properly pathologized. This feature of (i) places limitation on its usefulness to the neurodiversity movement. In this paper we explore some of the reasons justifying (i) which make it an important tool for achieving greater neuro-equality, while still

recognizing its limitations for achieving this goal. We hereby also suggest that these limitations point to a need to ground neuro-equality more adequately and in fact more forcefully by way of (ii), though admittedly we must leave any detailed discussion of this to another time. We will further narrow our scope by limiting discussion to those neurodiverse diagnosed with ASD. To that end, we will begin our discussion with a summary profile of autism.

On Autism

Autism is a spectrum neurodevelopmental disorder (or set of disorders) characterized by impairments in verbal ability and social reciprocity as well as obsessive or repetitious behaviors (Lord et al., 2000). In particular and among other symptoms, autistic children find it difficult to initiate interactions with others, engage in or maintain eye contact, employ imaginative play, distinguish linguistic play (e.g. sarcasm) from literal speech, and ascribe to others emotional states different from those they are currently experiencing (Frith & Happe, 2005:788). Many of those diagnosed with LFA are virtually indistinguishable from individuals with mental retardation (Burack & Volkmar, 1992:608; Lord et al., 2000:357). This contrasts with many of those diagnosed with HFA, particularly Asperger's Disorder, who can successfully attend pre- or post-secondary institutions and acquire employment including, sometimes, professional vocations (Harmon, 2004a; Grandin, 1996).

As a category, then, ASD covers a relatively wide range of phenotypes, typically described as behavioral or cognitive impairments or deficits, from the very mild to the quite severe. With the inclusion of Childhood Disintegrative Disorder or Pervasive Developmental Disorder–Not Otherwise Specified, it is doubtful that there is one simple cause of autism or that autism is even one underlying condition (Frith & Happe, 2005). Though this fact alone problematizes questions of treatment – including whether treatment is necessary at all – it is further complicated by voiced opposition from a number of disability advocates with autism (or their compatriots, friends and family). Rather than a disorder to be cured or eliminated from the human population, advocates contend that autism is, or perhaps certain forms of autism are, best regarded as different “ways of being” from what is commonly represented or understood as normal or neuro-typical. For these individuals autism is not something from which they suffer, but is rather who they are—an integral part of their personal identity (Harmon, 2004a; Sinclair, 1993; Trivedi, 2005) that is similar to the way that being deaf is integral to those persons identifying as members of Deaf culture (Lane, 1993:17-19,96).

On Resituating Autism

In discussions that seek to problematize the pathologization of autism, whether HFA or non-HFA, it is not unusual to find certain exceptional individuals show-cased as examples of the neurodiverse who contribute to society or who otherwise succeed as active, autonomous citizens in ‘the world of the normal’ (e.g., Temple Grandin, Lucy Blackman, Alan Turing) (Sacks, 1993; Rudy, 2006; Blackman, 2001). Though important for disabusing some

of the misconceptions surrounding ASD, showcasing the successful among the neurodiverse risks two untoward implications: (i) that the cognitive capacities of the neurodiverse (minus the exceptional cases) are still seen as typically lying outside of what is properly regarded as normal or functional for humans; (ii) that the cognitive capacities which are to properly qualify as functional, or at least non-pathological, must enable successful living in the world of those described as normal. (i) is problematic because of its inherently conservative view of what counts as functional or non-pathological. As we will argue shortly, cognitive diversity across taxa and within species supports a liberal understanding of those capacities that exemplify non-maladaptive variation (Scotch & Schriener, 1997:154-155). (ii) is problematic because it serves to obscure and conceal those features of common social institutions specially fitted to a narrowly construed view of normal human capacities (Nadesan, 2005:29-52). These features set up an environment that is not conducive to the full expression of capacities possessed by those described as neurologically impaired. It is unfair to use successful living in such an environment as a litmus test of who properly qualifies as functional.

There are also theoretical reasons for motivating a re-conceptualization of autism. One example consists of critically examining what properly counts as functional. In contrast to impairment, functionality (or being functional) implies a to-be-specified ability to succeed in the relevant behavioral domain. Success in independent living, for instance, is one way of understanding functionality as applied to the neurodiverse. Such an understanding of functionality is attractive in part because it coheres with a common view of autonomy (i.e. self-sufficiency), and autonomy is regarded as a necessary condition of human agency (Beauchamp & Childress, 2001:58). This sense of functionality suffers from at least two drawbacks, however. First, though individuals with HFA would qualify as functional so understood, this will not be the case (or only partially the case) for individuals diagnosed with LFA or those who fall somewhere along the spectrum between LFA and HFA. Second, those who do qualify as functional in this sense do so because of their capacity to integrate into the world of those described as normal (Willey, 1999), but, as we have already stated, this carries undesirable implications about ASD and also leaves unanswered the question of how those currently outside the norm should be granted equal status or inclusion.

Another, less biased, sense of functionality arises out of the notion of human flourishing—where “flourishing” is understood in the loosely biological sense of an animal faring well (broadly construed to include an animal's psychological state over time). This nicely connects flourishing with biological (qua psychological) functionality, though in a way that does not require fitness conferring capacities. This is an important feature of such a sense of functionality as it allows many of us currently described as normal to qualify as functional even though we possess traits that are not strictly-speaking fitness conferring (e.g., poor eyesight, poor sense of smell, slightly overweight, possessing a slight physical build and so on). Though the meaning of “human flourishing” needs

¹ We will understand “impairment” as “[a]ny loss or abnormality of psychological, physiological, or anatomical structure or function.” (Cohon, 2004:qtd on 656).

clarification, it can be indexed to such factors as contentment, self-worth, confidence and personal achievement (Fredrickson & Losada, 2005; Keyes, 2002). Under such a sense of functionality, an individual with ASD need not have HFA to qualify as functional. An argument in favor of adopting this sense of functionality can appeal to current moves to de-pathologize various physical or psychological impairments – which seem to appeal to the sense of functionality just outlined – and a principle of equal treatment (i.e., that like cases be treated alike) (Snyder & Mitchell, 2006).

A common defense of re-conceptualizing autism found in the literature contends that cognitive diversity, and the correlated neurological diversity, is the naturally occurring state of affairs for animals such as humans (i.e. cognitive diversity is normal) (Natural Variation - Autism Blog, 2007). Neuro-typicals, it is argued, hold too conservative a view of the extent of this diversity (Armstrong, 2005). The contention that cognitive and neurological diversity are the norm in the natural world gains partial support from the observed diversity of cognitive capacities as we move across taxa (consider the diversity associated with the class Mammalia). This is not enough, however. If this diversity is to problematize an overly homogenous treatment of human cognition or neurology, it must be observed within human and nonhuman species. Among chimpanzees (*Pan troglodytes*) and bonobos (*Pan paniscus*), who are neuroanatomically similar to humans, this diversity can be observed. Free-living and captive chimpanzees exhibit a variety of skills in using tools to forage for food, engage with conspecifics, groom themselves, and so on (McGrew, 2004). Bonobos in captivity can be observed using tools, something rarely seen in members of free-living populations (Fruth et al., 1999:67-68). Both captive chimpanzees and bonobos have been able to communicate with humans using lexigrams or sign language, skills absent among free-living populations (Fouts & Fouts, 1999; Savage-Rumbaugh et al., 1998). The variety of skilled behavior expressed by these great apes suggests differences in the neurological structures subverting the relevant cognitive processes. This, then, further supports the contention that neurological diversity is the norm in the natural world.

This defense of the normalcy of cognitive, and so neurological, diversity must respond to worries about over-inclusiveness—i.e., by regarding as normal the neurological structures that underlie the behavior of autistic individuals we run the risk of including maladaptive cognitive and neurological traits. A partial response can note that what qualifies as maladaptive, or adaptive, is context sensitive. What is fitness conferring in one environment may not be in another (e.g., peppered moths in industrial England). Consider cross-fostered chimpanzees—those raised by humans rather than conspecifics. Chimpanzees raised in captivity, but particularly those cross-fostered, have a limited skill set for dealing with the natural world. For example, releasing cross-fostered chimpanzees into the wild is not a responsible choice, their chance of survival and successful reproduction is low (Yeager & Silver, 1999:167-168). Despite this lack of certain fitness-conferring behavioral traits, however, cross-fostered chimpanzees enjoy a fit within their captive setting (i.e., they appear to flourish) (Fouts & Mills, 1997). Importantly for our discussion, it is not obvious that because captive chimpanzees lack certain fitness conferring traits they are properly described as cognitively or neurologically abnormal or dysfunctional.

In moving to the human population, we should acknowledge that we already tolerate, if not accept a variety of cognitive differences—again, attendant differences in the underlying neural structures. It is common knowledge that certain people excel in social skills, while others excel in analytic or physical skills. Even individuals who have noticeable problems socializing or who engage in obsessive behaviors – think here of social introverts or “computer geeks” – are typically described as “normal” (or normal enough to qualify as “normal”). Perhaps some of these individuals are properly regarded as autistic (i.e., as having Asperger’s Disorder) (Jackson, 2003), at least under the current diagnostic criteria (American Psychiatric Association, 1994), but this is not essential for our point.

From these observations we can conclude that, unless the relevant deficits qualify as dysfunctions (i.e., are maladaptive), the given cognitive and accompanying neurological differences—even when these are associated with deficits in skilled behavior—are not ordinarily grounds for pathologizing a certain way of engaging with the world. Accordingly, there is good reason to re-conceptualize HFA. Unfortunately, LFA, or forms of autism that fall along the spectrum between LFA and HFA, are not so ‘easily’ re-conceptualized. Here we are forced to own that the mere existence of neurological diversity within our species in and of itself does not require moral recognition. Though this feature of the argument from diversity indicates its limitations as a tool for the neurodiversity movement, two possibilities that might justify extending the conclusion beyond HFAs present themselves here: (i) even in what is described as LFA, there are individuals who excel in certain kinds of localized information processing; (ii) the epistemic standpoint of those generally diagnosed with ASD yields knowledge often missed by those who meet the current standards of normality (Happé, 1999).

(i) calls for a resituating of the received perspective on cognitive skill and deficit, seeing the generalized skills in information processing – which characterize those typically regarded as normal – as coming with their own deficits and seeing the localized skills in information processing – which can characterize those typically regarded as autistic – as skills (Mottron et al., 2006). This is not panglossian. We are not suggesting that those with LFA have an easy life nor are we denying that their carers sometimes shoulder a heavy burden of care. What is being problematized is a panglossian view of ‘the ordinary’ and an overly narrow perspective on expected neurological variety within the human species.

(ii) faces similar pitfalls to showcasing HFAs mentioned above. Defending the inclusion of the neurodiverse in the community of those currently described as normal by appealing to an epistemic success judged according to the standards of the neuro-typical risks othering the neurodiverse as abnormal (or sub-normal). If, however, we recognize accurate information states, arising from a to-be-specified sensitivity and responsiveness to changing environmental cues, as valuable to any cognizer, then the insights arising out of autistic experience can enjoy a high epistemic status not predicated on the epistemic standards of the neuro-typical. Temple Grandin’s ability to understand some nonhuman behavior and make breakthroughs in the treatment of slaughter animals (Grandin & Johnson, 2005) is just one example of many within the autistic community (Dekker, 1999) that point to autistic experience as an important epistemic standpoint. The general human

community of believers loses by failing to recognize the value of insights arising from autistic experience, but the value of an autistic standpoint need not depend on the general community recognizing it as such.

In sum, to pathologize the entire spectrum of autistic “disorders” sits uneasily with the observed variety of cognition (and the sub-vening neurological structures) seen across Hominini, including humanity. Even if many examples of LFA are properly pathologized, perhaps with reference to functionality as understood above, the current practice and accompanying general negative outlook on autism is unwarranted (Avdi, 2005).

Autism Resituated

Resituating, or re-conceptualizing, ASD has several implications for treatment. In addition to a required reassessment of how the neurodiverse are regarded in the health care system, we should re-conceptualize healthy living and independence (or independent living).

First, we should recognize that the neurodiverse are not necessarily in need of a cure, nor do they necessarily suffer from any condition, disease, disorder or illness (Dallos et al., 1997; Dallos & Hamilton-Brown, 2000). What’s more, to qualify as functional, the neurodiverse need not meet the standards of living accepted or assumed by those currently described as normal (Ward & Meyer, 1999). Consequently, the nomenclature used in descriptions of the neurodiverse – terms like “Autistic Disorder”, “Asperger’s Disorder” or “Autistic Spectrum Disorder” – should be revised.

Second, we should broaden our understanding of healthy or independent living. As stated earlier, individuals with HFA can enjoy healthy living (i.e., they can be functional). More importantly, much the same can be said for those who, though diagnosed with ASD, are not HFAs. What is crucial is whether they are content, have self-worth, confidence or enjoy personal achievements. This cannot be decided in the arm chair, or without re-seeing the putative patient and listening to her caregiver (Lynch, 1998).

What qualifies as independent living or autonomy should also be reassessed. Though many among the neurodiverse require special care and social support, this need not undermine the claim that they live independently or enjoy a degree of autonomy. Rather we need to understand independent living as inter-dependent living (Fisher, 2007) and autonomy as relational (Sherwin, 1998). This change in our understanding of independent living, or autonomy for that matter, is long overdue. As has been noted by others, our ability to successfully live together either in urban or rural environments requires us to inter-exist (Reindal, 1999; Stewart & Bhagwanjee, 1999). Arguably in societies like Canada, recognition of interdependence motivates the construction and maintenance of social institutions that protect the vulnerable and enhance the opportunities of the dispossessed. This sense of interdependence, and regard for others in one’s greater community, is not unrelated to the kind of support required to help the neurodiverse realize their full potentials.

Third, those diagnosed with ASD should be given more control over the types of treatment that they receive and when they receive it (Moloney & Paul, 1989). For example, it is not acceptable to expect that an autistic individual undergo behavioral therapy that teaches them to suppress various physical or verbal ticks. An important criterion for whether they undergo treatment is whether it is in their interests, understood as a recognizable interest from their perspective—i.e., what qualifies as being-in-their-interest enables their faring well.

Conclusion

In conclusion, naturally occurring cognitive diversity, and the accompanying neurological diversity, coupled with a robust understanding of functionality, make it impossible to maintain the current view that HFA is pathological. However, it is important not to fail to appreciate the limitations of appeals to cognitive or neurological diversity when seeking neuro-equality. Under such appeals LFA continues to qualify as pathological. This said, there is little doubt that both higher and lower functioning autistics can be functional in the sense we defended earlier, and this should impact how neuro-typicals perceive ASD. Such a re-seeing of ASD will advance the struggle to one day see equality beyond what is now regarded as normal.

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Neglecting the Social System: Clinical Neuroimaging and the Biological Reductionism of Addiction

A Special Theme Issue Article

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ABSTRACT

A main strength of neuroimaging and neuroscience is its reductionist focus on the brain. A limitation is that it runs the possibility of ignoring larger social factors. The brain image may not necessarily indicate the brain's neuroplastic 'rewiring' over time from genomic, epigenetic, environmental and social conditions. These factors are all necessary to understand the diverse nature of our brains, especially complex concerns such as addiction. For addiction to emerge it requires an intersection of genetic, environmental and social influences. It is foreseeable to ignore this multi-factorial interaction in the clinical setting when interpreting predictive brain imaging scans. This paper argues that relying too heavily on clinical neuroimaging in the treatment of patients who present a vulnerability to addiction can lead to cases of biological reductionism ignoring the influence social systems have on brain responses.

Introduction:

The rapid growth of molecular genetics appears to be reducing the brain to its most basic biological level. These developments are supported by the increasing availability of powerful biotechnologies such as neuroimaging. For the first time neural structures associated with various systems and mechanisms involved in diseases such as addiction can be 'seen'. As a result, the 'normal' brain is going through a conceptual transformation. Prior to these technological developments, nearly everything known about the operations, events and functions of the 'normal' brain required inferential observation and the acquisition of tacit knowledge (Young, 2006).

The brain is the most complex and perplexing organ in the human body. Empirical research on brain mechanisms examines

neurologically 'abnormal' brains – that is, those diagnosed with neurological or psychiatric injuries and diseases. The problem of interpreting, understanding, locating and conceptualizing the brain and its emergent mental properties is not a new phenomenon, yet it has continued to riddle scientists and philosophers for centuries. Psychologists, social workers, psychiatrists, nurses and other mental health support workers have similarly been attempting to achieve this task by applying therapeutic, psychotherapeutic and pharmacotherapeutic techniques and technologies in helping to alleviate suffering and improve the well-being of their clients.

Clinicians have been working with neurologically diverse clients for decades. This notion of neurodiversity is intriguing as it implies a standard or normalcy, or rather something that is divergent from the typical. Thus, the neurologically 'diverse' would be the identified 'other' – and in this case, the 'other' would be that of a psychiatric diagnosis. Historically this 'othering' has resulted in unfortunate stigma and discrimination against those with a mental illness or addiction. Yet the meaning of neurodiversity is incorrect as there are no two brains that are identical. While certain structures and corresponding mechanisms are common amongst most brains, the way each brain responds to various genetic and social pressures is unique due to the intrinsic brain mechanism known as neuroplasticity.

Neuroimaging research has encountered similar concerns. Studies in genomic neuroimaging tend to rely on averaged data of participants to determine the area of haemodynamic movement, and have had difficulty accounting for inter-subject variability (Canli, 2006). It is therefore more correct, then, to speak of diversity within our brains or the diverse nature of our brains. For that reason, the neuroimage of the typical brain is not so typical at all.

It is without question that fMRI, CT, SPECT, PET and other novel imaging approaches are and will be integrated into the clinical setting (Klitzman, 2006). Presently, brain scans can already help confirm a diagnosis where the behavioural etiology and standardized or suspected diagnostic criterion has been fulfilled (Glannon, 2006). Nonetheless, these advancements raise several concerns, specifically related to potential social and ethical implications of endophenotype interpretation and predictive neuroimaging.

While the strength of neuroimaging and neuroscience is its reductionist focus on the brain, its limitation is that it runs the possibility of ignoring larger social factors. The brain image may not necessarily indicate the brain's neuroplastic 'rewiring' over time from genomic, epigenetic, environmental and social conditions. These factors are all necessary to understand the diverse nature of human brains, especially complex concerns such as addiction which require an intersection of biological and social systems. It is foreseeable to ignore this key interaction in the clinical setting when interpreting predictive brain imaging scans.

This paper argues that relying too heavily on clinical neuroimaging in the treatment of patients who present a vulnerability to addiction can lead to cases of biological reductionism ignoring the influence social systems has on brain responses. What may present as a 'neurotypical' brain may only become 'atypical' given certain environmental and social conditions. Brain plasticity does not occur within a biological vacuum.

To examine these implications I will begin by providing a brief background to endophenotypes. Second, I discuss social and ethical issues concerning the clinical interpretation of predictive neuroimaging (endophenotypes) in addiction. Finally, I examine addiction neuroscience's position on addiction as a compulsive behaviour in relation to biological and social systems.

Endophenotypes

Irving Gottesman and James Shields (1972, 1973) introduced endophenotypes in the early 1970s with regard to schizophrenia. The original intention of endophenotypes was to quantify biological, cognitive, or behavioral markers identified prior to the onset of schizophrenia (Young, 2006). Presently, endophenotypes apply to the entire spectrum of brain disorders and are commonly associated with evidence derived from neuroanatomical, neuropsychological, neurophysiological, endocrinological, cognitive and biochemical research located along genotype-clinical phenotype pathways (Gottesman & Gould, 2003). Such research aims to detect mechanisms as opposed to markers. While a wide range of technologies exist in empirical research, presently neuroimaging provides the most precise depiction of brain structures and processes (Young, 2006).

Despite the incredible potential of endophenotypes, they are not the "only key needed to unlock the underlying biological mechanisms" (Glannon, 2003, p.280). More importantly, endophenotypes are restricted within the boundaries of the cultural, social and anthropological systems and norms from which they were interpreted (Illes & Racine, 2005). Though functional neuroimaging can associate a clinical phenotype to brain structures and regions (the endophenotype), the technology gives no inherent significance to the question of why the 'highlighted' parts are related (Young, 2006). In view of that, the endophenotype is correlative, rather than causative.

Addiction, Predictors, and the Clinical Setting

Addiction, like other phenomena, emerges from the interacting levels of biological, chemical, physical, technological and social systems (Bunge, 1979, 2003, 2006). Substance use, misuse and dependence occur along a continuum, with addiction resting at its distal end.

In what follows, the term client is used to refer to any individual using health care services, and clinician refers to the broad spectrum of service providers, ranging anywhere from addiction counselors to psychiatrists to outreach workers.

Human beings have a varied response to the behavioral and physiological effects of drugs, because the effects of the substances depend on intricate psychological, environmental and pharmacological interactions (Crombag & Robinson, 2004). Various markers, identifiers and candidate genes have been identified which indicate an individual's risk of developing a substance use disorder. For example, an increased EEG beta power in males is a likely predictor of purported vulnerability to alcoholism (Rangaswamy, Porjesz, Chorlian, Wang, Jones, Kuperman, et al, 2006) and a reduced P300 amplitude suggests both a vulnerability to alcoholism (Carlson, Iacono, & McGue, 2002), and an increased risk for developing a substance use disorder (Carlson, McLarnon, Iacono, 2007). A more recent biological focus has been on other vulnerability markers such as the D2 dopamine receptor allele (Young, Lawford, Nutting, & Noble, 2004).

Individuals of lower socioeconomic status (SES), marginalized, or disadvantaged, suffer disproportionately from addiction, and these factors are equally as important for research and consideration. For instance, lower SES has frequently been implicated in predicting substance use among youth (Frisher, Crome, Macleod, Bloor, & Hickman, 2007). Furthermore, a study by Noble, McCandliss, and Farah (2007) looked at the relationship between low SES and brain development in children. The authors found disparities in neurocognitive profiles in children of middle and low socioeconomic status, suggesting a new brain-based lens in viewing wider problems associated with poverty.

These discussions lend themselves to questions of, given environmental situations, how neurotypical any one brain really is. This has far-reaching implications on the way clinicians and individuals interpret addiction-related endophenotypes, and how to approach it clinically. For instance, both clinicians and clients may find it problematic to interpret an endophenotype that suggests a genetic predisposition or vulnerability for a condition such as alcoholism. One possibility is that clients may interpret such a brain scan result as a death sentence or an "unaltered fate" (Klitzman, 2006). This will be an important time for the clinician to engage with the client, as knowing one has a certain condition impacts individuals in various ways, as in adopting a "sick role" (Parsons, 1951). An alternate scenario would see an identified vulnerability offer beneficial insight regarding problematic symptoms and socially undesirable behaviours, such as persistent excessive drinking (Klitzman, 2006). Therefore, the interpretation can go two ways: either the client perceives herself responsible to herself and others for her drinking and acts accordingly, or the client

absolves herself of responsibility, as she is not culpable for something genetically pre-determined. What is further troubling is that the client may believe their brain to be abnormal, despite the fact that in some situations a mere change in environment may instigate a cessation of use – indicating an effect of neuroplasticity – as exemplified in the well-known example of Vietnam War Veterans and opioid use.

Addiction Neuroscience, Environmental Risk, and Neuroethics

Craving is widely considered as the cardinal feature of addiction. This has implications clinically, as interpreting brain images of craving in the absence of the social or environmental contexts ignores a huge component of the craving mechanism. Addiction neuroscience's position with regard to drug craving or a person with an addiction's 'compulsive' behaviour is that it is an aspect of a larger brain disease. The debate persists in the literature regarding this issue, focusing specifically on drug craving and consumption with respect to voluntary control (Hyman, 2007).

Drug craving has been studied extensively in neuroimaging research implicating both biological (Everitt, 1997; Kilts et al, 2001; Lubman, Yücel, Pantelis, 2004; Volkow et al, 2005; Wexler, Gottschalk, & Fulbright, 2001) and environmental factors (Lee, Lim, Wiederhold, & Graham, 2005; Pickens et al, 1991). Yet interpreting a drug craving brain scan as foundationally biological is troubling. First, cravings are largely cue-elicited and triggered by environmental stimuli (Childress et al, 1999; Grant, London, & Newlin, 1996; Loewenstein, 2000). Second, continued exposure to environmental triggers instigates a perpetual cycle of cravings. Therefore, not only is it more likely that cravings lead to increased drug consumption, but also that they precipitate an engagement in a series of behaviours that facilitate this process (Levy, 2007). Thus, a complete removal or an infrequent encounter of environmental-related triggers will do a great deal to decrease or heavily control use patterns.

Reducing addiction exclusively to biological levels could also encourage ethically problematic uses of powerful new biotechnologies as preventative measures. An example of such a technology is the cocaine vaccine (Martell, Mitchell, Poling, Gonsai, & Kosten, 2005). Coercive vaccination programs against the euphoric properties of substances may be necessary for individuals whom neuroimaging defines to be genetically and/or socially at risk, such as aboriginal or First Nation's people. But, these approaches – promoted by the seductive appeal of biological reductionism – will likely further marginalize these groups, restrict access to health care and other resources, help gain public justification for the unethical use of biotechnologies and act as a replacement to more sensible social, economic and drug policies from which all of society would stand to benefit (Carter & Hall, 2007).

If clinicians choose to implement addiction treatments – whether pharmacologic or psychotherapeutic – on a predictive brain scan without giving any acknowledgement to the intersecting biological and social systems, not only could iatrogenesis or biooping (Hacking, 1999) occur, but unnecessary harm could be inflicted on the client. The harm in this situation extends to the false creation

of a substance use disorder that might never have emerged, and the labeling of a brain as abnormal. The ethical implications here are profound. Even if the clinician recognizes the system intersections and their relation to addiction, the possible implications of putting into practice these approaches, or even standard addiction techniques such as motivational interviewing (Miller & Rollnick, 2002), should still be evaluated against the potential risks of withholding information from clients who are at an increased risk of substance use disorder (Glannon, 2006).

Of course, the science isn't perfect as the predictive accuracy of a pre-symptomatic substance use disorder is satisfactory at best. While the correlation may be strong between endophenotypes and future substance abuse disorder, this does not necessarily indicate a causal relationship. Having reduced P300 waves, experiencing symptoms of depression, or being male and having a familial history of alcohol use, will not directly lead to alcoholism. The likelihood that the event will happen is increased, true, but again, this is not the entire story. Therefore, at the clinical level, the increasing value placed on biological levels in individuals at an increased risk of developing an addiction has significant implications neuroethically.

Conclusions

As the technologies of neuroimaging continue to improve, it is becoming easier to not only understand the general design of the brain, but also the localization of the processes that contribute to our mental activities. These developments give new insight into the development and selection of treatments, based on a shared understanding of biological and environmental factors, by tailoring them specifically to meet the needs of the individual client. Advancements in neuroimaging research in addictions have not only helped to enhance the knowledge base, but can also affect the lives of those who suffer from the perils of addiction.

Progression in addiction neuroscience may foster a naïve enthusiasm for an exclusively biological approach. The path of addiction and depiction of the addicted brain are not without social and environmental contributors. The interaction of social, environmental and biological systems account for the emergence of mental activity, such that its phenotypic expression varies depending on the neurologically diverse makeup of that individual.

What may have originated as a normal brain, given an adverse environment and intrinsic neuroplasticity, may not be so normal after all. Therefore, what we are inclined to call normal has to be seen in a different light. Addiction is a process that has evolved over time – an interaction taking place between neurological maturation and genetic endowment within one's environment.

Nonetheless, the technology is still young. As predictive neuroimaging rapidly becomes more precise, its applications have yet to be established (Glannon, 2006). Clinically acknowledging social and environmental risk factors in addition to biological ones has the potential to reduce potential iatrogenesis and harm. Discussing all relevant factors with clients can help prevent distress and reduce stigmatization of a possible addiction by educating those who may feel neurologically abnormal as a result. How a client

digests this information, and the way in which a clinician presents it, will considerably affect the therapeutic process and the nature of the therapeutic relationship (Glannon, 2006).

Ultimately, if incorporated clinically, predictive neuroimaging has the potential to identify endophenotypes, highlighting those brains which present an increased vulnerability to addiction. These findings could initiate pharmacological and psychosocial interventions to aid the client and their families in preventing or helping to control present drug misuse. Yet clinical interpretation of these scans in the absence of environmental factors could lead to oppressive and coercive practices, as well as exercises in discrimination and harm, especially among marginalized populations. Further philosophical and scientific inquiry in the area of the ethics of vulnerability should be explored.

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Locked in Syndrome, PVS and Ethics at the End of Life

A Neurodiversity Theme Article

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I had my accident on the rugby field on July 29, 2000 about 2.00 p.m. during a simple line-out, even before the ball was thrown in. It just felt like another simple case of concussion (everything went blurry), I staggered to the sideline, the coach asked me "what's wrong"? He said I told him I just felt sick and to put me back on the field in 10 minutes. Then I collapsed, eventually blacked out and then was rushed to hospital unconscious in an ambulance with them struggling drastically to keep me alive.

After three days of being in there, they thought I was alright and were going to send me home. Then it started happening. First I nearly collapsed again taking a shower (I became extremely dizzy and lost a lot of balance). For days the specialists didn't know what was wrong with me. My girlfriend at the time, who had rushed down from Wanaka when she had heard it had happened (she and her mother were absolutely awesome throughout my time living in hospitals, considering the situation) went mad at the specialists to do something.

After six days of going in and out of seizures, finally after what seemed like all the tests known to man, they said I had suffered several brain stem strokes then one massive major one, which altogether had left me diagnosed with the extremely rare and unknown condition only known to a few as "locked in syndrome".

Locked in Syndrome (LiS) – the Phenomenonⁱ

LiS (also known as *coma vigilante*) poses problems for clinicians who often do not understand that their patient is a silent and unresponsive witness to everything that is happening to themⁱⁱ. In fact it is usually relatives rather than medical staff who realise the patient's predicament (they tend to notice that the patient is registering what is going on). In Nick's case, his mother and his girlfriend pleaded with medical staff to see that he was aware of what was happening and when that realization finally dawned, the climate of care changed. A patient in LiS cannot interact with us because he has lost the ability to control his body (except, in most cases, the ability to move the eyes up and down in the orbit) but the subliminal cues that intuitively alert us to the presence of another person are all that is needed for the suspicion to form and then the diagnosis to be confirmed by imaging and bedside interaction.

LiS is caused in one of two ways:

- (1) by a lesion in the brainstem (usually vascular); or
- (2) by extensive demyelination denying the brain its peripheral connections.

Nick's LiS was caused by a vascular occlusion of the basilar artery due to a propagated blood clot from a vertebral artery dissection after the artery had been damaged in its course through the neck.

Diagnosing Locked in Syndrome

In Nick's case, the diagnosis of LiS was delayed as it often is and, in fact, publicizing his case has made us aware that many patients are only belatedly realized to be in this state. In some cases the diagnosis has not been made and they have died. That mistake can

be avoided but it is a condition where the clinicians must actively think about pathophysiology and functional anatomy so that they ask the critical questions:

- (a) Where is the lesion?; and
- (b) What is the lesion?

The former is, these days, revealed by imaging techniques (although careful clinical assessment can tell one where and how to look). The latter is revealed by what older neurologists called a “badness time curve” for spontaneous medical conditions. The curve may be that of cerebro-vascular event (sudden loss of function), infection (relatively acute decline), tumour (subacute decline), or degeneration (slower decline perhaps with remissions and relapses) and it allows one to interpret the changes seen in imaging.

But, in the case of LiS we must also listen to those who know the patient because, as Nick’s story shows, they may notice subtle indicators that hold the key to the diagnosis and may be missed by busy health care professionals. Once the diagnosis is made, the ethical and epistemological predicament is clear: how can we establish communication with this person who is somebody (a being-in-the-world-among-us) but who cannot convey it to the rest of us?

The means to communicate with the patient are limited and dependent upon a number of contingencies which commonly include the preservation of Eye movements of some kind due to the spared circuitry to some or all of the extra-ocular muscles (through cranial nerves III, IV, and VI). This has allowed Nick to establish communication using a transparent Perspex board and a trained therapist (prior to his regaining some of the movements of his upper limbs which allow him to use a joystick and computer).

A Contrast: LiS and Persistent Vegetative State (PVS)

Still with mind and memory at 100% (sometimes I wonder if it’s a good thing or not), external feeling 100%, internal feeling about 30%. I have feeling throughout entire body, although just after accident I had no feeling. Despite some lack of internal feeling, all senses are normal, if not enhanced (e.g., sight and hearing). I’m just left trapped inside this body.

At times it feels so surreal and still does sometimes to this day.

To cut things short, considering I could only just hear (I couldn’t even open my eyes or breath by myself), without them even knowing that I still could hear, the doctors and specialists in front of me said I would die to my mum.

Notice that Nick, in LiS recognizes that his cognition is “100%” whereas in PVS we have almost the opposite: the higher levels of the brain have been devastated, usually by a combination of

shearing stress injury to neurones and global cerebral anoxiaⁱⁱⁱ. These selectively damage the higher brain – the cortical system and its ramified connections so that there are no longer enough “megabytes” to do the work of conscious experience and cognition. Consciousness and cognition comprise mental activity on data gathered from the environment (in the philosophical literature - intentional functions^{iv}) and depend on the extensive processing capacity of the neocortex^v. Consciousness, we could say, arises from the coordinated and holistic functioning of widespread and dynamically inter-connected cerebral functions. Nick is, from the time he “comes to” interacts with his environment and gathers information from it in as many ways as his impairments allow despite the fact that only a few people realized it. He recognized objects and people, conceptualized experiences, and experienced a range of feelings. These states do not survive in PVS because there is insufficient (and insufficiently integrated) brain function to support them. The extensive neurological injury (a loss of the neural capacity required for the intelligent adaptation to the environment that forms the basis of human mental life) entails that a patient in PVS no longer has typical human experience (as is indicated by the severely attenuated EEG and Evoked Potential activity seen in PVS). The person in PVS is not *conscious (simpliciter)* because he or she cannot engage in the many acts of being *conscious* of things that Nick was capable of.

Locked in Syndrome and Being Somebody

Note that LiS is a state in which communication is lost but consciousness, thought and memory are intact so that “there is somebody in there” and that person is desperate to show that he or she is *somebody*, a being-in-the-world-with-others.

It’s too difficult and extremely frustrating for me, most people just don’t know how to communicate with me.

For about four months I couldn’t use a call bell. So if something was wrong or I was in pain or I needed something, there was absolutely no way of attracting anyone’s attention.

I talk by using a transparent perspex board (about the size of an A2 sheet of paper) with the letters of the alphabet spaced out on it (identically on both sides). The person holds it up between our eyes (standing about 800mm apart). I spell out each letter of my sentence using my eyes (similar to a typewriter), with the other person guessing each letter I’m staring at, until I’ve spelt out whole sentence. Extremely laborious! It’s also very difficult (almost impossible) to express yourself or be sarcastic.

To be somebody is not just to be a body but it is to be there in the sense of being-in-the-world-with-others (a way of capturing the content of Heidegger’s *Da-sein*)^{vi}. As *somebody*, one has a name

and an identity which is formed and reformed as one shapes oneself and is shaped in a cultural and interpersonal context by interacting with others who share that time and place (a place bounded only by possibilities of communication). This is an aspect of one's subjectivity as a human being – to be recognised, engaged with and taken seriously by those around one through entanglement in the world and the many conversations whereby one articulates and develops one's own abilities to respond to the world through whatever means and by using whatever is to hand in one's context or environment. Nick converses but what is fit equipment for him to use in communication is his Perspex board and that imposes significant limitations on who he can be to others in that he cannot be witty or sarcastic in the free-flowing way he would like to be because the rhythm of his equipment for entanglement does not allow that.

We tend to forget the way that rhythm and timing are part of personality and identity so that an individual for whom these are altered (as in muscular dystrophy or cerebral palsy) must find ways of being in conversation that allow them to “come through” to others and transcend their neurological impairments. For Nick the possibility of an easy two way flow in which his identity and agency can be manifest is “kludgy”, bogged down, and made cumbersome in ways that frustrate his ability to be who he is and to develop his being through interaction and a permissive or non-intrusive mode of embodiment. His body is his being-in-the-world but there is both a continuity and a mis-match with the Nick whom he became through his lived narrative before his brain insult.

I'm just a typical mind imprisoned in this body, I feel as though I'm encased in concrete that I'm constantly and painstakingly breaking through ever so slowly. Since the physical gains I've made over the years, I imagine it's become similar to trying to fight your way out of a 'Straightjacket'.

Notice that although we might be tempted to invoke Cartesian conceptualizations here, as suggested by “a typical mind imprisoned in this body” we are vividly shown how much the mind and spirit, in detail, is a matter of the lived body through which one takes up modes of being-in-the-world as a person with a distinct personality and style of relating to others. Nick's imprisonment is a matter of altered being not just the impairment of a separable add-on to who he is (in essence or in himself) even though the echo or trace of who he is does transcend his present subjective embodiment as a psychosomatic whole and always has done.

Ethics and Endings: Three Principles

I feel extremely sorry for anyone with this syndrome that is scared of taking risks, most things I do involve some form of risk - even something simple like eating.

As it is in everyone's life - change is optional. I can choose to stay bedridden (which I once was), wither away and eventually die.

Don't will for death, it will come to you. Just sometimes sooner than expected.

Nick takes risks and so for him there is a fundamental phenomenological difference in value between life and death. To what extent is this conscious and to what extent merely instinctive? The difference between consciousness and instinct and the valorization of conscious rational choice is, to some extent, a product of post-Cartesian existential thinking in which everything valued becomes a free choice made at the level of rational conscious valuation^{vii}. In fact we live as subjective bodies – our embodiment is the condition of subjectivity. That is not to say that living as a human being is merely a matter of instinct because our being is to be the kind of beings for whom being is a question that can be asked. We live resolutely in the face of mortality and therefore we confront nothingness^{viii}. Nick also reminds us that the possibility of ending it all for a person in LiS, is a matter of lived subjectivity and not a paternalistic judgment from the “high moral plane” of “normality”. The subject who lives LiS can show us the world from his or her moral plane so all our elevated ethical deliberation is so much inauthentic “flummery and nonsense” conducted in abstraction and condemned to irrelevance because it does not inhabit the situation of the subject and situation is a crucial property of subjectivity. We can ask some standard questions but presuming to answer them on behalf of an-other who is radically other is a bridge too far.

When the subject is no more than a trace left displayed in a living inscribed body and is not a lived subjectivity the questions that can be asked touch on the following.

- (i) *Benefit or prevention of harm*: Is this leading to an outcome which now or in the future the patient would consider worthwhile?
- (ii) *Dignity*: Is living like this consistent with respecting the dignity of the person who this body has been?
- (iii) *Consent or implicit consent*: If s/he could be asked would the patient want us to continue with the interventions maintaining life in this state?

In cases where the patient themselves has gone beyond the possibility of participating in clinical decisions, we can ask these things on their behalf. But, as Nick himself testifies, we may have to confess that it is impossible to know the end from the beginning and therefore difficult to answer these questions in an unconflicted way.

It is definitely a crazy mixed up world I'm just glad to still be alive most of the time anyway. I accepted the fact that the accident did happen, long ago. Shit does definitely happen, I just have to make the most of each day in my journey towards recovery.

Some people think I should live a relatively normal life. Really how do expect someone who can't speak or move limbs properly live a relatively normal life.

Most of the time (when living like this) frustration levels are pushed to the max. and eventually I explode. Sometimes I wish I had died in the ambulance on the way to hospital. It would've been a lot less frustrating for me anyway.

Our questions have an important application where the subject (or the capacity for subjectivity of a distinctly human type) has been destroyed as in PVS. In such a case the questions serve to reconnect us as decision-makers with the person at their epicentre.

We can ask about *Benefit or prevention of harm* by asking “What are the prospects here?” We can further that question through the concept of *substantial benefit* - an outcome which now or in the future the patient would regard as worthwhile^{ix}. To that we might add a question about the RUB - “What is the Risk of producing an outcome that this person would regard as Unacceptable Badness?” Is it certain, or as near certainty as we can ever be that what we now have is just such an outcome in the person concerned?

Those questions have a direct bearing on the issue of *Consent* - “If per *impossibile* s/he could be asked, would this patient give you consent to do what you are doing?” And we follow that up with the further question, “Why should this patient, solely because he or she is unable to communicate, be treated in a way that s/he would not approve of?”

We can finally turn to the issue of *Dignity* by asking “Is this ending the right kind of ending for this patient’s life?” This is, however, deeply problematic because we tend to have a much too stuffy and conventional view of dignity whereby the pretentious and posturing stances that are taken by public figures become our model rather than the truly admirable human dignity required to persist in the face of hardship and degradation.

To be really honest I would erratically and uncontrollably without warning literary ‘shit myself’!!! Believe me, when you’re thirty it’s TOTALLY DEGRADING! No place more so than the public gym, in front of people. It definitely changes my mood extremely quickly when it happens, as you could imagine.

The specialists even wanted to operate and give me a colostomy bag.....stuff that!

Nick says that he does not want death to come, even to spare what we might think of as his dignity (even though he acutely feels its loss) but there are conditions where one could tellingly ask “Would this patient want to be remembered as the kind of person whose life ended this way?” or, in some cases, “Is what is happening consistent with the ethos of this family?” One might find that the most authentic answer one could give to these questions, in some cases, is to honour the person by stopping whatever intervention we are using to prolong the remnant of human life that remains of the subjective being who was once a being-in-the-world-with-us in a distinctively human way and took some pride in being the somebody they once were. In making this judgment we key in to a distinctly narrative framework for ethical questioning.

We should not, however, presume to answer them for a person when that person themselves is a being-in-the-midst-of-us who can answer them him or herself (like Nick). In that case our ethical responsibility is to reassure that person that we recognize her/him for who s/he is and want to find ways to add richness to his/

her being amongst us.

A Human Life and the End of the Story?

A narrative question about the end of a human life is: “Has this person reached the end of his or her human story?” There are cases in which we feel, intuitively that that is so, a thought that aligns well with the idea of a lived subjectivity as the core of a human life story. We could list among those conditions (where the subjective story has ended) PVS from whatever cause in that the person concerned is unconscious, with severe diffuse neocortical damage. PVS has laid waste the information processing systems of a human being so that it is the loss of subjectivity and intentionality and therefore the loss of the consciousness which can interrogate the world and find meaning in it. The diurnal variation in EEG characteristics that some patients show do not indicate (even in the “waking” phase) any consistent responsiveness to events around them and there is usually a distressing absence of consistent reactions to relatives or acquaintances. The patient needs complete nursing care, medical nutrition and hydration, and has no prospect of recovery (that fact should be established by suitably expert clinicians after a thorough review of the etiology and pathological diagnosis. The best we can do in such a case, and in the light of the consent related questions above, is to respect the person by ensuring that his or her life does not end in a way they would hate it to. The appropriate end does, however, vary from culture to culture and even from family to family (which may raise questions of justice in a publicly funded health system)^x.

In contrast to PVS (and closely related conditions), a patient with Locked in Syndrome can be reconnected with the world as Nick clearly and emphatically shows. PVS patients (in sharp contrast with LiS) cannot reconnect to the world and, on most accounts (even those framed within ancient and deep religious traditions), a person no longer connected to this world should not be kept tied to a domain of mortal change and decay. Therefore it looks appropriate to acknowledge this fact and to allow (in the words of a Maori spiritual guide) “the spirit to go on its journey to the place where it now belongs”. A secular ethicist may think of this as a realm populated only by the memories and stories of the living but a more religiously inclined observer might have a quite different way of capturing the reality that follows bodily death and is marked by ritual and myth^{xi}. In either case, for a person whose connection with the world has run its course, we are justified in making a certain kind of end-of-life decision to respect that fact and the very fact that it is proper, on many accounts, to make that decision reflects the radical difference between such a case and LiS.

What, by contrast, are our ethical dues to the LiS patient?

The Duty of Care

At the end of any clinical journey we should be able to reflect on a duty of care properly discharged through the clinical team’s engagement with the patient as the one most vitally concerned

with what happens. To conduct oneself in the light of that truth and the partnership it grounds is to exhibit certain features in one's clinical management.

Attention to and *recognition* of the patient as the creator of and living being at the centre of the story of his or her own life. This attention and recognition can only happen through *conversation* in which one exhibits care for the person concerned. Nick needed that recognition and partnership as a being-in-the-world entrapped by his brain injury in ways that pose a constant challenge to his spirit and determination. Only through that engagement can he transcend the limits we constantly assign to his potential.

Sometime in 2001 I had to meet with my Neurologist again. He wasn't at all positive (telling me bluntly), 'whatever gains you have made to date, they're all the gains you'll ever make'.

They first Speech therapist told me because of the severity of my accident and the damage it caused, I would never be able to even eat again.

When things are done in the right way – which often is more by friends and those lower on the hierarchy of health care than (“exalted”) specialists – the clinical experience is not a matter of determining limits which curb the potential of the patient but rather they embed a “being-with” properly enacted by those who have seen the problem before and others who are prepared to accompany the patient on a difficult and sometimes cruel journey. Recognising and witnessing to what a person is going through is deeply ethical in a way that is far more basic than any assessment of consequences or outcomes as it acknowledges a person's place among us as a moral community. Far too often the person who has suffered a physical or mental impairment of some kind (which go together in neurological disease) suffers the double injury of also losing their place as a member of the moral community or the kingdom of ends through paternalism, infantilisation, and the loss of dignity and respect that those attitudes imply.

For those whose subjectivity has been utterly destroyed or who are facing their own imminent mortality, being-with a person in the basic attitude of I-thou is the mark of a life juncture properly negotiated^{xii}.

What I Have Learnt from Nick.

I have learnt a great deal from Nick. I have learnt how much effort it takes when the subject who values his own being-in-the-world-with-others fights, in Luria's words, “with the courage of the damned to recover the use of his shattered brain” and remake something of his life^{xiii}. I have learnt that every human being needs recognition for who he or she is and needs witnesses to their living who reflect the truth about that life (as it is lived). I have learnt that the human spirit is truly transcendent of the human body and its ills even though it is still a fragile thing and is touched in its being by the ills that flesh is heir to. I have learnt

that who one is as a human being is an embodied subjectivity whose embodiment is inseparable from one's subjectivity even though one can also transcend many of the limitations of that embodiment. In those for whom the story has ended (as it most definitely is not for Nick) I have learnt that the clinician cannot go far wrong who gets alongside the patient (or their family) and has an open-ended conversation about what is happening and what should, in his or her opinion, be done, in the light of the thought that the outcome should be one that the patient would consider fitting (or worthwhile).

Competing Interests: None

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Endnotes:

- i) The indented passages in this article are verbatim transcriptions from Nick Chisholm's memoirs as a Locked in Patient.
- ii) Smith E Delargy M Locked in Syndrome BMJ 2005; 330:406-9
- iii) Multi-society task force on PVS medical aspects of the persistent vegetative state *New Engl. J. Med* 1499 1503 (1994).
- iv) Gillett G McMillan J *Consciousness and Intentionality* Amsterdam: John Benjamins 2001.
- v) Gillett, G Wittgenstein's startling claim: consciousness and the persistent vegetative state In Elliot C, editor *Slow cures and bad philosophers* Durham: Duke University Press, 2001 70-88.
- vi) Heidegger, M 1958 *Being and Time* (Tr J Stambaugh) New York (NY): SUNY Press, 1996.
Martin Heidegger
- vii) I have discussed the difference between consciousness of the human type and that of other creatures in several places but the fullest discussion is in *Consciousness and intentionality* G.Gillett & J.McMillan (Amsterdam: John Benjamins, 2001).
- viii) This is the way in which Jean Paul Sartre at least has made this ontic fact about us – that we in ourselves can question our own being and realise its contingency – vivid and memorable {Sartre JP, (1943 [1958]) *Being and nothingness* (Tr. HE Barnes) London: Methuen.}
- ix) Campbell, A, Gillett G, and Jones, D *Medical Ethics* (4th Edition) Oxford: University Press, 2005.
- x) I have discussed end-of-life issues at length in *Bioethics in the Clinic*

(Baltimore: Johns Hopkins University Press, 2004)

- xi) The term myth is used to indicate a structure of meaning that can be applied to an event and clothe it with deep significance for human beings and their understanding of themselves, their history, and their place in the scheme of things. It does not necessarily indicate a false belief or fantasy.
- xii) Martin Buber, (1970) *I and thou* (Tr. W Kaufmann) Edinburgh: T & T Clark.
- xiii) Luria AR, (1972) *The man with a shattered world* London: Penguin.

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The Crucible of Anorexia Nervosa

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ABSTRACT

Anorexia nervosa (AN) is a very serious condition because of the suffering and loss of life that it causes. However, the wishes of the people directly involved can be strongly opposed. The person with severe AN may not want treatment, yet her family beseeches professionals to unilaterally intervene and clinical teams are divided over the defensibility of involuntary hospitalization and treatment. The metaphor of a crucible is used in this paper to help identify how much is at stake and how much is in conflict when someone has AN. Frank (2004) cautions against ethical analyses that rely mostly on substantive principles or rules and institutional conflict resolution procedures. This paper applies his heuristic concepts of “ethics-as-substance” and “ethics-as-process” to a prototypical AN case to illustrate how process activities can expand understanding of, and responsiveness to, those who are living with this dire condition or those who are obligated to help.

Introduction:

Much has been written clinically about the serious eating disorder, anorexia nervosa (hereafter AN), which has one of the highest death rates of all psychiatric illnesses (Giordano 2003; Zhu & Walsh 2002). It seems that therapists’ use of forced hospitalization and feeding to rescue someone with severe AN prompted lawyers and ethicists to enter the debate, as evidenced by Rebecca Dresser and Norman Fost’s 1984 articles. Laws are socially sanctioned, penalty-bearing rules and regulations for individual and group behaviour in a community setting. On the other hand, ethics, as defined by Arthur Frank, is “the institutionalization of responding to troubles” (2004, 355).

AN clearly qualifies as a very troubling state for both the person who “has it” and those connected to her or him. The emotional toll is real, as shown by these comments: for the person: “it can make you feel you are being punished when you are [involuntarily hospitalized]” and “they were treating me like I was about ten [years old], and I was a vegetable” (Tan et al 2003, 640); for the family: “So how does a mother feel? Failed, useless, bad, stupid,

guilty, guilty, guilty” (Whitney et al 2005, 446) and “I just feel so helpless about it, I don’t know what to do anymore, I don’t know what to say” (Tan 639). And clinical teams often react with anger, mistrust, dislike, and fear of these clients (Brotman et al 2006; Surgenor 2003; Hébert & Weingarten 1991).

Based on these experiences, the metaphor of a crucible is fitting for having chronic, treatment refractory AN and responding to people with AN. In manufacturing or chemistry, a crucible is a device in which powerful forces are used to create, change or destroy very resilient materials. It is a vessel to bring together and contain such dynamics and it must be able to endure them. But crucibles are not limited to technology. Arthur Miller’s 1953 play, “The Crucible,” dramatizes the Salem witch trials wherein communal forces of public confession and religious absolutism counter individual forces of fidelity and honesty. As Judge Hathorne duly warns a petitioner, “We burn a hot fire here; it melts down all concealment” (78). Because these forces arise within the relatively young Salem community —itself a kind of bounded, phenomenological vessel—the forces’ potency endangers the community’s own survival.

In the case of AN, several strong ethical “forces” are at play. I believe these forces qualify as “ethics-as-substance,” a heuristic concept formulated by Frank (2004). Ethics-as-substance involves theories, principles, rules, and procedures to help make ethically sound decisions. Familiar examples include the theory of utilitarianism and virtue theory, the principles of truth telling and fairness, rules against patient abandonment and exploitation and institutional procedures for ethics consultation. Yet if substantive concepts are relied on exclusively, Frank foresees serious problems because they “miss something and what is missing eventually limits the force of ethics” (355). Accordingly, he recommends adding “ethics-as-process” as part of addressing everyday as well as crisis situations in healthcare. Ethics-as-process involves attitudes and approaches for responding ethically to other people. Examples include the attitudes of being non-judgmental and accepting uncertainty and approaches guided by imagination and existentialism.

This paper uses Frank’s two concepts to critique the reasoning and arguments commonly used in ethics-related discussions about AN. And the crucible metaphor is used by focusing on those most directly involved and the kinds of justifications typically offered for their actions: the person with AN, the family, the clinical team, and the community-at-large. This analysis is valuable because it shows how augmenting various substantive concepts with process

considerations improve ethical understanding of and responsiveness to a person with chronic AN.

To help ground the discussion in reality, assume that the situation-at-hand is much like that commonly described in the clinical literature: the young woman (e.g., 21 years old) has lived with AN for four years, been in different in-patient and outpatient therapy programs and has never sustained the weight gained from such interventions. Today, her body mass index is below 16 (18.5 to 24.9 is considered normal; NIH 2007) and the thinness of her face, hands and neck is clearly visible to others. Since she believes she is okay, she turns down suggestions to resume individual or group, in-patient or outpatient psychotherapy. Her parents and teenage brother are very worried and very exhausted by the chronicity and repeated regressions of their daughter and sister's illness.

From the Client's Perspective

Many writers justify this client's preference for her current situation by appealing to such substantive concepts as the theory of liberalism (Lester 1997; Silber 1989; Fost 1984) and the concepts of autonomy (Guarda et al 2007; Beumont & Carney 2003; Tan et al 2003; Gans & Gunn 2003; Draper 2000) and independence (Griffin & Berry 2003; Goldner 1989; Dresser 1984). Liberalism holds that what matters ethically are individual rights and freedoms. So as a starting point, she has the right to refuse recommended treatment and decide, without others' interference, how she wants to live. Patient autonomy, the counterbalance to professional and familial paternalism, focuses on conscientious choices someone makes to pursue his goals and interests. The young woman can therefore be held responsible and accountable for her decision. And at 21 years of age, she is an independent adult and so it is her life to live as she wishes.

However, these three substantive concepts are worrisome for some theorists. For instance, provocative phrases such as "dying with their rights on" (Treffert 1973) and "rotting with their rights on" (Appelbaum & Gutheil 1979) remind us that while rights are very important "means," attention must also be paid to the kinds of "ends" a person can hope for.

With respect to patient autonomy, it is sometimes treated as one of Charles Taylor's (1989) "hypergoods." A hypergood is something considered so important that it serves as "the standpoint from which [other goods] must be weighed, judged, decided about" (63). Gaylin and Jennings wrote *The Perversion of Autonomy* (2003) to argue against autonomy trumping all other relevant values and silencing other viewpoints. Sue Sherwin (1998) chose a different tack: she rehabilitated traditional Kantian autonomy by developing the concept of relational autonomy, wherein ongoing consideration of others' welfare and interests is required, important and normal.

Various feminist theorists (Sherwin; Donchin 2000; Nelson & Carse 1996; Gilligan 1982) and writers in disability studies (Smith 2001; Silvers 1999) dispute the traditional view of people being characterized as independent decision makers. They point to the reality of human experience. From cradle to grave, no matter how advantaged, educated, physically or mentally able a person

is, he relies on a host of other people and a host of people rely on him. Furthermore he is neither alone nor totally self-sufficient. Instead, he is interdependent. As a substantive concept replacing independence, interdependence reflects the ontological fact that humans have multiple temporal, asymmetrical, reciprocal and evolving interrelationships. Therefore substantive concepts for the young woman to use in examining her own situation should be revised to include alternative "ends," relational autonomy and interdependence.

How might ethics-as-process help assess the young woman's situation from her vantage point? In two ways, I think. Frank states that, "...almost all clinical troubles arise as consequences of prior decisions" (2004 356). Accordingly, it is important to ask: how did she come to be here, now, like this? Her history of having AN and all that she has been through informs who she is today. Therefore taking the time to learn from her, letting her voice be heard, and understanding her lived experience constitutes ethics-as-process or "the ongoing work of being ethical" (ibid). Tan's (2006, 2003) studies of patient and parents' experiences are one such example.

The second way begins with Frank's (1997) extensive work on the meaningfulness and identity-forming consequences of living with a long-term illness or not fully recovering from an illness. Rather than just focusing on the physiological consequences of rejecting or accepting clinical treatment, the young woman could ask herself, "Who [do] I become as a result of making this decision?" (2004, 357). When she studies the decisions she has made and questions her reasons for earlier choices, she is engaged in an ethical process of self-reflection and growth.

In summary, many writers employ ethically substantive concepts to defend an AN person's refusal of clinical treatment and care. Unfortunately, these concepts may be thin (i.e., rights alone), imperialistic (i.e., autonomy), or even inaccurate (i.e., independence). Fortunately, rehabilitated versions or substitutes have been developed. More recently, too, writers offer ethics-as-process approaches to deepen our engagement and understanding of the young woman.

From the Family's Perspective

Family requests for involuntary hospitalization and/or treatment usually are justified by four ethical concepts. First, love and fidelity motivate the young woman's parents' deep concern and fear for her well-being and her future and their ongoing efforts to access effective therapy. Complimenting this is the instinctive and socially expected parental duty to protect one's child from danger. The fourth concept is substitute decision making. When an adult is found to lack capacity for a treatment or admission decision, those who know him best and care about his welfare are good candidates to be responsible for his healthcare decisions. If there is no serious conflict of interest between the young woman and her parents, most institutional procedures for substitute decision-making will consider her parents the most appropriate SDMs if she is clinically deemed to lack the requisite capacity.

Substantive concepts are about what matters ethically. For themselves and for their daughter, the parents value her life and returning to more common activities and goals. But their daughter values something quite different. When more than one person is involved, different opinions should be expected as to what matters and how much. If the hope is for an outcome that everyone can, at a minimum, accept and still remain connected, then ethics-as-process is required.

Three processes are relevant to this situation. First, discussion as an ethics-related process is much more than communications, which can be one-way. To underscore the depth of this process, a favoured ethics term is “dialogue” which is meant to include sincerity, openness, mutuality and respect. Dialogue fails if participants retain isolationist positions or they vow never to be connected again.

Second, the family’s own history is important: over the four years, how have her parents and brother dealt with their daughter and sister having AN? The family unit qualifies as a crucible because it involves powerful forces: creating children and helping to mould them into capable and caring adults as well as children themselves impacting the parents’ parenting. Irrespective of what actually causes the young woman’s AN, her family’s reactions to her behaviours and her appearance are potent factors in its evolution. Family therapists and developmental psychologists’ work treating people with AN reflects the importance of familial experience (Giordano 2003; Gans & Gunn 2003; Tan et al 2003; Goldner 1989; Dresser 1984).

Third, people often ask for a decision-making framework for ethics and various ones have been developed (Pacquiao 2002; Devettere 2000; Jonsen et al 1982). Frameworks, however, can ignore the uncertainty and ambivalence attending most treatment decisions for serious illnesses and injuries. Ethics-as-process holds that the most important outcome is not a final decision, but instead “people coming to feel that how they acted was as good as it could have been” (Frank 2004, 355-6). In a study of parents of anorexic adolescents, Honey and Halse (2006) found that parents use various tactics to face their role in the situation:

We don’t go looking for a reason [anymore]. But I guess I’ll spend the next few years thinking, well, what if we’d done that differently or what if we’d done that differently. I guess you still, you still do. And that’s just, that’s just being a parent, isn’t it? It’s not, um, it’s not going to help you, and I guess just in time it, time will heal it (623).

Because her parents must decide between forced interventions (which, to be successfully administered, may require a lot of restrictions, ongoing surveillance, strong persuasion, and even physical restraints) and their adult daughter’s life-threatening preferences, they are faced with the kind of choice “people should never have to make” (Frank 2004, 355).

Just as identity is relevant for the young woman, so too for her parents. By having a daughter with AN, her parents might wonder, “Who do I become if I tolerate my child looking so neglected?” She looks the same as people pictured in charities’ advertisements for humanitarian aid to very poor and distant countries. Or people pictured in journalists’ reports about brutalizing wars. Or the parents might ask, “Who do I become if my child dies of a revers-

ible illness?” As Vialettes et al note, “They fear of delegating their responsibilities as parents, without control, to a third party” (2006 308). Applying Frank’s point to this fear, the parents might worry, “Who do I become if I insist strangers institutionalize, restrain, and make my daughter do what she hates most?” And what of the teenage brother:

You know [my son] and I went to pictures a lot. We went out to tea a lot. We’d spend a lot of time just going for a drive that, yeah. Just to be away from the situation. And then we’d come home and [my husband] would go out. So he could have time to regroup (Homey & Halse 2006, 624)

Pleas by families that their loved one be forcibly treated are often defended using various substantive ethical concepts. These concepts may not reveal all that is at stake when someone has chronic, treatment refractory AN. Using process notions such as dialogue, familial history, and familial identity can increase our understanding of the situation-at-hand as well as of the kinds of help each member truly needs and from whom.

From the Clinical Team’s Perspective

Several writers support clinical teams involuntarily hospitalizing and treating a person with AN whose life is in danger (Guarda et al 2007; Tan et al 2003; Giordano 2000; Draper 2000; Goldner 1989; Fost 1984; Dresser 1984). They justify their support with two substantive concepts. First, healthcare professionals have an *a priori* duty to rescue someone at risk of death. Second, as per the tenets of informed consent, they would not be required to honour the young woman’s refusal if they conclude she lacks the requisite capacity to decide.

Previous activities reflective of ethics-as-process have tempered the enduring professional duty to rescue. Sustained clinical and ethical debates on end-of-life situations have produced a general consensus that some people may conclude that not living their life is more desirable than continued living of their life, and that for some people, the burdens experienced from clinical interventions may greatly exceed the benefits (Giordano 2005; Draper 2000; Hébert & Weingarten 1991). An outcome of these past and often highly public discussions (e.g., Sue Rodriguez and her legal fight for physician-assisted suicide¹), high quality palliative care—wherein death is not fought against—is considered an important healthcare service.

Clearly, informed consent is a valuable ethical concept for healthcare. Yet for the case of AN, its potency is diluted somewhat because of the significant clinical uncertainty surrounding the epidemiology of AN. There are many hypotheses as to its cause(s): a psychiatric illness or delusion (Guarda et al 2007, Gans & Gunn 2003; Kaplan & Garfinkel 1999; Fost 1984), a desire to protest society’s expectations of women (Gans & Gunn 2003; Kaplan & Garfinkel 1999; Dresser 1984), a need to regain power or control (Tan et al 2003; Gans & Gunn 2003; Surgneor 2003; Lester 1997), a wish to master something difficult (Griffin & Berry 2003; Kaplan & Garfinkel 1999; Lester 1997), or a reliance on distorted values (Andersen 2007; Tan 2006, Giordano 2005; Beumont & Carney 2003). Moreover research on AN is difficult to conduct because

of its high morbidity and mortality rates. Not surprisingly, then, no single treatment has proven reliably beneficial (Garfinkel 2002; Kaplan 2002; Zhu & Walsh 2002). In other words, the “troubles” are even greater for those involved here.

From my experience, substantive ethical concepts often become clear only after understanding what is known clinically. When much remains uncertain or not known about the condition and available treatments, ethics-as-process is useful for figuring out how to move forward. Viaettes et al (2007) suggest clinicians try “modest tenacity;” in other words, continued participation in the crucible of AN. Yet over and above coping with clinical uncertainty, clinicians can react strongly to the symptomatic behaviours of AN. Surgenor (2003) and Hébert and

Weingarten (1991) describe the anxiety, fear, and frustration felt. Kaplan and Garfinkel (1999) elaborate further about the range and depth of clinicians’ negative reactions; for instance, disgust when told about vomiting and laxative use, and helplessness when the person refuses “the seemingly simple task of feeding [her]self to prevent death” (668). With the passage of time, if a clinician answers the Frank-ian question “Who am I becoming by continuing to work with this client?” with “I am becoming someone else,” the clinician is likely being damaged. Accordingly, the healthcare institution should help him by providing added resources, such as physical and responsibility relief via team rotations, emotional relief via psychological counselling, and “integrity relief” via ethics consultation. Even when clinical uncertainty renders reliance on substantive concepts tenuous, the process of involving other people “operationalizes” ethics in the guise of solidarity, caring and fairness.

From the Community’s Perspective

In *The Crucible* (1981), the community of Salem participates in the trial of John Proctor, either explicitly or implicitly. Criteria that apply to all members are established for determining which behaviours reflect being a witch, which statements qualify as legitimate accusations, and which procedures constitute a fair trial. The legal sanctioning of these criteria reflects explicit communal involvement. Since it is possible that prosecuting one man or woman could produce witchcraft accusations against many others,

Deputy Governor Danforth: “And do you know that near to four hundred are in the jails from Marblehead to Lyon, and upon my signature?”

Francis Nurse [a citizen]: “I-”

Danforth: “And seventy-two condemned to hang by that signature?” (Miller 1981, 80)
the small community of Salem itself is implicitly at risk.

In the case of the young woman with AN who does not want treatment, her parents who want involuntary treatment, and a healthcare team willing to provide such treatment, the community’s involvement exists as per two substantive concepts. The first concept is *parens patriae*, a Latin term which means someone’s native country or homeland has parental responsibilities for that person. In other words, the “ruler” or “rulers” have obligations to protect those who cannot care for themselves. Relative to healthcare situations, this obligation exists in Canada and the United States as confirmed by civil trials and health legislation that permit

clinicians, with the assistance of the community’s “guardians” (i.e., the police), to involuntarily hold and/or treat people seen as a serious risk to themselves or others.

The second ethical concept comes from Cartesian dualism (Lester 1997). In the *Meditations* (1993), Descartes searches for irrefutable truth. One thing that he finds impossible to doubt is his ability to think, as per the historic phrase “Cogito ergo sum; I think therefore I am.” This epistemological conclusion prompts an ontological conclusion: human reason is separate and superior to human physicality. Privileging reason has continued to today and is in evidence in contemporary healthcare: when a patient disagrees with a clinician’s treatment recommendation, a common response by clinicians—and even ethics consultants—is to immediately wonder, “Does the patient have the capacity to decide?”

Many feminist writers reject favouring reason over other human attributes as well as dividing human nature into the physical and the mental. Embodiment, a substantive concept, is offered as a corrective to Descartes. Every person is an embodied self, which means that the self is inextricably linked with and influenced by the body. Moreover our bodies are not just instruments we use. Instead, if you had a markedly different body—perhaps you were 15 centimetres taller, had a very efficient cardio-respiratory system, or only one fully-formed hand—your identity and your life would likely be different, too. In political debates about and legislative initiatives for people living with a disability, the concept of embodiment is clearly involved. Embodiment is a useful concept for exploring the meaning of some women’s AN behaviours. For instance, Lintott (2003) and Lester (1997) suggest that an anorexic person may not want her self to be completely defined by her body and so she tries to control its demands. With this said, though, the influence of communal norms is inescapable: “Women cannot simply make thinness mean whatever they want it to mean” (Lester 487).

As an example of ethics-as-process, the Salem witch trials are meant to help protect the community from Satan and those in his employ. Yet the process is logically flawed (i.e., if someone is accused of engaging in devilish behaviour, has actually behaved in this way, and voluntarily confesses, he or she will not be punished. But if he is falsely accused and thus does not confess, he will be punished). In the case of AN, our community extols thin female bodies. Accordingly this value is used to fuel our consumer-based economy. Ethics-as-process would demand public debate to challenge the ubiquitous thin paradigm in our community. While some people have taken up this challenge (e.g., fashion houses not hiring too thin models, retailers offering “plus size” lines), I think it is very uncertain how much this will increase and be sustained in our highly competitive marketplace.

At first blush, the community is among the participants in the crucible of AN because of its *parens patriae* responsibilities and its emphasis on human reason. However, focusing just on reason is ethically problematic because it erroneously trivializes human bodies. Including the concept of embodiment in public and institutional deliberations should help increase our understanding and, as appropriate, support of people who have AN. And ethics-as-process is important for our community because open debate and dialogue are necessary if we are to relinquish unhealthy, fatal and singular ideals for female beauty.

Conclusion

It's possible the young woman will not live to celebrate her 23rd birthday. It's possible her parents will have to contact several treatment programs to find the long-term, involuntary hospitalization they believe their daughter needs. It's also possible her hospital care team will be deeply divided over the repeated use of restraints when she is artificially fed. The stakes are high for everyone involved with AN. In this paper, I have explained how published articles about severe, treatment resistant AN commonly use substantive ethical concepts to support a woman's refusal of treatment, families' insistence on mandatory care, and clinicians' strong reluctance to honour the patient's wishes. Furthermore, I have argued that some of these concepts warrant modification, namely autonomy with relational autonomy, independence with interdependence and human rationality with embodiment.

Frank's distinctions between ethics-as-substance and ethics-as-process have been used to demonstrate additional types of ethical engagement needed in situations of AN. Frank identifies four shortcomings with ethics-as-substance analysis: (1) it usually focuses on having a decision made, such as whether to accept the young woman's treatment refusal or whether to forcibly bring her to hospital. But decisions are only part of what is happening. Ethics-as-process focuses more on how people work through their troubles, (2) the focus on decision making can mean the focus is on the here and now. This can ignore the woman and family's lived experience of the past four years. Disregarding the past has two negative implications: epidemiological information is overlooked and their struggles and successes are disrespected. Ethics-as-process demands that events leading to today must be understood if effective and defensible decisions are to be made, (3) in healthcare, ethics-as-substance has tended to focus solely on the client and her illness or injury. Ethics-as-process broadens the focus to include other key participants and their inclusion means that there will be conflicting interests to address, and (4) even if our concern was supposed to be directed only at patients, the substantive concept of patient autonomy is now trumping other values patients might hold.

The metaphor of a crucible confirms that powerful forces are involved in AN. They include suffering in the presence of others, preventable death, familial-professional-communal duties to act, uncertainty of clinical knowledge, incommensurable values, and individual integrity. This paper has explained how ethics-as-process can deepen our engagement and understanding of these forces in hopes that no one is sacrificed as the situation moves inevitably towards some type of conclusion.

Endnote:

1. In 1993, the Supreme Court of Canada dismissed Ms. Rodriguez's claim that British Columbia's legal ban on physician-assisted suicide was discriminatory. Ms. Rodriguez suffered from amyotrophic lateral sclerosis (i.e., Lou Gehrig's Disease) and in 1994 she died, either by her own hand or with others' assistance.

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Part I: Psychiatrists and Social Justice - The Concept of Justice

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ABSTRACT

These two papers consider the concept of social justice and the ethical obligations psychiatrists may have in its regard. In this first paper, the concept of social justice is defined in terms of the successful function of the social contract. Basic conceptions of justice are then considered.

What is Social Justice?

Articulating justice, particularly in relation to psychiatry, is difficult. Attempts to define justice usually refer to principles of equity or moral rectitude. Some conceptualisations refer to the application of a particular law in an impartial manner. Other definitions of justice rely upon the process of receiving what is owed or deserved, either reward for merit or punishment for wrong doing. Conceptions of justice are contextual to a particular place or time – what was just in medieval France may not be just in the contemporary United States. Justice applied to the distribution of resources in a society (distributive justice) and justice in the context of rebuilding communities after politicised violence (a form of restorative justice) are the scope of this paper. In the light of the insoluble problems of language surrounding the notion of justice, this survey of psychiatry and social justice will yoke the definition of justice to that of the notion of the social contract.

In the most simple terms, the social contract tradition of ethics involves rational individuals choosing to abide by consensual agreements about how to behave towards each other. Ethical maxims are, therefore, a form of negotiated agreement between individuals within a society. This self-interested approach works on the basis that the actors within the covenant of the social contract all benefit from the agreement. The conditions of the contract are enforced by a sovereign, or what the English philosopher Hobbes (1651) called a “Leviathan” (Hobbes, 1651/(1985)), so that those who violate the social contract are punished or excluded. Hobbes had argued for the need for a social contract because he believed in the innate violent aggression of humans in a regressed ‘state of nature’. Other social contract advocates saw the need for such arrangements as a means of securing rights of private property, in

the case of Locke (Locke, 1960) , or Rousseau’s (Rousseau, 2005) notion of the need to return to some primitive state of halcyon bliss denied us by modern life. The modern conception of social contract theory is evidenced in the work of Gauthier (Gauthier, 1986), who emphasises the ‘self interest’ aspect of contractarian arrangements. Gauthier argues that individuals enter into social contract arrangements to safeguard their own interests, rather than the best interests of the community.

The core of social contract theory is, therefore, the rational agreement between participants of the process to not act in a manner which disadvantages others, and the submission of the participants to a sovereign power to enforce the contract. There are, however, circumstances where the social contract process fails:

- a. What of the mentally ill who may be incapable of rational agreement to the social contract process, yet need the protection of the sovereign?
- b. What of those members of society who are ‘second class citizens’ and do not benefit from the social contract, yet are expected to abide by it?
- c. What if the sovereign fails in its responsibilities?

These three scenarios will be the themes explored in the second paper of this series.

Psychiatry, Society and Justice

The first assumption in this paper is that psychiatrists, as physicians, are professionals, and are therefore beholden to the ethical parameters that all professionals abide by. A profession is, in simple terms, a group who possess specialised skills and knowledge applied for a collective good (ABIM Foundation, ACP-ASIM Foundation & EFIM, 2002; Pellegrino, 1999). The tenets of this beneficent conduct have been specified as patient welfare and autonomy as well as the just allocation of resources (ABIM Foundation, ACP-ASIM Foundation & EFIM, 2002). One of the key elements in this definition of professionalism is the ‘contract’ between the profession and society, in particular what is defined as a “collective good”.

This collective definition of professionalism is balanced with the Hippocratic tradition of the individual physician as non-maleficent healer. There is potential for significant tension between these two traditions of 'ethics' as it is possible that an expected action in the interests of a collective good may be deleterious to an individual patient. An additional complexity in this equilibrium is the involvement of third parties, a recent phenomena in the history of medicine brought about by market forces. Such a dilemma has been outlined specifically in the case of psychiatry, with a call to reflect upon the inherent tensions within the notion of medicine as the trade of applied technical skills (Dyer, 1988).

In any setting, the psychiatric profession is thoroughly integrated with the norms of the society in which it exists. Such norms influence both diagnostic and treatment approaches, and exert coercive pressure upon psychiatrists through the imposition of laws which govern many aspects of the way they practice their craft. As such there is a particularity to the ethics of psychiatry functioning in different socio-cultural settings. Such a complex network of relationships and obligations implores psychiatrists to consider the integration of their own personal sense of an ethical life and the virtues of a physician, the discourses of professional ethics of the psychiatric profession and the expectations of the social contract, clearly embodied in law.

This dilemma is not new to moral philosophy, and the ideas of the German philosopher Hegel provide a useful means of conceptualising the 'moral' individual and their relation to the 'moral' society. Hegel distinguished 'Moralität' - an individual liberal morality and 'Sittlichkeit' - a community based morality, linking individuals to their community (Hegel, 1952). In considering the *Sittlichkeit*, Hegel saw morality manifest in a community of legal relationships and moral standards, embodied in social institutions and laws. *Sittlichkeit* is thus a socially constructed ethical order. Hegel defined Morality as an internalisation of external, socially constructed laws.

In professional settings, Hegelian *Sittlichkeit* exists as small communities of what the bioethicist Engelhardt called 'moral friends', who shared a meaningful notion of the good (Engelhardt, 1996). Small aggregates of medical practitioners have been described as 'moral worlds' (Turner, 2002), although the influence of such communities is not always for good and this process has been touted as a possible mechanism for the conspicuous moral failures of German psychiatry in the 1930's and 1940's (Dudley & Gale, 2002).

It has been argued, therefore, that psychiatric ethics are a network of interactions between the individual morality of the psychiatrist, the immediate collegiate relationships of the psychiatrist, and the relationship between the psychiatric profession and the broader society (Robertson & Walter, 2007b). The corollary of this is that psychiatry exists within the auspices of a social contract in that, as a profession, it has a tacit contractual obligation to society, and through its dialectic relationship with common morality and the law, has its professional ethics constituted by the society and culture surrounding it. As such, psychiatrists are profoundly impacted by failures of the social contract.

As was described earlier in the paper, one of the particular problems with social contract approaches to social justice is the situa-

tion of a member of society who requires the benefits of the social contract, yet may be incapable of a rational choice to abide by it. This is a particular problem with the severely mentally ill, and those who are afflicted with mental retardation or dementia. In contrast to the so-called 'moral free-rider', who seeks to benefit from the social contract without abiding by its requirements, those who cannot necessarily commit to the social contract, by virtue of irrationality or impairment, present an ethical dilemma. Most civilised societies provide some form of decent minimum in terms of basic social goods, such as welfare and some access to health care, however, it is apparent that the mentally ill of most developed societies have failed to benefit from the alleged prosperity of the post-industrial globalised economy. Whether this failure to benefit relates to the incapacity of many mentally ill people, either individually or as a group, to advocate on behalf of themselves or more to the stigma associated with mental illness is unclear.

If the problem relates to stigma, this presents another problem with the social contract tradition, that of the 'second class citizen'. Second class citizens are, in essence, those members of society who are expected to fulfil the expectations of the social contract, without reasonable expectation of the benefits. Second class citizens may become so either through latent prejudices within a society (often on racial or gender grounds) or through government policy. Regardless of the type of failure of the social contract, the clear imperative faced by psychiatrists and their ethical responsibility to their patients, is one of advocacy. The advocacy role presents another ethical tension for the psychiatrists as moral agents – whether their role is as members of a profession, or as a private citizens. Advocating directly to government has been standard practice in most developed societies, particularly in regards to allocation of health care resources. Indeed, such undertakings are listed in many professional codes of conduct for psychiatrists. Advocacy in the public sphere has become more difficult, particularly when psychiatrists risk politicising their advocacy role by speaking out against government policy. Such a dilemma has confronted Australian psychiatrists in recent years, in the face of their Federal Government's policy of mandatory detention of refugee children (Silove, 2002; Steel & Silove, 2004). In the USA, the problem of advocacy has been most acute in the face of the implementation of market forces in healthcare, under the auspices of Managed Care. Managed Care has delivered a number of 'unethical' health systems in the USA, leading to calls for psychiatrists to resist the processes in such systems which disadvantage the mentally ill (Green & Bloch, 2001). There is evidence accumulating that managed mental health care may adversely affect clinical outcomes (Green, 1999) as decisions made on apparent utilitarian grounds of cost containment seem to have the value of reduced access to, rather than improvement of clinical services (Thompson, Burns, Goldman, et al, 1992). The dilemma faced by psychiatrists, and physicians in general, is to reconcile the needs of the patient with that of the society. Such considerations often bring the physician into conflict with the rest of society (Levinsky, 1984). The notion of a tension between psychiatrist's obligations to their patients, and to third parties is protean and has been considered in terms of the so-called 'dual role' dilemma in psychiatric ethics (Robertson & Walter, 2007a).

Distributive Justice

Just allocation of limited mental health care resources is, arguably, a global issue and forms part of the World Psychiatric Association's Declaration of Madrid (1996), which states "psychiatrists should be aware of and concerned with the equitable allocation of health resources" (WPA, 1996). Several recent articles in *The Lancet* have also implored psychiatrists to consider issues of just allocation of resources in a global setting as part of their ethical obligations (Dhanda & Narayah, 2007; Herrman & Swartz, 2007).

The late Harvard philosopher, John Rawls, crafted a conception of distributive justice over his career (Rawls, 1971; Rawls, 1993; Rawls, 2001). The elements of Rawls' contractarian approach to justice related to a hypothetical notion of having moral agents conceptualise an 'original position', which was pre-social and pre-historical. The participant in this social contract would be blinded as to who they were going to be in this future society through a 'veil of ignorance'. Based on these constraints, the moral agents would then define a just distribution of goods in this future 'well-ordered society'. Rawls believed that all would operate on the assumption that they would end up the least advantaged person in the society and through a process of "constrained maximisation" allocate resources accordingly. Such 'resources' were not merely wealth, but also freedom, mobility of labour and equal access to opportunity to achieve fulfillment in life. In stark contrast to Rawls' liberal egalitarianism was the free-market 'libertarian' ideas of Robert Nozick (Nozick, 1974), who averred that the only constraint the state should place on the free exchange of resources within a society should be ensuring of the legitimacy of the acquisition and subsequent exchanges of property. Libertarianism has become the dominant paradigm in post-industrial developed economies and many health systems have evolved based upon the principles of such free exchanges of goods and services between individuals.

Whilst Rawls' contractarian method was ingenious, there are problems with what he defined as 'social goods'. Rawls saw that all members of a 'well ordered society' had equal entitlement to access social goods to have the opportunity to live fulfilling lives. Rawls took the Kantian view that individual fulfilment is a product of autonomy, or rational self-governance. As such, social goods are instrumental in achieving this, and the just distribution of these social goods assists members of society to achieve this autonomous existence. As Nussbaum points out, such an approach falters when we consider the situation of those whose capacity for autonomy is impaired life-long. A person with disabling chronic schizophrenia may never be truly capable of autonomy and so their needs are poorly met in Rawls' philosophy. As such, Nussbaum builds on the so-called 'capabilities approach' to justice (Sen, 1993) to provide a more workable account of the primary social goods at the centre of Rawls' distributive justice (Nussbaum, 1999). Nussbaum's capabilities are necessary for the capacity for the ultimate end of a life with dignity, rather than Kantian autonomy. The capabilities extend from reasonable life expectancy, sensory and bodily integrity, through to capacity for affiliative behaviour, play and some control over one's environment. Nussbaum thus sees that the ends of just public policy with regards to people with psychiatric or intellectual disabilities is the guarantee of their basic dignity (Nussbaum, 2006).

Rawls' theories have been extended to the specific areas of health care by Norman Daniels (Daniels, 1995). Daniels defines 'healthcare' broadly, as varying from individual medical services, preventative interventions, public health initiatives, workplace safety and social resources for chronically ill and disabled. Daniels argues that the 'right' to healthcare carries the implicit assumption that access to healthcare is on a parity with other civil rights, which equates healthcare with other social goods. Daniels provides a closer consideration of what healthcare actually is by citing an "argument from function" defined as "the needs which interest us are necessary to achieve or maintain species-typical normal functioning (my italics)" (p. 26). To Daniels, such functioning refers to the individual's capacity to construct a plan for life or a conception of 'the good'.

The rationale of providing healthcare paid for by third parties, such as government is, therefore, to help restore normal function by decreasing the effect of disease or disability. This compensates for the 'natural lottery' in which liability for disease is considered an accident of birth, rather than the individual failings of the sufferer. A guarantee of access to healthcare does not have the goal to enhance well being or general capability, but merely correcting for the natural lottery.

Sabin and Daniels (1994) have applied these concepts specifically to mental health (Sabin & Daniels, 1994). They advance a 'normal function model' in the light of how mental illness may affect that function. They propose that the goal of mental health care is to obviate the disadvantage arising from mental illness, thus making everyone equal competitors for social resources. Their model of justice, achieved through mental health care, has three dimensions :

- a. A "normal function model" of mental health care seeking to create 'normal' competitors for social resources
- b. A "capability model" seeking to create equal competitors for resources.
- c. A "welfare model" addressing the fact that people suffer because of attitudes or behaviours they did not choose and cannot choose to overcome, which should justify access to mental health care.

The 'normal function' model allows a society to draw a plausible boundary around the scope for insurance coverage. They argue that the capability and the welfare models are the most morally substantive, but are the most problematic in implementation.

Conclusion

In this paper, the principles of social contract theory and Rawlsian distributive justice have been outlined. Rawls provides us with a form of social contract theory which ensures the least privileged in society are protected. As such, a Rawlsian based social contract system is a worthwhile approach to psychiatric ethics. Nussbaum's modification of Rawls, in particular her emphasis upon "dignity" as the ultimate good, enhances this approach to psychiatric ethics. It is clear that the individual moral agent cannot be decontextualised

from the socio-cultural environments in which he or she exists. Psychiatry, as a profession, is in a contractarian relationship with the society in which it exists. The mentally ill present a dilemma to social contract views of social justice both in their putative status as second class citizens, and their incapacity to participate as rational choosers in the social contract.

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Part II: Psychiatrists and Social Justice – When the Social Contract Fails

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ABSTRACT

This second paper explores psychiatrists' ethical obligations in the face of the failure of the social contract – inherent failures in distributive justice, the failure of the sovereign and the reconstitution of the social contract in post-conflict societies. Such situations present many sources of ethical tension between the professional ethical obligations of psychiatrists to their individual patients and to their society.

Distributive Justice and the Failure of the Social Contract

In the previous paper, I outlined the system of distributive justice outlined by Rawls (Rawls, 2001) and subsequent writers. I also noted that issues of justice play out on both global and national canvases. In this contractarian arrangement, 'rational choosers' partake in a process of negotiating the allocation of social goods in order to have equal opportunity of access to either a fulfilled life or a life with dignity. The dilemma posed by the needs of 'non-rational choosers', incapacitated by virtue of the natural lottery, represents a source of failure of this system of distributive justice. I also emphasised that Rawls' emphasis upon the protections of the least privileged in a society made such an approach a worthwhile basis of psychiatric ethics. This approach will form the 'ethical lens' through which this paper views the particular issues of justice.

It would seem intuitive that part of psychiatry's obligations to those who suffer mental illness is to provide a rational voice on their behalf in the ongoing negotiations of the allocation of resources within the social contract. This is enshrined in various codes of ethics of professional organisations representing the interests of psychiatrists. The goal of this advocacy is to ensure the mentally ill have access to healthcare resources to compensate for the vicissitudes of the 'natural lottery'. Whilst mental health differs from physical health, the experience of the Oregon Health Plan indicates that there appears to be public sympathy with the position that mental illness has parity with physical illness as a

cause of disability (Sabin & Daniels, 1997).

On the 'flip side' of this argument are the ethical responsibilities faced by psychiatrists in resource allocation. Whilst the procurement and protection of access to limited healthcare resources is one issue, the alternative is the need for some form of financial responsibility. Much of the cost of healthcare is decided at the individual clinical level and whilst exercising fiscal responsibility should not be with the goal of aiding the obscurity of Health Maintenance Organisations diverting health dollars from the clinical setting to corporate profits, the psychiatrist does arguably have ethical obligations to spend mental health dollars wisely (Singh, Hawthorne & Vos, 2001). One of the problems associated with this obligation is that of quantification. The international standard measures of utility in regard to healthcare is the Disability Adjusted Life Year (DALY) (Murray & Lopez, 1996) and the Quality Adjusted Life Year (QALY) (Williams, 1988), despite the fact that these are insensitive measures when applied to psychiatric disorders (Chisholm, Healy & Knapp, 1997).

The social contract routinely fails in considering the needs of non-rational choosers who, by virtue of the 'natural lottery' are incapable of fulfilling its requirements, yet are in need of the benefits of the social contract. This presents an ethical obligation to psychiatrists manifests in both advocacy on behalf of psychiatric patients and restraint on behalf of society's limited resources. The ethical dilemma remains in balancing the tension within these roles.

Psychiatrists' Role When the Sovereign Fails

The social contract may fail and lead to social injustice when there is a failure of the sovereign to maintain law and order. This breakdown of law and order may occur as a consequence of some calamity occurring in the state, such as natural disaster or foreign invasion, or when the sovereign perpetrates oppressive violence against its citizens. These circumstances have been seen in totalitarian regimes, where widespread persecution by the state occurs. A vivid example of this was the human rights violations seen in Argentina during the period of the military dictatorship which ended in 1982, documented in the CONADEP report (1984). In other circumstances, the

sovereign may fail to provide the benefits of the social contract to members of a society who may be part of a persecuted or neglected minority. These groups may be denied the benefits of the social contract as a result of institutionalised racism or on political grounds. Many 'decent' members of the international community, themselves signatories to international covenants of human rights, are capable of such social injustice.

In these circumstances, the ethical remit of psychiatrists in regards to social justice may extend beyond advocacy for those with established mental illness, to all those who are disadvantaged and at risk of developing mental illness. The mental health consequences of politicised violence or denial of the benefits of the social contract arguably represent an area of ethical responsibility for psychiatrists. Moreover, psychiatrists may have ethical responsibilities in the process of restorative justice, in which communities rebuild after such failures of the social contract.

Psychiatrists who live in totalitarian regimes have often been persecuted as a group, or for individual actions or beliefs. Individual psychiatrists were 'disappeared' in Argentina under the dictatorship simply for treating survivors of the regime's torture and imprisonment practices (Knudson, 1997). In other circumstances, such as in the former USSR, psychiatrists have been complicit in persecution of citizens of a totalitarian regime, often confecting politically based diagnoses as justifications for imprisonment (Bloch & Reddaway, 1983).

In modern Australia, psychiatrists face a particular ethical dilemma, which is an exemplar of the problem of the abuse of human rights in otherwise stable and liberal societies. The policy of recent Australian Federal governments has been to enact a draconian approach towards refugees, who arrive 'unlawfully' in Australian territory. Part of this process involves the mandatory detention of all 'unauthorised illegal entrants', including women and children, in privately operated "detention centres". Children detained in these settings have been exposed to suicide attempts and self-injurious behaviour by other refugees, compounding their experience of the trauma of the regimes they fled and the perilous voyages made to escape (Steel & Silove, 2001). Given the deleterious consequences of such treatment (Steel, Silove, Brooks, *et al*, 2006), it is clear that this represents an instance of the sovereign of a nation violating its obligations under the social contract. Whilst such propositions can be obscured by debates over nation-state's rights to sovereignty over territory and the status of unlawful entrants under the social contract, the situation faced by psychiatrists in Australia is, quite simply, the perpetration of the abuse of human rights by the state with whom they exist in a contractual professional relationship. Australian psychiatrists face the ethical dilemma of abiding with the reprehensible policy of their society, manifest in the actions of the popularly elected government, or risk politicising the profession by speaking out against harmful actions by a popularly elected government (Dudley, Jureidini, Mares, *et al*, 2004). Such decisions often invoke the political and moral views of individual psychiatrists, resulting in divisions within the profession.

Ethical Dilemmas Faced by Psychiatrists in the Process of Restorative Justice

When societies reform following politicised violence, there are inevitably processes of retribution, reconciliation and reparation. These usually occur within the context of an ongoing narrative within a society, taking the form of myths, stories, art, literature and institutions such as memorials or museums (Edkins, 2003). This is argued to be important in the psychiatric care of the survivors of trauma, whose journey to recovery from traumatic stress requires their experience to be contextualised, or 'historicised' (Lykes & Mersky, 2006). In recent times, post-conflict societies have opted for a process of formal narrative occurring under the auspices of so-called 'truth commissions'.

The paradigm truth and reconciliation commission was that held in South Africa following the end of Apartheid. The South African Truth and Reconciliation Commission ('TRC') was created by the 1995 *Promotion of National Unity and Reconciliation Act 34* (2003). It has been observed that both the individual and collective experiences of politicised trauma exist in a dialectic relationship, and that there are parallels between the processes of recovery occurring in individual psychotherapy and at a societal level, in the process of restorative justice (Brendal, 2006; Swartz & Drennan, 2000). This was one of the presumptions of the convenors of the TRC (Allan, 2000). This assumption placed the psychiatric profession in a similar dialectic between their obligations to individual patients and to their society amidst such processes of recovery. Like all of the ethical dilemmas discussed, there exists a tension as to how psychiatrists position themselves amidst such a process. In the case of South Africa, the conflicting obligations were to the collective good, served by their patients giving public testimony, and to the protection of the individual patient against the deleterious effects of the process (Allan, 2000).

Apart from this fundamental dilemma, the TRC presented other significant ethical problems for the psychiatrists and other mental health professionals involved. The compulsion for the survivors to forgive the perpetrators in the interest of national unity appeared to compromise their mental health (Swartz & Drennan, 2000). The underlying philosophy of the TRC was heavily influenced by the religious views of its convenors (Allan, 2000). The TRC convenors operated under the assumption that national 'healing' would translate into individual recovery for the survivors. This was proven, ultimately, incorrect (Kaminer, Stein, Mbanga, *et al*, 2001; Swartz & Drennan, 2000). The TRC convenors appeared to have seriously underestimated the mental health care resources that were required for the process. The political reality a decade after the TRC is that there has been no real improvement in the situation of the survivors of the human rights violations of Apartheid, who continue to struggle to receive adequate health care (Simpson, 1995).

Subsequent truth commissions have shown that such processes are not universally successful, nor do they translate into improved mental health for the survivors. In recent times, the Commission for Reception, Truth and Reconciliation in East Timor (CAVR) provided a different perspective to the TRC. The shame induced by public testimony among the East Timorese survivors proved deleterious to their mental health, again begging the question of

whether survivors suffer adversely when expected testify publicly about their traumatic experience. Apart from the clinical care and advocacy for adequate resources for survivors, the psychiatric profession has to balance the dilemma of protecting individual patients against harm, with the need to participate as both a profession and as citizens in a process of national healing. In a Lancet editorial, the observation was made that “perhaps the greatest gain for East Timor is that members of society have been free to engage in a spirited debate about the limitations of the CAVR without threat of political repression or of opposing voices resorting to open conflict” (Silove, Zwi & le Touze, 2006).

Conclusion

These two papers have argued that that “social justice” is best conceptualised as the successful operation of the social contract. When based upon Rawlsian ideas, this represents an approach to social justice in which the least privileged are protected by the contract. As a basis of psychiatric ethics, this approach places psychiatrist’s ethical obligations is to safeguarding the interests of the least privileged in a society, either those with established mental illness or those vulnerable to mental illness by virtue of social disadvantage. Psychiatric ethics appear to exist in a tension between the contractarian nature of professional ethics and the ethical stance of individual psychiatrists or small ‘ethical communities’ of psychiatrists. The social contract is problematic in regards to citizens suffering from mental illness, who do not benefit from the social contract either because of incapacity to be ‘rational choosers’ or defaulting into the status of second class citizens. The social contract also fails when the sovereign fails to discharge responsibilities, either in stable societies or when the social order collapses. I have argued that the ethical aspects of psychiatrists responsibilities occurring after failure of social contract relate to :

1. Advocacy on behalf of those who cannot be rational choosers;
2. Resisting attempts by the sovereign to disadvantage those with mental illness;
3. Provide care for, and awareness of, the plight of those who are disadvantaged by the failure of the social contract;
4. Balancing the individual and collective mental health needs of post-conflict societies

Within all of these is a tension between the psychiatrist’s obligation to their patients, and to the societies they serve. This tension appears to lie at the core of the ethical dilemmas presented to psychiatrists by the concept of social justice.

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Part I: Conceptualizing, Framing and Politicizing Aboriginal Ethics in Mental Health

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ABSTRACT

This article looks at how mental health issues are conceptualized from the lens of Aboriginal world views. It refers to the legacy of colonization and the resulting historical trauma as the root of mental health "illnesses." But it also raises questions on how definitions of "mental illnesses" are arrived at by one's world view or lens. What may be seen as a mental health problem from one world view can be seen as a positive, healing spiritual experience from another.

Introduction

In writing about Aboriginal cultural protocols and ethics within the area of mental health, three major questions come to mind:

- How do Aboriginal world views conceptualize mental "illness" and healing processes?
- What are the challenges in considering Aboriginal ethics in the area of mental health?
- Can Aboriginal and Western approaches to healing work ethically together?

Throughout this paper, the term Aboriginal peoples will be used to refer to the descendants of the original people of Turtle Island or the colonized name Canada. The term Aboriginal peoples is inclusive of those who are First Nations, Inuit and Metis regardless of status under the Indian Act. We make up about 4% of the Canadian population, have 11 major language groups with at least 58 dialects, include 596 bands, and live on 2,284 reserves or in urban and rural communities (Frideres, 1998). Needless to say, Aboriginal peoples are greatly diverse in terms of cultures, lifestyles, languages and opinions. Thus, using a generic term such as "Aboriginal" or "Indigenous" can be problematic as we are not a homogeneous group. However, Aboriginal peoples do

share basic world views and are also tied together by the legacy of colonization which, to some degree, creates a common political agenda and collective identity among diverse groups.

In this paper, I make references to Aboriginal world views, but I will not be addressing Aboriginal cultures. World views, the foundation or lens by which peoples look at the world and includes values and ethics, is fairly generalizable to all Aboriginal Nations. However, cultures are not. Cultures are the day to day practices of specific Nations in specific geographical territories. As mentioned, Aboriginal peoples are diverse in terms of languages, lifestyles and teachings. To assume that the cultural practices of the Inuit in the far north of this continent are similar to those of the Onieda in southern Ontario or the Haida in British Columbia is equivalent to assuming that the cultural practices of the original peoples of Mozambique are similar to those of Egypt or Nigeria.

Let me introduce myself: I am of Mi'kmaq and Irish descent, originally from northern New Brunswick. My clan is the fish (salmon) and my spirit name translates as something like The Woman Who Passes On The Teachings. I am made up of multiple identities – mother, partner, teacher, social worker, a woman living with two diagnosed "mental health illnesses."

Conceptualizing Mental Health Issues

In looking at the mental health issues of Indigenous peoples around the world, clear parallels stand out suggesting that there are common processes and experiences amongst them, despite diversity (Hunter, 1993; Kunitz, 1994; Spencer, 2000). By far the presenting mental health issues that most Aboriginal peoples bring to the attention of helping professionals are depression, anxiety, suicide attempts, and alcohol and drug misuse (Westermeyer, 2001). These issues tend to be viewed as a state experienced by a person rather than as a characteristic of the identity of that person. For example, in the Inuktitut language spoken by the Inuit, the word "isumaluttuq" means something like "too much thinking" which can lead to the mental health issues listed above (Brown, 2003). Thus, terms such as "alcoholic" or "schizophrenic" are not attached to people.

The many traumas that Aboriginal peoples have faced has created a spiral of effects that stem from unresolved guilt, disenfranchised grief and internalized self hatred which is the legacy of colonization. The guilt, grief and self hatred are all symptoms of what has come to be referred to as the “historic trauma response” or “soul wound” (Yellow Horse Brave Heart and DeBruyn, 1998, p. 61; Duran and Duran, 1995, p. 10) which is unique to Aboriginal peoples. Aboriginal peoples tend to access services when these responses or effects have grown out of their control.

Unresolved guilt occurs due to genocidal practices towards generations that have left present day Aboriginal peoples feeling that they do not deserve to be alive when so many of their relations were raped, tortured and killed. These atrocities that Aboriginal populations have been subjected to have not been properly mourned, as many of the traditions around death and dying have been taken from us through colonization, leaving many people without culturally appropriate ways to grieve and heal. In addition, the Western idea of the stoic Aboriginal person has also hampered the grieving process by creating an environment where the “loss cannot be openly acknowledged or publicly mourned” (Yellow Horse Brave Heart and DeBruyn, 1998, p. 66).

These traumas, faced by generations of Aboriginal peoples, are now part of our collective memory. These painful and destructive memories, passed from one generation to the next, perpetuates the cycle of unhealthy interactions and relationships towards family members, other community members and the self which is the struggle that needs to be addressed as a whole. The effects of disenfranchised grief, named as anger, guilt and helplessness, have created shame within Aboriginal peoples. This shame of ones’ culture and community has spurred internalized racism and hatred that must be worked through even before the guilt and grief.

As important as referring to trauma as a means of addressing the personal and collective harm endured by Aboriginal peoples may be, it raises complicated issues for both healing and the prevention of mental health challenges. The following quote provides an explanation of this complexity and my earlier statement on the parallels amongst the mental health of Indigenous peoples world wide:

The emphasis on narrating personal trauma in contemporary psychotherapy is problematic because many forms of violence against Aboriginal people are structural or implicit and so may remain hidden in individual accounts. It is

tempting to focus only on the stories that can be told about explicitly traumatic events and use these to explain persistent inequities, but these individual events are part of larger historical formations that have profound effects for both individuals and communities – effects that are harder to describe. These damaging events were not encoded as declarative knowledge but rather “inscribed” on the body or else built into ongoing social relations, roles, practices, and institutions. Social analysis to delineate these structural forms of violence and oppression is needed to aid efforts to resist them and to promote change (Kirmayer, Brass & Tait, 2000, 607).

Aboriginal World Views Frame Ethics

A review of the literature reveals that little has been published on the subject of Aboriginal ethics in the area of mental health. This may be, in part, because Aboriginal ethics are rooted in a context of oral history and storytelling which are framed within a process rather than as a specific code (Ellerby et. al, 2000). Ethical decisions, then, will be made within the context of a particular situation and will likely involve the individual, family and community members. This is because there is no separation between the individual, family and community, between the mind, body, emotions and spirit or between all of these and the cosmos.

In defining ethics generally from an Aboriginal world view, Brant-Castellano (2004) states:

Ethics, the rules of right behaviour, are intimately related to who you are, the deep values you subscribe to, and your understanding of your place in the spiritual order of reality. Ethics is integral to the way of life of a people. The fullest expression of a people’s ethics is presented in the lives of the most knowledgeable and honourable members of the community. Imposition of rules derived from other ways of life in other communities will inevitably cause problems, although common understandings and shared interests can be negotiated. (103).

It is crucial, then, that Aboriginal peoples, be in control of constructing their world views and identities which, in turn, frame their ethics because these shape our understanding of “mental illnesses” and our approaches to those who carry them.

Of particular importance within Aboriginal world views are the ethics of relatedness and reciprocity. Needing help, and being able to offer it, is seen as fluid. Today you may need my assistance and I give it to you because I can. Tomorrow or next month or next year, I may be in need of help and you will offer it to me because you can. Relatedness and reciprocity may also involve a level of self-disclosure on the part of service providers. Aboriginal peoples who access assistance tend to ask questions that go far beyond a helper’s education and qualifications. Rather, Aboriginal community members are much more likely to be interested in who the helper is. Such questions focus on where a helper is from, who his family is, if she has children, what his spirit name is, what her clan is, who he knows, what she believes in, what his life experiences have been, etc. For those helpers who practice from Aboriginal world views, it appears unethical to ask intrusive questions of a service user and expect her/him to tell us everything about themselves without revealing much of anything about ourselves. Hence, there can be a strong emphasis on developing and maintaining emotionally sincere relationships between service users and service providers. Health care ethics which emphasize professional distance between service users and service providers may conflict with the belief that relationships hold significant power within the healing process (Ellerby et. al., 2000).

Aboriginal world views, ethics and healing processes also include knowledges which construct methods of healing and forms of

medicine. In contemporary times, the word “traditional” is often attached to these as in “traditional healing” and “traditional medicines.” These English terms are uncomfortable for some Elders and healers who prefer to see helping practices and beliefs simply as “knowledges” and “medicines.” This preference lies in the fact that the term “traditional” came from European peoples who had the intention of separating their beliefs from those of Aboriginal peoples, thereby creating an “othering” of Aboriginal knowledges (Martin-Hill, 2003).

Nevertheless, Aboriginal organizations, Elders, healers and researchers have come to an agreement on an accepted definition and use of the term “traditional” (RCAP, 1996; Martin-Hill, 2003; NAHO, 2003). According to the Report of the Royal Commission on Aboriginal Peoples, volume 3 (1996), “when Aboriginal Peoples in Canada talk about traditional healing, they include a wide range of activities, from physical cures using herbal medicines and other remedies, to the promotion of psychological and spiritual well-being using ceremony, counseling and the accumulated wisdom of elders” (348). Martin-Hill (2003) further elaborates on this by adding that a definition of traditional medicine includes “everything from diet, lifestyle, identity, knowledge of language and culture and expressions of love and comfort (hugging and smiling), positive verbal reinforcement, herbal and ritual knowledge, and spiritual doctoring” (24). The National Aboriginal Health Organization (2003) emphasizes balance and respect as two key principles of traditional medicine. Maintaining balance includes methods such as “healing circles, sweat lodges...songs, dancing, feasts, and other ceremonies” while respect is necessary “for changes to take place in people’s health [whereby people] must have respect for themselves and their place in the world” (5).

Aboriginal world views inherently include an epistemology that has ethical and moral dimensions. For example, within every relationship, obligations and responsibilities are entered into with spirits. Hence, when someone comes into a relationship with specific knowledge, that person is not only honoured and transformed by it, but must also take responsibility for it (Newhouse, 2004). Such a relational perspective teaches one to have a social responsibility for living an ethical and moral life in the present, to honour the past through spiritual care of those who have passed on and to always keep the future in mind by taking care of the earth for the next seven generations to come (King, 1990). Living an ethical life is particularly important of Elders, healers and other service providers as they are known within the community they work in and their efficacy and moral behaviour are open to scrutiny. Being a helper involves issues of power which need to be open to critical examination by those accessing services and by all community members.

Everything is Political Including Ethics:

When it comes to healing, Aboriginal world views also focus on transformative actions and outcomes which is a process of decolonization. Within the healing journey is an understanding that before we move to action, there is mourning and dreaming (Laenui, 2000). Mourning for what has been taken from us is a holistic healing process which we must move through and leave

behind so that we do not remain stuck in and paralyzed by intense emotions. Dreaming or visioning is about exploring our own cultures, imagining what we want for the future, and considering how we will put our aspirations and hopes into reality for the well being of the collective.

When it comes to addressing historical trauma, Denham (2006) suggests that “historical unresolved grief” and the “historical trauma response” can be healed through the use of reframing the trauma or the wound into an act of resistance through the use of stories and narratives. This is a means to acknowledge the strength and cultural power that Aboriginal peoples, families and communities possess even though they may not be conscious of it. He suggests that by finding the connections to a lived experience and passing that knowledge on to the next generation Aboriginal peoples can heal, de-colonize and strengthen communities, families and individuals. This can be done in an Aboriginal person’s life as s/he can use her/his own personal story that might include sexual abuse and drug and alcohol misuse, to explain the effects of colonization upon her/himself.

Asserting our position to implement Aboriginal ethics in the work that we do as helpers means challenging the discourse and the conventional rules of how mental health services are provided to service users. It involves challenging accepted terms such as “cross-cultural” practice which implies that “other” cultures do not have their own valid epistemologies which results in Western subjectivity being imposed on Aboriginal peoples (Duran and Duran, 1995). When we understand who we are as Aboriginal peoples and practice what we know with confidence, we are better equipped to help others and, in so doing, we determine which Western ethics we can abide by and which ones we cannot. However, this is a difficult and draining stand to take alone. It is really only powerful and possible when the struggle becomes a collective one.

Thus, the politics of identity construction become integral in resisting and challenging domination within the professions of psychiatry, psychology and social work. Aboriginal peoples must have control over the construction of Aboriginality. The politicizing effects of this control within these professions can be emancipatory and anti-colonial because control helps us move away from victimization -- having practices done to us, rather than actively participating in the restoration of our health and well being. As Young (1990) notes, “assumptions of the universality of the perspective and experience of the privileged are dislodged when the oppressed themselves expose those assumptions by expressing positive images of their experience. By creating their own cultural images they shake up received stereotypes about them” (155).

Decolonization also involves the political processes of both recognition and reconciliation in order to redress the horrific impacts of colonization. These processes need to include a dialogue that confronts the histories of colonial encounters as they occurred all over the world. In Canada, 12 years ago, a reconciliation proclamation was developed by a Sacred Assembly of representatives who share a common spiritual foundation (Brown, 2003). This proclamation states that actions must be taken to overcome injustice through respecting treaties, fairly settling land rights reclamations, implementing self-government and creating economic development leading to self-sufficiency. Faith communities in particular took a strong position to further the process of healing by providing

forums and supports, advocating for justice, holding governments accountable for implementing just policies and educating about issues related to land rights, self-government, economic development and racism (Brown, 2003).

In keeping with the notions of recognition and reconciliation, the mental health of Aboriginal communities appears to be linked to local control and cultural continuity, which is seen as a psychological and spiritual connection to the past, present and future. Recent successes in negotiating land claims, renewing cultural practices and control of local government initiatives point towards improved mental health for community members. For example, a study by Chandler and Lalonde (1998) identifies a strong connection between levels of community control and suicide rates in British Columbia. These researchers found that of the 196 First Nations communities in B.C., those that have greater local control and cultural continuity also have substantially lower youth suicide rates. They, and other researchers, note the presence of six indicators within the area of First Nations' autonomy and lower suicide rates:

- Community control of fire and police services;
- Community control of health;
- Community control of education;
- Existence of local facilities for cultural activities;
- Self-government; and
- Involvement in land claims (Chandler & Lalonde, 1998; Kirmayer, Brass & Tait, 2000; Brown, 2003).

It is likely, then, that providing more health care and supporting traditional forms of healing are critical in improving mental health for Aboriginal peoples, these do not address the root causes of the issues. Rather, local control is necessary to respond to community needs and promote collective efficacy and pride that contribute to positive mental health and well being. Clearly, political work in reclaiming Aboriginal peoples' rights, justly settling land reclamations, and redistributing power and control via self-government will lead to healthy communities.

Conclusion

If we believe that every Canadian has been impacted by colonization, Aboriginal peoples because of all that was stolen from them and non-Aboriginal peoples because of the loss of opportunity for what could have been possible via a partnership between the two groups, then we also understand that every one of us must participate in the processes of de-colonization. The following article – Working Together in the Circle: Challenges and Possibilities Within Mental Health Ethics -- takes up the topic of Aboriginal and Western service providers working together with those who are facing the impacts of colonization which show themselves as mental health struggles.

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Key Words: *Aboriginal peoples and conceptualizations of mental health world views, ethics*

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Part II: Working Together in the Circle: Challenges and Possibilities within Mental Health Ethics

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ABSTRACT

This article explores how ethics are framed for both Aboriginal and non-Aboriginal helpers. It examines both the challenges and the possibilities of working in the area of mental health, particularly if one is looking at the world through only a Western lens. It finishes with a brief exploration of how the two groups of helpers – Aboriginal and Western – might be able to work together ethically.

Introduction

In considering how helpers with differing world views can work together within the area of mental health for Aboriginal peoples, three questions arise:

- What are the challenges in considering Aboriginal ethics in the area of mental health?
- What are the possibilities that sharing space with Aboriginal world views and ethics can bring to the area of mental health?
- Can Aboriginal and Western approaches to healing work ethically together?

As explained in the previous paper, the term Aboriginal peoples will again be used to refer to the descendants of the original people of Turtle Island or the colonized name Canada. The term Aboriginal peoples is inclusive of those who are First Nations, Inuit and Metis regardless of status under the Indian Act. We make up about 4% of the Canadian population; have 11 major language groups with at least 58 dialects; include 596 bands; and live on 2,284 reserves or in urban and rural communities (Frideres, 1998). Needless to say, Aboriginal peoples are greatly diverse in terms of cultures, lifestyles, languages and opinions. Thus, using a generic term such as “Aboriginal” or “Indigenous”

can be problematic as we are not a homogeneous group. However, Aboriginal peoples do share basic world views and are also tied together by the legacy of colonization which, to some degree, creates a common political agenda and collective identity among diverse groups.

As in the previous paper, I make references to Aboriginal world views rather than writing about Aboriginal cultures. World views, the foundation or lens by which peoples look at the world, and includes values and ethics, is fairly generalizable to all Aboriginal Nations. However, cultures are not. Cultures are the day to day practices of specific Nations in specific geographical territories. As mentioned, Aboriginal peoples are hugely diverse in terms of languages, lifestyles and teachings. To assume that the cultural practices of the Inuit in the far north of this continent are similar to those of the Onieda in southern Ontario or the Haida in British Columbia is equivalent to assuming that the cultural practices of the original peoples of Mozambique are similar to those of Egypt or Nigeria.

In case you have not read the previous paper, please let me introduce myself: I am of Mi'kmaq and Irish descent, originally from northern New Brunswick. My clan is the fish (salmon) and my spirit name translates as something like *The Woman Who Passes On The Teachings*. I am made up of multiple identities – mother, partner, teacher, social worker, a woman living with two diagnosed “mental health illnesses.”

Challenges

Mental health practitioners who are unfamiliar with Aboriginal peoples' world views, spirituality, etc. may misdiagnose certain behaviours as psychotic for two major reasons. One of these can be the incorrect identification of cultural beliefs as delusions. For example, spiritual abuse can be the cause of mental health challenges rather than psychopathology. By spiritual abuse, I mean the erosion, breaking down or prevention of a people practicing their own cultural and spiritual beliefs while, at the same time, forcing another belief system upon them. In Canada, as in elsewhere in the world, when it came to Indigenous populations, spiritual abuse was an organized state and church initiative which was implemented through the residential school system (Haig-

Brown, 1988; Johnston, 1988; Knockwood, 1992; Lomawaima, 1993; Armitage, 1995; Miller, 1996; Chrisjohn, Young & Maraun, 1997; Fournier & Crey, 1997). Spiritual abuse results in a sense of “I don’t know who I am” which can lead to, for example, depression, anxiety and substance misuse.

Another reason for the misdiagnosis of the mental health of Aboriginal peoples on the part of service providers could be a lack of understanding of spiritual experiences which may be sought as a means for resolving a crisis, setting a life journey or seeking direction for a major life goal which is often referred to as a vision quest. These can be mistaken for hallucinations and/or delusions occurring in visual or auditory realms which are then assigned meanings usually with the assistance of an Elder or other guide (AHT, 2000a; AHT, 2000b; AHT, 2005). Having these spiritual experiences is a positive thing and many Aboriginal peoples work hard at developing these abilities to, for instance, see spirits or hear their voices.

Misunderstandings, such as that described above, raises a discussion on the ideology of colonization as based on an entrenched stand that one way is the right way and everyone else in the world will be measured by this yard stick. Everyone else is expected to behave in this “right way”, but the unwritten rule is that, no matter what, they will never measure up. In addition to this, the ideology goes so deep that the descendants of the original colonizers are not even aware that they are biased and apply their own values to everyone else.

Along with this comes Eurocentric ideas of how to make sense or interpret Aboriginal peoples’ thoughts and behaviours which is another major issue when working with Aboriginal peoples who carry mental health challenges. This includes an assumption that something needs to be done about Aboriginal peoples’ thoughts and behaviours, that some sort of intervention needs to occur even though the people in question have responses that make complete sense to them within the framework of Aboriginal world views. However, if the response does not fit into the Eurocentric social construction of what a person’s behaviour should look like, then something has to be done about it.

What is particularly ironic about this approach is the fact that, according to the codes of ethics of the professions involved in helping, one of the values emphasized is that of non-judgment. However, it appears to me that much within these professions does the exact opposite. The histories of these professions with Aboriginal peoples have been dominated by judgments stemming from their particular world views (Duran and Duran, 1995). Aboriginal communities are the only ones who ought to be defining what the “problems” and solutions to mental health issues are for their populations.

A further issue that needs to be addressed is the idea of objectivity. I do not think objectivity, as defined in conventional usage, exists. We bring who we are and what we believe – our values – into everything we do, whether that be within a social work assessment of a family or a psychiatric evaluation of an individual. The decisions we make are neither neutral nor objective. Rather, they are based on our values and ethics and on how we express these through our actions. What is significant is whose values we are interpreting actions through or whose lens we are looking

through. The helping professions are not neutral or objective, nor are the people who work in these areas. They cannot be.

I would say that what is needed is respect, rather than holding on to the notion that objectivity exists. At its roots, the meaning of respect involves “looking twice” at something, which allows for an open mind. It means going beyond one’s initial reactions or assessment and looking at a situation again in a closer, deeper way, taking everything possible into account.

Another piece to the notion of working ethically with Aboriginal peoples comes out through the idea that we need rescuing. There are some in the helping professions that pity us, feel sorry for us. Despite the reality that we have survived all that has been inflicted upon us, they see us as unable and incapable. I would say this comes from arrogance or guilt. Arrogance in that the Eurocentric way is the right way, Aboriginal peoples need to be further assimilated into these ways because they can help us and because within these ways are the solutions to “our problems”. Guilt because of the impacts of colonization which some helping professionals have some knowledge of and, therefore, feel a need to alleviate this feeling in themselves through helping the victims.

Associated with the guilt of some helping professionals is the idea of a general “Canadian guilt.” By this, I am referring to the reality that atrocities in the world can be made public information, even to children in educational institutions, as long as they are not atrocities committed by Canadians. Canada continues to put much energy into presenting itself to the rest of the world as a peaceful, decent multicultural nation. To face up to a “Canadian holocaust” certainly contradicts this façade. I wonder, however, how we as a country will ever be able to move forward into a future that is inclusive of all peoples without acknowledging the wrongs of the past and committing to change. People cannot be allies nor can they do what is ethically right if they remain stuck in feeling guilty.

Can We Work Together in Ethical Ways?

Consider this: part of the role of medications, crisis intervention and hospitalization in a Western framework is to re-establish needed connections to reality, the here and now, etc. and to alleviate symptoms. The goal of, for example, sweat lodge ceremonies, the meals that follow them, and the use of herbal medicines is to activate a new relationship between body, mind and spirit. Both of these approaches may calm the person and ground him in human relationships so he can make an informed choice about his treatment or healing.

Consider this: a mental health issue is not seen as only lodged within a person, but also as reflecting problems in that person’s family, peer group and community. The body is one part of a triangle together with a person’s spirit and the world of relatives which need to work together in order for health and well being to be re-established. Thus, it is necessary for all relatives of a person with mental health challenges to be present, involved and working on a common desire for the person. Restoration

of a person's health, then, needs to include restoring relatedness within that person's family.

Consider this: ceremonies often help to strengthen one's sense of identity as an Aboriginal person and provide a sense of respect for one's community. Ceremonies can also provide guidance in terms of locating a Western practitioner who will help an Aboriginal person on her own terms. Often, family members of a person with mental health challenges often speak of how ceremonies help them realize how they can help their loved one.

Consider this: Western practitioners can also work with families through the modeling they do in responding to those who are struggling with mental health issues such as how to be calm with a person who is experiencing an anxiety attack or how to assist the person in coping with ongoing symptoms of anxiety. Such modeling can aid in increasing the skill and competence of the family while assisting them in building the confidence to know that they can help.

Consider this: although the recovery model within the area of mental health, advocated primarily by Deegan (1988, 1993, 1996) in the U.S. and Campbell (1998), Coleman (1999), May (2000) and Perkins (2001) in the U.K. is gaining attention in other countries such as Canada, New Zealand and Australia, it may not be a good fit for Aboriginal peoples. The recovery model is an individualistic process (Carpenter, 2002) that is monocultural (O'Hagan, 2004) and ignores the socioeconomic concerns that are the prime difficulties for those with mental health challenges (McLean, 2003; Reville, 2005). I agree with Masterson and Owen (2006) who argue that "the widespread acceptance of the recovery model is not something that people with mental health problems can achieve on their own. To a large extent its success very much depends on changing the way that the rest of society conceptualizes mental illness, and it is always easier for people with social power and status to resist unacceptable re-conceptualizations" (30). As long as recovery focuses on transforming the individual rather than the system, it cannot be a part of the de-colonization process. However, Western practitioners can join with Aboriginal peoples to address not only the specific vulnerabilities of those struggling with mental health challenges, but also the past and current sources of oppression – social, political and economic – which is where transformation is critical.

Conclusion:

I have a further challenge to those who hold the power in the helping professions. The topic of Aboriginal ethics in mental health holds a great deal of potential to make contributions to services for diverse sociocultural peoples and communities. Perhaps by incorporating ethics that emphasize pluralism and cultural context, Western practitioners can relate to the needs of the whole person. In Canada, should Western practitioners learn first how to respond appropriately to the ethics of Aboriginal peoples, they may have a basis upon which to be more responsive to the ethics of members of many diverse ethnocultural communities (Ellerby et al., 2000). What do you suppose is the ethical thing to do?

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Informed Consent in Child Psychiatry – A Theoretical Review

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ABSTRACT

In this theoretical review we examine the issue of informed consent in child psychiatry. We describe the development of the concept of informed consent in the history of medicine and review the limited research on its application in child psychiatry. We analyze special features of informed consent unique to our field, such as the capacity of the child to give consent, the status of the “mature minor”, the special situation of the child within the family, the place of informed consent in psychotherapy, and the ability of child psychiatrists to give full information prior to consent. We conclude that children, even under the legal age, should be part of the process of giving consent to treatment. On the other hand the complex process of obtaining consent should be aimed at achieving real involvement of patients and families and not merely adhering to formal requirements.

Introduction- The History of Informed Consent in Medicine

Some 3500 years ago, the Hebrews, made their exodus from Egypt. When God gave them the Torah, they said: “We will do and (then) we will understand”. This was probably one of the first instances of consent where no claim was made for information. Since then for many years, individuals and societies blindly followed prophets, Gurus, leaders and accepted everything they suggested, including death. They did this with no demand for any information. They followed their belief. The history of medicine reveals how physicians were similarly treated in ways that were usually reserved for gods.

The basic principles of Hippocratic medicine were beneficence and paternalism and they were dominant in the practice of medicine throughout the medieval time and late into the early

modern times (for review see Faden and Beauchamp, 1986). This meant that withholding information from patients was considered justified if it served the interest of the treatment. This practice is reflected in other times and cultures. For example, both physicians and religious leaders were called “wise” (H’akim) in the Arabic language. The use of Latin to communicate and describe diseases added to this linkage with religion and God. Physicians had the power to save from death and by doing so were competing with God. If by fear or by respect people did not ask them for any information but only for reassurance and support in their lives. It is not surprising that physicians used and abused this power.

Starting in the 19th century a progressive and steady move towards appreciating the telling of truth to patients as a value became apparent. Still deep into the 20th century there was a tendency of physicians to prefer a paternalistic approach towards patients over respect of their right for autonomy (Katz, 1984). This was even more so in the field of medical research. Until the middle of the 1950’s research in medicine was sparse, intuitive and heroic. Pioneering researchers took for granted their own justification and contribution for human kind and therefore felt no need to ask for consent. For practical reasons researchers used as subjects prisoners, the mentally retarded of all ages and orphans. After World War II, the world was outraged by the murders carried out in the name of science by Nazi physicians. In the Nuremberg Code, the judgment by the war crimes tribunal at Nuremberg, were laid down standards to which physicians must conform when carrying out experiments on human subjects. Among them was specific address to principals of informed consent: “Ethical practice requires the investigator to inform the participant of all features of the research.... Openness and honesty are essential characteristics of the relationship between investigator and research participant... Ethical research practice requires the investigator to respect the individual’s freedom to decline to participate...or discontinue...” (Nuremberg Code, 1948-1949). This was followed by other major international declarations such as the Helsinki Accord in 1964 and the UN Convention of the Rights of the Child in 1989.

Although initially addressing research, these basic principles of the Nuremberg Code are now accepted as the basic moral ethical and legal concepts of all aspects of medical practice: among

them, and first of, the voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent and should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit or duress, and with full information regarding the issue at hand.

Still, the implementation of these principles to daily clinical work is far from satisfying. Harth and Thong (1995) found that parents did not understand many of the details of the informed consent they gave for their children to participate in a clinical trial. Many times, doctors do not fully discuss risks and benefits of treatment and do not make sure that their patients understand them. When patients have access to more information they make different decisions regarding the proposed treatments (for review see Deyo and Patrick, 2005).

Mentally ill patients found their place among other sick persons only relatively recently, some 150 years ago. Considered as possessed persons, cursed by God, scary and threatening, they did not deserve any consideration as medical patients, let alone treatment, until the implementation of moral treatment to psychiatric patients by Pinel, at the end of the 18th century. The shift from paternalism to respect of autonomy in psychiatry was even slower than in other fields of medicine. Considered as unable to have access to any normal communication and understanding, the best doctors thought they could do for them, was to impose their care, and even force them to receive this caring treatment. The new awareness for patients' rights is reflected in more recently formulated laws for mentally ill persons in different countries, which limit considerably psychiatrists' power to make unilateral decisions for their patients.

Informed Consent in Child Psychiatry

The ethical dilemma of paternalism or beneficence vs. autonomy is much more pronounced in the treatment of children with psychiatric disorders. Children were always thought of as inseparable from and dependent upon their parents. Having a psychiatric disorder makes them much more so. Although lengthily detailed in various modern charters and documents, children's right for autonomy, according to their emerging capacities, is far from being fulfilled, even in developed countries. There are no studies on the implementation of recommendations and laws regarding informed consent in child psychiatry. In our experience clinical practices vary from real efforts to explain to the child in her own words about the procedure, treatment or research to be conducted, to merely "lip service".

Child psychiatrists and psychotherapists, less frequently discuss the sphere of medical ethics. Jurists, in collaboration with developmental psychologists, have made the most important contributions in this field. The study of consent depends in large measure upon the social contexts in which medicine is practiced, and on the laws in force in different countries. The stress placed on certain aspects of consent (age limits for example) clearly depends on the criteria governing the laws applicable in each country. For years the legal systems in many countries considered that children and adolescents were incapable of making impor-

tant decisions concerning their life including the management of their health. A discrepancy exists between the different rights granted to minors. Thus, in many countries the courts have been more explicit and liberal when determining the rights of minors in criminal or penal cases, granting them rights and capacities of which they were deprived in the field of health. However, in the last decades, rights have been regularly granted to minors in certain fields of health management such as contraception and abortion, and also access to psychological treatments (Schowalter, 1978, Guyer et al. 1982, Potter and Evans, 2004). Thus, the participation of the child in decisions which concern him /her should be encouraged and developed for ethical and for legal reasons.

The Ability of the Child to Give Consent

Studies of children's ability to consent are many times based on the work of Piaget and his successors, with the aim of establishing chronological norms of cognitive, and to a lesser degree emotional, development (Green and Stewart, 1987). The stress placed on chronological indications is all the more marked since the criterion of age has been one of the most commonly accepted in many countries. For centuries, age has played an important role as a necessary guide for fixing the important stages in a child's place within the community and in the modification of his/her role. But in regard to the needs and expectations of children and adolescents, different countries have used these chronological guides in very different ways. In terms of consent the relevant Piagetian key stages are the passage from pre-operational thought to concrete operations towards 7-8 years, and the development of formal thought between 11 and 13. Experimental studies carried out to determine the competence of minors regarding consent are very few. They are based on the principle that the child is capable of 'consenting' if s/he is able to grasp the nature, importance and possible consequences of the treatments or investigations suggested. The results of these studies bring to the fore the early capacities of children to take decisions concerning their treatment.

Weithorn and Campbell (1982), administered to 96 children and adolescents a measure developed to assess competency according to 4 legal standards. Their findings confirmed that access to formal thought was necessary for a subject to be able to consent. While minors of 14 years of age had a degree of competence identical to that of adults, children of 9 had lesser understanding of the difficulties of taking into account the various factors involved in the choice they are being asked to make. However, they were found to be capable of expressing, like adults, their preferences concerning treatments, and of participating actively in decisions. Susman et al. (1992) and Dorn et al. (1995) found that knowledge of children about their participation in a medical research protocol was related to emotional factors of anxiety and feeling of control more than to age and cognitive development. That is the reason Laor (1994) suggested that no distinction would be made by age but by evaluation of competency for all ages.

Scherer and Reppuci (1988) found that a minor in a situation of consent, faced with social and normative pressures, may respond

by making a show either of conformity or of compliance, but also of “reactance,” which is a form of anti-submission. In their study adolescents responded to parental influence. Parents’ pressure had the effect of weakening their decision about the choice of treatment that they prefer. They did not tend to oppose their parents systematically, because of the severity of parental reactions, or because the decision about their treatment lacked importance in their eyes. The gravity of these decisions regarding the treatment was a major factor that affected the adolescent’s response to parental influence: the more important the consequences and implications of the treatment, the less the adolescent submitted to parental influence. The modalities of their decisions were not different for psychiatric treatment.

More recently, Billick et al. (1998, 2001) demonstrated again that competence to give consent in pediatric patients was correlated with age and measures of intelligence. No correlation was found with psychopathology.

The results of such studies encourage clinicians to treat even their youngest patients as active partners in decisions concerning their health. For some, the respect of the child’s rights and autonomy prevails, for others it is a matter of encouraging compliance with the treatment. But to what extent do children and adolescents who are capable of discernment wish to exercise their rights? The answer to this question is undoubtedly linked to sociological as to individual factors. The position of the child and adolescent psychiatrist enables him/her to estimate and analyze the intrapsychic and interpersonal dynamics that underlie these situations. These issues have to be addressed by formal research.

Working with Parents and Families

Studies of the child’s consent must be considered in relation to the status of the child within the family. Recognition that the interests of parents and children are not always the same (this is obvious in cases of abuse or neglect) must lead to greater attention being paid to the child’s opinions. The contract which links therapist and parents is accompanied by the therapist’s moral contract with the child, whose interests and rights must be defended. As in any other medical disciplines where treatment is given to children, therapeutic measures in the field of mental health cannot be applied without the consent of the parents or legal guardians. The therapist must be sure that the parents are capable of meeting the requirements of free consent. The only situations in which treatments can be administered to a child without obtaining consent from the parents are rare urgent medical situations or crisis situations.

It is good clinical practice to be respectful and non-judgmental when approaching the parents of mentally ill children’s. But to what extent does the child psychiatrist fulfill his/her duty to inform the parents? Though in various countries, the scope of the duty to inform is more or less defined by legal texts, it seems to us that in our social context at least, a considerable degree of reserve is often maintained regarding certain aspects of the information involved. Many parents are not informed of the precise diagnosis of their child. Some therapists fear the negative effects such information may have on the parents’ image of their child,

particularly when grave diagnoses are structurally conceptualized (for example, childhood psychoses). Others stress the difficulty of giving information whose value sometimes seems of limited significance. Such reticence seeks to protect the patient or his entourage, but there is no doubt that it is not always justified, and may even be contrary to the expectations of most parents. Many times, this reticence is merely another manifestation of the frequently ill-founded fear that the announcement of a diagnosis has regrettable repercussions on the patient.

The dissatisfaction of our patients’ parents often arises from the limited nature of the information they are given about the modalities of treatment and the treatment’s results. The limitations imposed at present on research on the results of many forms of treatment pose ethical problems, and must incite us to prudence regarding the value of information given to parents about the benefits to be expected from certain treatments. This aspect of information plays a fundamental role in obtaining real consent. The information parents want is not always the information we can or want to give them. It is not always relevant in our eyes or they may be searching for specific information that supports their beliefs or their position. Their consent is never easily achieved but is the result of a consistent and positive discussion. Clinicians should also be careful not to take advantage of parents who are in such despair that they are ready to allow complete freedom with their children.

The obtaining of parents’ consent must be perceived in a broader context which includes an understanding of the particular dynamics of each family, of the kind of efforts invested in the patient, and of the repercussions of the child’s symptoms on the family economy. It is often the outcome of a process, which aims at creating a therapeutic alliance with the parents and the child. Where psychotherapeutic or institutional treatment is recommended, a long preparation is often necessary. During this phase, the clinician also has the opportunity of evaluating parents’ possible attitudes towards the freedom of decision they grant their child. For some parents, the considerable powers they allow their young child are the projection of their own childhood desires of omnipotence and, under the guise of liberalism, they translate a difficulty in recognizing the child’s need to be accompanied in his choices and decisions. Clearly, in this analysis of the capacity of consent within a family, the clinician asks himself/herself questions about his/her own system of values and about his/her counter-transference attitudes on this subject.

Working with families involves dealing with conflict of interest as well as their change over time. Refusal of treatment after a period of investigation is one of the most frequent modalities of a breakdown in the relationship. Out of respect for the family’s integrity and parents’ autonomy (as responsible for their dependent child), it is very rare that steps are taken to defend the interests of the child and her/his right to psychiatric treatment, unless other aspects of the family environment fully justify State intervention. This attitude is dictated by the fear of placing the child in a conflict of loyalty with his/her parents, a conflict that would have regrettable repercussions on the therapeutic process. Many psychotherapists are extremely reticent about undertaking treatments, which are opposed by one of the parents, even when that parent no longer has parental authority. Though the consent of both parents is always desirable, indeed indispensable, the

seeking of this consent in cases of conflict between the parents sometimes obscures the desire and expectations of the child concerning treatment, particularly if s/he is not yet capable of giving full consent. In our view, the child should not be deprived of her/his right to psychotherapeutic treatment providing that the treatment is not an expression of the parental conflict. Further, the framework of the treatment must allow for a clarification, or even an interpretation of the child's conflict in the face of the parents' disagreement.

Informed Consent in Psychotherapy

Psychoanalysis and psychoanalytically oriented psychotherapy are treatments. Whoever conducts such treatment has the lawful obligation to obtain an informed consent for it. The therapist has to explain the patient all advantages and disadvantages, indications, contra-indications and also all alternatives to this treatment. Such an implementation of the law makes any psychoanalysis impossible if accepted at all. There is no way to elaborate on any transference, positive or negative or to elaborate on unconscious motivations among other components of the therapeutic tools. Theoretically that makes every psychoanalyst and psychotherapist overruling the rights of the patients even if practically there is no other way of presenting the treatment to them.

Family therapies give rise to a particular problem because the risks and benefits differ from those of individual therapy. They can produce effects which one member of the family considers undesirable. Sometimes this therapeutic approach is refused, because not all family members wish to participate, or because some the family members feel under pressure. This can upset the balance that exists in the family. Most forms of family therapy (and other psychotherapies as well) employ certain types of manipulation, which limit a "true" informed consent, and the freedom of choice of treatment.

The Mature Minor

The U.S. courts and many State legislatures have evolved the concept of the "mature" or "emancipated" minor (Schowalter, 1978, Guyer et al., 1982), and the same process occurred in other countries such as the UK (Bridge, 1997). This means that certain minors are considered as adults and as such are capable of being informed and would understand the nature and consequences of the medical treatment or procedure in question and thus should be considered as having the capacity and right to give informed consent.

Despite the greater autonomy granted the child, a certain number of problems remain which limit the youngster's access to treatment. The possibility offered to minors capable of giving consent to benefit from psychotherapeutic treatments without their parents' knowledge, does not automatically lead to a greater use of treatment facilities. The lack of information concerning such rights often goes hand in hand with difficulties created by the financial aspects of the treatment contract. We can respect

the need for confidentiality of treatment even if parents remain responsible for the financial aspects of such a contract. Confidentiality is a condition of success of treatment and as such is in the parents' interest to be respected. Moreover, this confidentiality gives the child a sense of her/his autonomy and what positive human relations have to offer. Caring parents, who are not competing with their child or afraid by him/her, will profit from this change.

Informed Consent and Research in Child Psychiatry

Within the research framework, the child enjoys very special protections and another important right is granted to her/him, for in general, if s/he is over 7 years of age, her/his assent is officially necessary in addition to the written consent of his parents (Munir and Earls 1992). Children's motivations to participate in research are complex and complicated. Beyond their alleged understanding of the design of the research, children are faced by the advantages and disadvantages to be a research subject. If this research does not have any direct profit for the child (as a control for example) they can be satisfied to serve society in an altruist way. They might enjoy skipping school that day, or receiving some incentives for participating. Researchers and IRB members should judge whether these benefits do not interfere with the neutrality requested in obtaining informed consent

Limitation of Informed Consent

Silverman (1989) considers obtaining informed consent a myth. We share this opinion. If patients or their legal representatives do not understand, or incorrectly understand, or insufficiently understand the implications of clinical research, what can one expect of children or adolescents, especially if they are mentally ill?

The ill person's state of mind is the state of mind of a person threatened by death. As such s/he is totally dependent on the only person who claims to be able to save him/her: the doctor. The state of being ill is regressive by nature. Ill people seek refuge in another's arms, they seek a heart to believe in and feel secure. As such, patients are never absolutely free people and their choice can never be a free choice due to the threats related to their illness and their dependence on their doctors. Doctors apparently choose their profession for these similar reasons: being this person. The ability to exercise complete freedom of choice does not exist, not for healthy human beings and certainly not for the ill person. This occurs all the more so for mentally ill children.

It is impossible to give all relevant information concerning diagnosis, treatment or research. It is inconceivable to answer all questions asked by patients or research subjects. In our field of mental health it is accepted that we are not obliged to disclose rare side effects. For example neurological changes, hormonal changes and weight gain occur frequently as a consequence of antipsychotic medications. An honest disclosure of all side ef-

fects will lead to refusal or reconsideration of most medication. Recent studies on informed consent reveal that there exists a positive correlation between the amount of information and the amount of detail given to patients, and the rate of refusal or postponement of treatment (Deyo and Patrick, 2005).

Even in its politically correct formulation, there is a flavor of coercion, persuasion, if not manipulation in informed consent as stated by Faden and Beauchamp (1986). People are forced to sign forms that are more useful for the physician than for the patient and certainly the young mentally ill kid. This form is presented to patients when they are in despair and need for any medical help, when they can hardly ask their questions.

Summary

It has become clear that the Nuremberg ethical codes regarding informed consent are, at least in the way that they were worded, just a 'sleight of hand', an illusion, utopia. Better moderate, or humanize the rules than making them impracticable. An impractical or impossible to implement ethical recommendation is unethical in itself. It merely serves as a fig leaf and discharges its users without giving real protection and without fulfilling its real purpose.

The history, theories, philosophy, legacy, of informed consent are an expression of ambivalence between two values. Child mental health is the field where this ambivalence comes to its most extreme level. These two conflicting values are: 1) the value of a person's autonomy, self-determination, free will, which means providing complete and comprehensive information to the patient, and 2) the aid the patient receives regarding his sickness, which means, giving the patient the best known treatment even if it involves avoiding her/his opposition to this treatment if s/he knows "too much" about it. That does not imply imposing this treatment against his/her will but it does imply the use of fair information, and thus convincing him/her of the physician's good intention to treat her/him the best s/he can. We respect the patient's right to receive other opinions, including those of non-medical persons, like priests or rabbis or other significant figures in their lives. We will have to compete sometimes with these opinions or accept them if we are sincere enough in our intention and will to treat and help. The patient and her/his advisors cannot have the same quality and quantity of information the medical staff has. It is utopian to share all information in the name of a free and full decision-making process.

It is absolutely ethical to try to convince our patient that our treatment program is the best for her/him if this is done from a position of a caring and sincerity and not for any other interests (that we are conscious of) such as glory, promotion, publication, peers competition, etc. Informed consent, as it is formulated by laws and regulations in many countries is threatened by irrelevance because it is impossible to implement, not only for mentally ill children, not only for children but for all patients. It is a law that can be only transgressed, detoured (consciously or unconsciously), and reduced to a minimum in the avoidance of law suits. This is certainly not in the best interests of the child or of adult patient. Hippocratic paternalism is preferable

to hypocritical informed consent. Paternalism is not always a pejorative concept. It is the doctor's answer to a patient's basic will and needs.

Ethics as such is the concern for human relations and is present and can be considered regarding every human encounter. Medical Ethics should be approached in 3 stages:

The first one is to question every procedure: treatment, research, training, administrative decision, in terms of moral values: There is no routine, nothing is evident, and no automatism can be endorsed. This questioning leads to the second step: *formulating the ethical dilemma.* This is a dilemma between values, two or more good, acceptable and moral possible solutions to the problem. These values can be freedom of human beings, self-determination, respect of autonomy and commitment, among others. *The third step* is not less important, though perhaps more often forgotten. *It is the choice of one, unique possible solution among others and action according to this decision.* The answer to the ethical dilemma has to be given by the person, physician or other, in direct charge of this specific patient. Even if advised by ethicists or a council, or an IRB the final decision is his or her own decision and s/he has to endorse it. Too many discussions on Ethics conclude with a question mark. The ethical attitude is an operative one. These decisions are based on knowledge, experience, counseling and staff discussions and no less on physicians own values rooted in their education received from their family, their community and in their school of medicine. Ethics can be taught but it is more than just knowledge. Doctors can be trained to take ethical decisions through their contacts with teachers and peers, by participating actively in elaboration of ethical dilemmas and their solutions, by imitating the moral attitude of their seniors.

The late Donald Cohen taught us that it is better to get to know your doctor than to try to know what he knows. Reliability is of greater value than having an illusion of knowledge. He taught us that informed consent, as a powerful principle, cannot be implemented except when taking into consideration people's needs and sensitivities. It has to be more than anything else an **involved consent.**

Competing Interests: None

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Key Words: *informed consent, child psychiatry, ethics*

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“Hey Bill, smoking is bad for you...”

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THE CASE

Bill is a 54 year old man who suffered a sudden cardiac arrest 9 months ago that rendered him unconscious for about 20 minutes before normal cardiac rhythm returned. As a result he now has a marked amnesic disorder as a result of hypoxic encephalopathy, and was admitted to a psychiatric facility for stabilization of behaviours secondary to his memory problems. Prior to his cardiac arrest he had no history of cardiovascular illness, but was a smoker, having smoked a pack a day of cigarettes from age 14. He has no other history of cardiac risk factors.

Currently, he has marked short term memory impairment, being unable to remember having had a meal even a few minutes after he has eaten, or forgetting that he has had his medications only a few minutes later. He has trouble remembering that he is in hospital, and why, and so will attempt to leave the hospital to attend to some responsibility that he remembers from the past. He can be easily re-directed, and understands the explanation as to where he is and why he is there, but after a time will again forget, and will confabulate, coming up with some story explaining where he is and what he has to do. Cognitive assessment two months after his injury showed marked impairment with a Mini Mental State Examination (MMSE) score of 14 out of 30, but his most recent MMSE was 24/30, with the primary deficit being in short term memory. He does have good recall for events prior to his cardiac arrest, and for more distant memories. He does not experience delusions or hallucinations, and there is no evidence of depression or anxiety.

For 6 months after his cardiac arrest, he was hospitalized on a medical ward, with one to one care to prevent wandering, and during that time did not smoke. Upon admission to the psychiatric unit, he informed staff that he did smoke in the past, but had quit. Throughout the time in the previous hospital, he did not have access to cigarettes. Once in a psychiatric facility he was again amongst people who smoked, and thus began borrowing cigarettes from others and then insisting on some of his own.

Bill was asked about smoking and stated that he did not want to smoke much, but wanted to have cigarettes available to him if he decided he wanted one, and anticipated smoking perhaps 6-12 cigarettes a day, less than his previous pack per day habit. He was not spontaneously aware of

any risk this would pose to him but when advised that this would increase his risk of another heart attack or stroke, he recognized this was the case, and did ask for help to minimize his use of tobacco, although he still expected that he would want to smoke on an occasional basis. When asked about the impact on his health of smoking on a subsequent day he was unable spontaneously to state what the risk was but with prompting recalled again the risk of another heart attack or stroke.

His next of kin, who is his substitute decision maker, with authority both for medical care decisions and financial decisions, did not want him to smoke due to the risk it entailed with respect to his cardiovascular health, now that he had already experienced an episode of cardiac arrest. His next of kin requested that he be prevented from using his own modest income for this purpose and indicated they would not send any money to him while he was in hospital if cigarettes were going to be purchased for him. He recognized that he could not be kept entirely free from smoking as Bill would still have access to cigarettes given to him by other patients in the hospital.

The staff at the hospital recognized that there was a conflict between the desire on both the part of staff and family to protect Bill from further physical harm caused by smoking, recognizing that an acute medical event like a heart attack or cardiac arrest was often helpful in triggering people to quit smoking, while at the same time wishing to help Bill retain as much autonomy as possible with respect to various aspects of his life. As Bill was felt to be incapable of managing his own finances, his family did have the legal authority to determine what part of his income would be available for day to day use, including purchase of cigarettes. Although he had not previously indicated a desire to quit smoking before his cardiac arrest, and had by his actions indicated a desire to smoke then, his risk factors had changed with his cardiac arrest, such that it could be argued that he had not expressed a prior wish about smoking post heart attack. From a systems perspective in our jurisdiction there has recently been a move to ban smoking in and on the grounds of all health care facilities for patients, staff and visitors, so that staff were quite sensitive to their role in overall health promotion, making this issue feel even more challenging. The question was raised as to whether or not he was capable of making this financial and health related decision, as it was not certain to what degree he could fully appreciate the impact of smoking on his physical health, and his finances.

Commentary by:

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College of Psychiatrist Philosophy Group, UK**

Thinking about this case, initially in a legalistic way (and using the Mental Capacity Act 2005 (MCA), which governs England and Wales), the first question is whether Bill has capacity to make decisions about his smoking. He certainly has a disorder of his brain that puts his decision-making abilities in jeopardy, which is the first stage required under the MCA in order to say someone lacks capacity.

The second stage is to consider recall, understanding, the ability to weigh up and to communicate. He can communicate. He can also recall relevant information. The Code of Practice for the MCA states that the person need only recall for a short time. It also suggests that people should be helped to make decisions if at all possible. Therefore, the fact that ‘with prompting’ he again recalls the risk of another heart attack or stroke suggests that, to this extent, his recall is sufficient. And there is nothing here to suggest that he does not understand. Indeed, his MMSE of 24/30 is reassuring. The main deficit is in ‘short term memory’, so again it is not obvious that he cannot ‘weigh up’ the information; at least, if prompted, he should be able to overcome difficulties. In fact, when the various risks are discussed, he asks that attempts should be made ‘to minimise his use of tobacco’. In itself this seems to suggest some weighing up of the pros and cons involved in the decision. Hence, on the basis that he can recall, understand, weigh up and communicate sufficiently, I would be inclined to judge that Bill has capacity to make the decision about smoking.

His decision is that he would wish to smoke 6-12 cigarettes per day. The staff may wish to write down this decision as an agreement, which could be given to Bill and produced when staff feel they need to limit his smoking, given that he is likely to forget the limit himself. All of this would seem to be to honour the spirit of the MCA, which is all about trying to allow people to make decisions for themselves insofar as they are able. One of the basic principles of the MCA is that capacity should be presumed. In making the judgment that Bill has this capacity we are taking that presumption seriously and trying to be on his side.

In which case, his family should let him have money to purchase cigarettes. If they do not, he is likely to borrow cigarettes in any case and may thereby become unpopular if he cannot reciprocate. Presuming that Bill lacks the capacity to make decisions about his financial affairs, his family still need to act in his best interests and his capacitous decision to smoke about 10 cigarettes a day must be given very significant weight. Indeed, for the family to use their control of the finances to block his decision would seem to be an illicit use of their power. They would need to argue that the risks attached to smoking were so great that, when they entered this fact into the check list for determining best interests (see box 1), it completely outweighed Bill’s own capacitous wishes.

There are several complicating factors. First there is an issue to do with ‘lacking capacity to make decisions about financial matters’. It should be, after all, that Bill is encouraged and helped to make decisions about those matters within his competence. Bill might not have capacity to make a decision about buying a new house, but buying a packet of cigarettes would not seem to require the same level of capacity. For practical and legal reasons it may be that Bill has to be declared to lack the capacity to manage his financial affairs tout court. Even so, he should be helped and encouraged to participate as much as possible in these decisions (even in the decision to buy a house). So, on the face of it, since he probably does have capacity to make the decision to buy cigarettes, his decision should be supported.

Secondly, if we presume he lacks financial competence completely, is it the case that this lack of capacity should be allowed to block the exercise of an alternative capacity, namely the capacity to make a decision about smoking? The spirit of the MCA, it seems to me, is that he should be allowed to make those decisions that he is able to make. Hence, he should be allowed to make the decision to smoke a restricted number of cigarettes a day.

Thirdly, although he has no other cardiac risk factors beyond smoking, having suffered a cardiac arrest, he is undoubtedly now on some form(s) of treatment. If the family wish to argue that the risks of minimal smoking are so great as to outweigh his capacitous wish, there would need to be some clarity about what these risks actually are in numerical terms. There would need to be an estimation of the risk of further cardio-(or cerebro-) vascular insults as things now are with or without the risk of smoking 10 cigarettes a day. My guess is that the increased risk would not be overwhelming, even if it were significant. (Ignoring the previous history of cardiac arrest and any current medication, the risk of a 54 year old man with healthy cholesterol levels and normal blood pressure having a heart attack in the next 10 years changes from 4% to 8% if he smokes [<http://hp2010.nhlbihin.net/atp/iii/calculator.asp> (accessed on 4 December 2007)].) If it were overwhelming, then it is not obvious why this could not be put to Bill, who could (presumably) make a capacitous decision with this information to hand.

Finally, it is simply not clear why on any grounds Bill’s capacitous decision-making should be blocked. It would seem to be a straight forward infringement of a basic human liberty. Of course, for other reasons (to do with the risk of passive smoking and the importance of health promotion) the state (or the hospital) might insist that smoking is banned in certain places. In which case, however, this law must be applied equally and fairly. The rationale for such a ban would need to be couched in terms of broader considerations of democratic justice: that the state has a duty to protect its citizens from certain harms in a fair way and based upon rational evidence where the justification for such a policy is broadly accepted within the body politic. But all of this is by-the-by as far as Bill is concerned. At present there is no such law, so he should be allowed to smoke in a controlled manner.

All of the above comments reflect the legal context in two countries (England and Wales) and are based on the judgment that Bill has capacity. To my mind these judgments also reflect an ethical approach. But what if he lacks capacity? We are then thrown back

upon determinations of best interests and in the same jurisdiction we must use the best interest check list (Box 1). Again, this seems to me to be an ethical way of approaching matters. But now let's dig below the legal approach. After all, determining best interests might just lead to deadlock, with the family arguing against cigarettes and Bill still wishing to smoke.

Below the legal surface we come across different, conflicting values. The job then becomes one of negotiating between these values, which requires that they are aired explicitly. This is to engage in values-based practice (Fulford 2004), which should complement the facts (evidence-based practice). It should recognise that weight needs to be given to the views of the family, but values-based practice places Bill's views centre stage.

There has been a debate, in the context of dementia, concerning whether we should pay more attention to a person's previous views or to their present views. In this debate, Jaworska (1999) suggested it was important to continue to recognise the extent to which the person was still a valuer, able to express his or her own values. Rightly or wrongly, Bill still values cigarettes. He is sensible enough to seek to have his desire limited by staff. If we are to value Bill as a person, we must value his values. To take this stance is to make a statement about the importance of values. Of course, we are never fully autonomous, so our values cannot run riot and rough shod over the values of others. That might be the reason for banning smoking altogether in a hospital. But short of this step, it is an argument in favour of supporting Bill in his desire to smoke, in a controlled way and in a way that does not upset other people. To override this value is to undermine his standing as a person. Whichever way we look at it, therefore, and whatever our personal views about smoking, with all the caveats in place, if we are to respect Bill he should be allowed to smoke.

Competing Interests: *None*

Acknowledgements: *None*

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Box 1

Determining best interests: The checklist from the Mental Capacity Act 2005 governing England and Wales

- 1.** There is a reasonable belief, following assessment, that the person lacks capacity
- 2.** Avoid discrimination
- 3.** Consider all the relevant circumstances (medical, psychological, social, spiritual and so forth)
- 4.** Put off the decision if the person is likely to regain capacity
- 5.** Encourage the person to participate as fully as possible (e.g. by using communication aids, pictures etc., or by improving sight, hearing or language, and by consulting with appropriate experts)
- 6.** If the decision is about life-sustaining treatment, ensure it is not motivated by a desire to bring about the person's death
- 7.** So far as is reasonably ascertainable consider the person's past wishes and feelings
- 8.** So far as is reasonably ascertainable consider the person's present wishes and feelings
- 9.** So far as is reasonably ascertainable consider the person's values and beliefs likely to influence the decision
- 10.** So far as is reasonably ascertainable consider other factors the person might consider, e.g. cultural background, religious beliefs, political convictions, past behaviour or habits and any effects on others that might be relevant to the person
- 11.** If it is practicable and appropriate consult anyone named by the person
- 12.** If it is practicable and appropriate consult anyone engaged in caring for the person
- 13.** If it is practicable and appropriate consult anyone interested in the person's welfare
- 14.** If it is practicable and appropriate consult anyone with power to act as an attorney
- 15.** If it is practicable and appropriate consult any deputy appointed by the court
- 16.** Decide on the least restrictive measure if at all possible in the person's best interests
- 17.** Seek a way to balance the concerns of all involved
- 18.** Settle any disputes
- 19.** Reach a decision in the person's best interests

Note: of course, not every one of the provisions covered by this checklist needs to be relevant in every case; but the checklist forms a framework for deciding on a person's best interests. In addition, differences in legal systems might make some of the items less relevant. Still, from an ethical perspective, the framework of broad thought and consultation seems likely to apply widely.

Commentary by:**Sameer P. Sarkar, MD, LLM****Diplomate, American Board of Psychiatry and Neurology, Inc., Consultant in Forensic Psychiatry and Psychiatry, Wokingham, United Kingdom****Issues in this case**

- Autonomy vs. welfare
- Capacity on a sliding scale
- Consent vs. lack of dissent
- Status of advanced directive
- Paternalism or the tyranny of health

The issues in this case can be summarized simply as the perennial conflict of autonomy as a principle versus the other principle of bio-ethics, welfare. The principles of beneficence and non-maleficence can be subsumed under the broad umbrella of welfare and under this umbrella, often in psychiatric cases, comes welfare of the society. In this case, the welfare of society is not that apparent although it can be argued tenuously that a healthy citizenry can only be beneficial to the whole society. The competing interest, or the countervailing argument in these types of cases will be that the society also benefits from allowing people to act in autonomous ways, often in irrational ways, with certain caveats. The most obvious of those caveats would be that in exercising one's autonomy, one is not encroaching on somebody else's welfare or autonomy. All of the above is true under the assumption that it is a capacitous (or competent) person exercising his right to be autonomous, or for that matter, the right to act foolishly.

The equation changes slightly in favour of the society when the player is not competent or incompletely competent to decide or exercise his autonomy. Society has by convention, usurped the role of a parent to protect not only the well-being of the incompetent (*parens patriae* power) but also to prevent harm to its citizens through the actions of another, competent or not. This is loosely called the police power. In this particular case, the police power does not seem to be an issue but capacity is. Capacity (or competence) is roughly tested through a 4-stage test that is used in legal settings but remains an essentially clinical test: can a person understand information given to him, can he retain the information so given, can he manipulate (cognitively) that information to come to a choice, and finally, can he register his wishes based on the above three. It is not required that he exercises or expresses a choice which is correct, or agreeable to others, or even rational. At the very least it requires to be shown that a choice (however irrational) has been made through all of the four stages. A capacitous or competent decision is thus inviolable save certain circumstances.

In this case, clearly there are areas that will give rise to doubts in the mind of the assessing clinicians. It is agreed that Bill has an amnesic disorder secondary to the hypoxic encephalopathy howsoever caused. How it was caused has relevance in the later

stages. The amnesic disorder manifests itself at the very least by Bill's inability to remember having a meal only a few minutes ago. So clearly, in absence of the ability to retain new information (as evidenced by the scores of MMSE and the deficit areas in short term memory), he fails the first test. A capacity test is 'all or none' i.e. all four limbs have to be satisfied. So for all practical purposes, Bill is judged to be incompetent. Following on from the foregoing, Bill is likely to fail the second limb, the third limb, and by extension the fourth limb, that is, ability to express a choice based on the first three criteria. For any decision based on retention of new information, he would be deemed globally incompetent.

The issue of remaining in hospital thus merits further analysis. Although it would appear that Bill is in hospital voluntarily, it can be best described as being in hospital without dissent (assent) rather than true consent. A 'nod' rather than a shake of the head. A true consent must be a competent decision based on the tests above, plus certain other factors such as lack of duress or coercion. This lack of consent to remain in hospital is not an immediate problem, but will become crucial in later stage of our analysis.

Bill's choices could be executed even in this stage when he has lost capacity, if either he had an advanced directive registering his wishes when he was capacitous or if a substitute decision maker properly appointed makes that choice on his behalf. It would appear that Bill does not have an advanced directive informing the team what shall be done to him, or with him, in the event of his losing capacity. Therefore this decision falls on the substitute decision maker, be it his next of kin or the Court. In both these circumstances, the substitute decision maker will have to express a choice which will not only be in his best interest, but something that is consistent with what Bill would have wanted when competent. It would appear that Bill never wished to stop smoking when he was autonomous. But then he never had a heart attack before either. So there is no way of knowing what Bill would have done in the event of him having a heart attack (but retaining autonomy) with respect to a desire to stop smoking. A reasonable construction would be that if Bill was competent, given the new risk factor that has developed since (the heart attack), he might have been minded to quit. Bill now says that he wants to smoke much less, would like help with minimizing his use of tobacco but should retain the option of having a cigarette (or two) as and when he desires.

And here is where paternalism comes into play. At its most benevolent (and benign form) it is making substitute decisions for Bill by his carers, which would be in his best interest. Reduced tobacco intake may decrease his chances of another heart attack but no one can be sure by how much, assuming that there may be other factors in the causation of a heart attack. However, best interest is not merely 'best medical interest' that doubtless will be served by him quitting smoking, but also in retaining his autonomy and dignity, as much as possible. Just like Bill could not be forcibly stopped from smoking in his pre-heart attack days, he can not now be stopped forcibly, just because it is good for him, unless it is documented that the chance of harm is statistically so great that it is imperative that he be prevented and there are no countervailing interests, such as loss of dignity, operating. Best interest should also take into account his financial interests in so far as he should not be allowed to blow all his money on something

harmful. A difficulty then emerges if he is smoking all his money away (although in this case it would appear he is not).

All things considered, it can be argued that Bill ought to give up smoking for his own health and finances (and should have done long ago), and now is the best time to do it. The timing is crucial because now Bill faces at least three more hindrances: 1) he is in a hospital that, although it does not have a no-smoking policy, is moving towards it for greater good; 2) he has lost his capacity to do as he pleases with both his money and his health; 3) a substitute decision maker has made a decision not to allow him to smoke based on an assumption of what Bill might have done if he had the new information. Law requires the substitute decision maker to decide what Bill would have done rather than what a reasonable man in his situation would have done. In this situation, without any concrete indication of what Bill would have done (actually, there is some evidence he might have decided to the contrary), the substitute's decision is suspect, although clearly the decision has been taken in good faith and with very good intentions.

A further caveat to complicate the whole matter is whether Bill's previous position on smoking was autonomous given he was suffering from an addiction and perhaps was powerless to do otherwise. But that's a matter for another day.

Competing Interests: *None*

Acknowledgements: *None*

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Actual Case Outcome:

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What we did:

The team worked with Bill first to develop a plan to help him reduce his smoking by prescribing bupropion, and offering him nicotine gum when he requested a cigarette as an alternative, but providing a cigarette if he insisted on one. His family continued to refuse to send money to purchase cigarettes. We anticipated at some point being unable to continue to provide him with cigarettes unless the family relented and sent money. We advised Bill of this situation. To complicate things further, Bill will require placement in residential care as his behaviours have settled significantly and many of those facilities are non-smoking which will either force him to stop, or limit his placement options, prolonging his hospitalization

Competing Interests: *None*

Acknowledgements: *None*

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Leaving the Room to Scream - The Place of Mercy in Mental Health

Andrew Fullerton, Ph.D.

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I used to know a man who lived in a boarding home in a neighbourhood of Toronto. Real estate leaflets plug certain houses by saying they're set in a 'preferred location', which is ad-speak for 'rich people live here'. Not this house: its neighbourhood is scruffy and densely packed, a way-station gathering immigrants who anticipate a new life, and a terminus for defeated souls who await the old life's end. Like the boarding house that housed him, this man was tattered, tired and dejected; on a downward drift from higher, happier days. I visit that house still in the company of a chaplain who has made it his work to befriend people clinging near the bottom of society's ladder, living isolated lives in houses like these. Some have lived on and off the street for years. A few have fallen from higher rungs of respectability. Jobs, houses, money, families, friends and self-esteem have been lost from their lives like coins flung from a pocket on a downhill fall. Some have been in prisons and psychiatric hospitals. Almost all take drugs prescribed for this or that brand of mental illness. Wretched side effects are the price they pay for fragile relief from psychotic symptoms.

I said I 'used to know' this man. That's because, a few months ago, he disappeared. He may be dead now; it's likely I'll never see him again. For awhile, police were unusually keen to find him, questioning anyone who might have known or seen him, pasting onto telephone poles his 'missing person' face, which covered up similar posters pleading for lost cats or selling used furniture. I wonder what conflicts he'd had with the law in the past that he'd be so keenly sought *now*? Was he such a danger, a social threat? In the past, when someone had gone missing from this boarding house, police response was slack. I knew he was capable of violence and destruction – but then, who isn't? I'd heard menace in his voice, seen fury in his gestures. One day, he yanked out telephone and TV cables that ran along the side of the house. The next week he pulled down gutters from the porch roof. Yet I never knew him to attack fellow residents, nor be physically violent towards anyone else. Instead, he *screamed* his violence. At what? He screamed at a vision that was vivid only to him, though he often growled the word 'therapy', and shouted vituperation about social workers, psychiatrists and psychologists. He spoke the word 'therapist' the way Senator McCarthy said 'communist', launching volleys of rage like underground missiles long stored up inside him. If there was fear or pain in his scream, it was muffled by a thick layer of voluble, visceral anger. Yet his anger, I suspect, was in fact an epiphany of misery; and the core of this misery was an unmet craving for mercy.

Yet there was courtesy in his behaviour. Never did he scream in

the company of others, never in the sitting room where everyone gathered when the chaplain paid his weekly visit. He always left the room to scream. He screamed in the hallway, on the staircase, in his dull room; he shouted on the battered porch, the crumbling sidewalk, the weedy lawn. He left the room to scream the way you or I might turn aside to sneeze, to excuse ourselves in advance in a reflex act of courtesy. When his need to scream subsided he returned, visibly shaken, exhausted, muttering weak groans like receding thunder from a storm that had now passed. Always he was quietly welcomed back. And in my memory of his leaving the room to scream and his coming back to be with others – his exit and return – I find in microcosm the chronic experience of those afflicted by mental illness, their frequent and disputed crossings, as if by revolving door, of a threshold marking social inclusion from exclusion. For we detect mental illness, not in an intrinsically malicious will, but in those aberrations of behaviour and talk which we attribute to chronically flawed perception and damaged consciousness. We find it in behaviour – like this man's screaming – that disturbs social equilibrium. If such behaviour escalates, society swiftly checks it with rebuke, punishment and expulsion. It's no accident, and rather too placidly accepted, that prison populations have a higher incidence of mental illness.

And yet, alongside this man's alarming manifestation of a troubled mind – this compulsion to scream at visions seen only by him – I also witnessed his remarkable courtesy. He displayed it in a perfectly rational (may I say 'sane'?) adjustment of his behaviour to his own and others' needs. He must have long ago learned that it's less painful to exclude yourself *before* you're made to leave. And yet, if human need made him leave the room to scream, human need also drove him back: I mean his need (and ours) for conversation, recognition, understanding; and for a community where these things might be allowed to happen.

Mercy is what makes this happen. It's the social power that 'welcomes back' after we've 'left the room to scream' (so to speak) – or perhaps we've been sent away. Mercy is just what we require from and for each other. It enlivens our capacity, not only to accommodate, but also to be enriched by each other's eccentricities, deviations and differences. Mercy issues from our resolve to be with and for each other *despite* the countervailing power of mental illness to isolate its victims. And by 'isolation' I mean, for example, not just the self-imposed solitude that goes with depression, or the depersonalisation imposed by health institutions on those they're meant to serve; but also the ostracizing of schizophrenics from social life; the scapegoating of those whose psychoses offend law

and custom; the diagnostic stare which sees not a person but a bundle of symptoms; and the madding crowd's disregard for the damaged soul who squats by a bus shelter, craving a moment of kindness as well as spare change. Mental illness shows itself in those deviations of perception and behaviour which place its victims at the lonely ends of the 'bell curve', beyond the centre, outside the 'norm'; and therefore, very often, at the margins of society too. Mercy looks to the margins, wanting to welcome them back.

The 'margin' is the name medieval monks gave to the white space that bordered the texts they copied so assiduously. They also called them 'gutters'; and, being monks, their minds were often in them. They'd use the gutters for graffiti, obscene cartoons, paranoid comments about other monks, or scathing remarks on the boring pages of Aristotle they'd been hunched over all afternoon. In the gutters, to the margins – that's where we shove our 'shadow' side, as Carl Jung called it; our deviant thoughts, aberrant perceptions and abnormal desires. They're the troubling features of our society and our own psychology which we fear to face; and if others saw them in us we fear they'd judge us 'sick'. Mercy is the social energy we need to see and retrieve from the gutter those openly judged to be 'sick', psychologically ill, so we may reconcile them to communal life – and perhaps, in the process, we may better understand and accept ourselves as well. For mercy is a way of seeing each other kindly; and it requires a way of 'being ourselves' that is simultaneously a way of being for each other. And this reaching for 'wholeness' and integrity in the social body, for re-gathering the displaced and discarded, helps to heal not only those afflicted by mental illness but the whole social body too. This is why a community that fails to be merciful actually injures *itself* as well those it marginalizes, though the community may fail to see this, believing it's actually defending its health by purging itself of 'diseased elements'. Religion can be especially rife with this behaviour. It fiercely hates doubters and heretics because they arouse the 'true' believer's own carefully suppressed doubt and heresy.

This hazard is more acute in a society too invested in 'keeping up appearances', too wedded to dominant ideology, too ready to believe its own propaganda, too desperate to seem 'normal' (whatever *that* is). Such a society may punish talk and behaviour that calls the dominant ideology into question, labelling it deviant, a symptom of mental illness, when it may just be conscientious objection, the disclosure of truths a society needs to hear and heed. In 1851 the American psychiatrist, Samuel Cartwright, coined the term *drapetomania*, from the Latin *drapeta*, meaning 'fugitive', to denote what he colloquially called 'flight-from-home madness'. Why were slaves fleeing their masters? He reasoned that, since there was nothing wrong with slavery, there must be something wrong with delinquent slaves. So any slave who tried to run away more than twice he diagnosed 'insane'.¹ Not just real or imagined totalitarian regimes, then, like Stalin's Soviet Union and Orwell's Oceania, but 'open societies' which make democratic noises may also brand as 'sick' those whose talk and behaviour betoken unsavory truths hidden by the whitewash we call 'normal'. For we do resist facing the shadows we hide within the borders of society, or inside our very selves. And a time-honoured way to avoid our own aberrations is, under the pretext of social health, to punish those aberrations in others, pushing them to the margins. Why *are* we so loathe to speak to mentally-damaged souls who crouch in a literal gutter, begging for a bit money and a word of kindness? I suspect it's because we're loathe to face what their presence says about us.

More than any other kind of malady, mental illness calls our very sense of self into question. If something goes organically wrong with my heart or liver, it certainly disrupts my life. The disruption might even 'mean' something. It may call into question certain aspects of my life, showing me things I need to know and change. Doctors help patients, not just when they prescribe drugs and operate on them, but when they teach them what the body reveals in the course of a disease. For the word doctor *means* teacher (or it used to); and 'understanding' – both the kind that's given and the kind that's received – is always healing for the spirit, and often for the body too. But if my illness is not specifically bodily, but 'mental', impairing my consciousness and perception, something much more frightening happens: my very sense of self is now in question. If my mind senses its own impairment, if it is not 'my body' but this 'I' who feels damaged, then who *am* I? I need mercy. I need to be seen, heard and addressed not just as one more object of an organic disease process, but as a subject experiencing a crisis of meaning. For I am not an 'it' but a 'thou', as the philosopher Martin Buber put it. I am not just a routine problem in organic chemistry and physiology wanting to be solved, but a personal mystery needing witness and recognition. I need to see and be seen, to hear and be heard, by another subject, another 'thou'. "I am because I am *seen* at a certain depth," writes Rowan Williams. "I require a faithful presence to hear my narrative....I have no reality as a subject that is not also a reality for and in another subject."²

A merciful community knows, consciously or not, that mental health resists reduction to complex brain chemistry and physiology. Of course consciousness must involve chemistry and physiology, but I've never understood how it can be reduced and held to this level of explanation. For mental health must involve, irreducibly, the experience of *meaning* which erupts from our complex brain chemistry into consciousness. My I borrow a shop-worn analogy? Paintings are made from paint, which are made from pigments, which (like our brains) are made from complex chemistry. But we're drawn to look at paintings, not because they're made by chemistry, but because they're made by an artist. So although, in one sense, a painting is nothing but a complex array of chemicals daubed onto canvas, in another sense it's so much more. And that 'much more' is conveyed by the conscious intention of the artist who has arranged the paint *this* way rather than that. There is 'reason' in art, as well as emotion. It's in the arrangement, the physical pattern, that we find meaning and delight; sometimes we call it an experience of 'beauty'. In a similar way, our mental health requires a higher level of care and explanation than chemistry and anatomy alone can afford, one that recognizes human intention and motive, thought and emotion, and brings our perceptions to speech. It would be an odd doctor who diagnosed a patient complaining about 'excessive blushing' with a physiological condition called 'excessive surface blood flow', and tackled the problem on *that* basis, rather than diagnosing a psychological condition called 'excessive shyness', and explored ways to improve the patient's self-confidence. For blushing is, of course, a symptom of self-awareness – or rather, the awareness of self-exposure. And it is a dazzling mystery that this wet sponge we call the brain evolves a conscious identity; not just awareness but *self-awareness*, the sense of an 'I' who is the ground and subject of experience; an 'I' who both becomes itself and exposes its 'sense of itself' in speech and action. So I'll never understand how mental health could *not* involve, irreducibly, the experience of *meaning* which erupts into consciousness from the brain's complex chemistry. And I've never

understood why those drawn to the task of healing mental illness would want to avoid exploring this meaning.

Our own flourishing requires that we recognize consciousness in others. We want and need to see and be seen by others, to know and understand each other, as an 'I' relates to a 'thou', as two living subjects. And this too is why our mental health relies on mercy. "Any human face is a claim on you," says Marilynne Robinson in her novel *Gilead*, "because you can't help but understand the singularity of it, the courage and loneliness of it."³ But institutions of mental health frequently *do* fail to heed this claim. My friend, the chaplain who visits boarding homes, one day asked a boarding home gathering about their own experience of mercy. At the mere mention of this word the room erupted in urgent talk, for he had touched on a deep wound – not the wound addressed by mental health practitioners, but the wound *caused* by them. Here are some of the things they said: "Mental illness is the most low-down illness you can have....It's worse than being a criminal....The government takes us and sweeps us under the rug like we were pieces of dirt....Medical staff use cruel talk, they blame people for having an illness, they talk down to them." One man said over and over: "Bad, bad, bad, bad, bad. A very bad thing. They have no feelings for you." Another man acknowledged the good care he'd received, but wondered why it didn't extend to those 'on the street'. Something has gone terribly wrong when institutions of healing, in the very process of trying to heal one kind of wound, inflict another – an attack on damaged souls; belittlement and blame; and the scapegoating of those whose symptoms stir up what we fear in ourselves.

The wound touched on by the chaplain that day exudes a harrowing pathos. He heard the uttered agony of souls unaddressed by mercy, the pain produced by their need to be known not as things but people, not as objects but subjects, and by their helplessness to enforce this claim. For mercy can't be forced, only freely given; and such powerlessness is only a further indignity. Mercy won't be legislated into existence by codes of behaviour, institutional policies, and administrative guidelines. Mercy can't be captured or specified that way. Its gestures are "too much a matter of human art to be made a consistent matter of human routine," as Michael Ignatieff says in his exquisite little book, *The Needs of Strangers*.⁴ For mercy is not defined so much by what we speak and do as by *how* we speak and do it, by the spirit in which it's done.

This is why mercy requires attention and regard for those with whom we have to do, a willingness to be vulnerable, open to amendment and critique, open to the kind of conversation that exchanges not just information but risks an 'exchange of selves'. Only imperialism and arrogance would foreclose on talk, on the possibility of finding something unguessed at and new in each other, whether that 'something' is another culture, another discipline, or another tortured mind. Oppression happens, as Rowan Williams says, when "one party's language reaches out to incorporate the other's experience, which cannot speak for itself."⁵ I think native people might understand exactly what he means; so might those afflicted by mental illness. Their sense of themselves, already in crisis, may be too quickly and too generically encapsulated by clinical categories and procedures, the way pale vegetables are shrink-wrapped in grocery stores. For oppression ends conversation prematurely, before it ripens. Your perceptions are framed and evaluated *for* you, leaving you outside those ex-

changes of talking and listening, mutual perception and shared recognition, in which we deconstruct and reconstruct our sense of ourselves. To be denied the chance to do that is to feel like an object, an 'it' – not a person, a 'thou'. Even a routine disease of the body can be misdiagnosed by a physician who has lost the art of listening, who has been made impatient by a patient's narrative, who rushes to dragoon the most obvious and objective symptoms into a diagnostic pigeon-hole, to *tell* a patient what he or she has 'got'. How much more hazardous and arduous it must be, then, to have to take a patient's *subjectivity* into account, to take time to diagnose and treat those elusive, difficult-to-discern symptoms that plague a troubled mind. They don't show up on an x-ray or blood test; they show themselves in verbal reports of emotion, thought and perception, in aberrations of talk and behaviour. How often it must be that the psychiatrist has done "no more than apply a poultice of polysyllables to a wound he could neither see nor understand", as Peter De Vries puts in his novel, *The Blood of the Lamb*.⁶ How frustrating that must be for everyone.

On the day my colleague, the boarding home chaplain, asked about mercy and the whole room erupted, one person *did* say this: "Speaking the right words can put some illness to flight." So it can; not because they're magic words, but because they're merciful. Edward Shorter, in his *History of Psychiatry*, describes the modest success of the 'therapeutic asylum' that emerged in Europe in the early 19th century. The relief from mental illness they provided their patients – and sometimes it was dramatic relief – had little to do with science and more to do with rudimentary kindness and attention. "This kindness," he writes, "offered a therapeutic grip on the patients, a hold by which to pull themselves back to wellness."⁷ (Notice, by the way, that similar language is now used about the benefits of anti-depressants.) These early asylums were small-scale communities quite unlike the notorious industrial-scale versions that developed much later. At their worst, those later asylums applied bizarre procedures on patients whom they judged as 'lost causes' and treated as objects of experiment. For example, early in the 20th century (yes, the *20th* century) the American psychiatrist, Henry Cotton, "believed in pulling out his patients' teeth and removing their large bowels to cure psychiatric illness."⁸ The best of the early asylums, however, were small-scale communities of mercy. Staff and patients lived together, following the ordered routines of work, leisure, common meals, privacy and socializing, overseen by a superintendent who was a clergyman or doctor. Happy was the patient who came under the merciful regime of someone like William Charles Ellis, a doctor who founded an asylum in Yorkshire. He wrote this in 1838: "[The] most essential ingredient is constant, never-tiring, watchful kindness: there are but few even amongst the insane, who, if a particle of mind be left, are not to be won by affectionate attention."⁹ If mercy can mend the mind, does its absence not harm it?

Mercy, I said, is our capacity to see and welcome back those who are displaced to the margin, in the gutter, outside the human world of self-exchange and conversation; And this can be healing, both for those so marginalized and for the social body that thus restores its own integrity, its 'wholeness'. A merciful society prizes conversation; it's flexible and tolerant because it knows how necessary it is for human flourishing to be with and for each other, to see and understand, to be enriched by each other's eccentricities, deviations and differences. Above all, mercy is our power to see into the depths of each other and find, not problems to be solved and

deviations to be hammered into conformity, but the unfathomable mystery of a unique 'thou' who craves to be seen and engaged by another 'thou'; yet who rightly resists becoming a 'thing', an object under another's controlling gaze.

This tug-of-war between mercy and manipulation is a conflict felt by Martin Dysart, the psychiatrist in Peter Shaffer's play, *Equus*. The adolescent he must treat has done something deviant and criminal, yet he knows the boy's aberrant passion springs from a deeper, inner mystery he can neither fathom with science nor control by its techniques. It's symbolized first to the boy, then to the doctor, as an untamed mythical beast, the horse god he calls 'Equus'. "I can hear the creature's voice," Dysart says in one of his eloquent soliloquies. "It's calling me out of the black cave of the Psyche.....He opens his great square teeth and says – Do you really imagine you can account for Me?"¹⁰ It's as though Dysart encountered through this boy an archetypal figure, wild, beyond good and evil, but rooted in the roots of every human consciousness. His therapeutic talk with this patient calls into question his own vocation to heal mental illness; indeed, it calls into question his own vulnerable self. For although he knows he can 'cure' this boy, it will not be by healing his passion, but by killing it. He must return him to society not through the offices of mercy (for society won't forgive him), but by *making* him 'normal' once more. "The Normal," he says, "is the good smile in a child's eyes – all right. It is also the dead stare in a million adults. It both sustains and kills – like a God. It is the Ordinary made beautiful. It is also the Average made lethal. The Normal is the indispensable, murderous God of Health, and I am his Priest. My tools are very delicate. My compassion is honest. I have honestly assisted children in this room. I have talked away terrors and relieved many agonies. But also – beyond question – I have cut from them parts of individuality repugnant to this God, in both his aspects. Parts sacred to rarer and more wonderful Gods."¹¹ And so, in the end, he severs the boy from his passion, killing the wild energy rooted in the root of him. Why? To make him normal. At the end of the play Dysart concludes a climactic speech and turns on the audience with these words: "Passion, you see, can be destroyed by a doctor. It can't be created."¹²

It saddens me that I shall never come to know the meaning of the screaming of that man; who, in mercy for me, left the room to scream all alone, but whose return, again and again, was a hopeful plea for mercy on *his* behalf, and a declaration that mutual regard is the heart of human life. "Every death is like the burning of library," Alex Haley is supposed to have said. I'll never read this man's life, never know what his screaming meant; what guilts he groaned, fashioned by what fears; haunted by what visions, vivid only to him. I'll never know what panic he felt in the agony of his mind's crumbling incoherence, lost in his own labyrinth. Whatever I might have learned from him, and how this learning may have enriched me, I shall never know. For one day he left the room to scream and never came back. I had that chance. It's gone now. I was too afraid to take it.

Competing Interests: none

Acknowledgements: none

End Notes:

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4. Michael Ignatieff, *The Needs of Strangers*, (Harmondsworth: Penguin, 1986), p.16
5. Rowan Williams, *Lost Icons*, p.113
6. Peter De Vries, *The Blood of the Lamb*, (Chicago: University of Chicago Press, 2005), p.151
7. Edward Shorter, *A History of Psychiatry*, (New York: John Wiley & Sons, 1997), p.20
8. *Ibid.*, p.112
9. *Ibid.*, p.42
10. Peter Shaffer, *Equus*, (London: Penguin, 1977). p.75
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AHMED V. STEFANIU - IS THE SKY REALLY FALLING?

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Introduction¹

More than three decades ago in the case of *Tarasoff v. Regents of the University of California*² the Supreme Court of California found a psychologist, Dr. Moore, liable for the death of Tatiana Tarasoff. She was murdered by one of his patients. The patient had confided to Dr. Moore an intent to kill Ms. Tarasoff. He requested that the campus police detain the patient. However, they released him a short time later as he seemed rational. No one warned the woman or her family. When, several months later, the patient killed Ms. Tarasoff, her parents sued Dr. Moore and other employees of the university. Dr. Moore argued that by reason of patient confidentiality he had no duty to warn Ms. Tarasoff or her family. The court rejected that defence:

The confidential character of patient psychotherapist communications must yield to the extent that disclosure is essential to avert danger to others. The protective privilege ends where the public peril begins.³

The *Tarasoff* decision has been referenced in several Canadian decisions; it has also been the subject of a number of academic articles.⁵ Although it now represents an established legal principle, the burden it places upon mental health professionals towards third parties remains somewhat controversial.

An example of that controversy is found in a recent decision of the Ontario Court of Appeal. In *Ahmed v. Stefaniu*⁶, the Court of Appeal upheld a finding of liability against a psychiatrist who had released a patient from a psychiatric facility. Fifty-nine days after his release the patient murdered his sister. This decision, to which the Supreme Court of Canada denied leave to appeal⁷, has created a “buzz” among members of the Canadian psychiatric community. A decision of the Ontario Court of Appeal, the highest court of Ontario, is considered a very weighty legal authority in Ontario and other provinces. Some would argue that the decision has created an unreasonable imperative for defensive psychiatry in this country. As one reviewer put it,

Psychiatrists will have to err on the side of caution, and keep patients committed or commit patients themselves at the first sign of intended aggression.⁸

This article will examine the legal context for the Court of Appeal’s decision and provide, it is hoped, some reassurance for those who may have concluded that it constitutes a major precedent for evaluating the legal responsibility of other psychiatrists in similar circumstances.

The Evidence

Justice Armstrong, who wrote the Court of Appeal’s unanimous decision⁹ set out the following background:

5 In October 1995, Johannes was admitted to the Scarborough General Hospital as an involuntary patient. He was said to have threatened his landlord and engaged in aggressive behaviour. He was prescribed medication to treat a psychotic disorder. After his release from Scarborough General Hospital, he was readmitted as a voluntary patient with a diagnosis of acute psychosis. After his second hospital stay, he lived with his sister and her two daughters where he functioned reasonably well. He returned to work.

6 In the summer of 1996, the condition of Johannes deteriorated. He exhibited bizarre, aggressive and paranoid behaviour. On September 25, 1996, his sister contacted Johannes’ family doctor and expressed concern about her brother. She told the family doctor that Johannes had threatened to hurt her if she did not prove that she was “on his side” within two weeks.

7 The following day, September 26, Johannes was forcibly taken by the police to the emergency department of the Humber Memorial Hospital. On September 27, 1996, the appellant assessed Johannes and concluded that he was lacking insight, with severe paranoia, and that he had a potential for violence. On September 28, 1996, Johannes was admitted to the Humber Memorial Hospital as an involuntary patient pursuant to a Form 3 under the *Mental Health Act*. The attending physician on September 28, 1996, found that Johannes was likely to cause serious bodily harm to another person. He was also declared not mentally fit to consent to treatment.

8 Johannes appealed his involuntary hospital admission to the Consent and Capacity Review Board. A hearing was held on October 8, 1996. In its decision, the Board concluded:

[T]he Board is of the opinion that at this time, without treatment, there is a likelihood that the patient if he left hospital would continue to deteriorate to the point where there is a likelihood that he will cause serious bodily harm to another person. He would simply lose control due to anger and frustration.

9 In mid-October, the appellant recorded the following in a progress note concerning Johannes: "further deterioration of his mental state with potential for self harm and/or harassing others".

10 On October 24, 1996, Johannes struck another patient. He had to be placed in two-point restraints due to his level of agitation. On October 31, 1996, Johannes threatened the Department Chief and a staff psychiatrist. Following the latter episode, Johannes was involved in a fight with two staff porters. Two security guards were required to subdue him and place him in four-point restraints. While in Humber Memorial Hospital, physical restraints were used on Johannes on 25 different occasions.

11 In mid-November, the hospital security records disclose that Johannes attempted to assault two patients. On December 2, 1996, the appellant did an assessment of Johannes. Her progress note refers to Johannes as remaining delusional and paranoid.

12 The nurses' notes of December 3, 1996, describe Johannes as very angry, loud and intrusive, with threatening body language and a rigid posture. He is further described as "extremely hostile". On the following day, December 4, 1996, Johannes threatened a nurse.

13 In addition to the above, there was also evidence before the court that over the course of his hospital stay, Johannes became less threatening in his manner, facial expression and interactions with the hospital staff. Although not a model patient, there was observed a general trend of improvement in his behaviour.

14 In the early evening of December 4, 1996, the appellant carried out an assessment of Johannes. In her progress notes, she described Johannes as having no signs or symptoms of paranoia or psychosis. She found him very appropriate, co-operative and with a great sense of humour. During this assessment, he told the appellant that he had no intention of harming himself or anybody else, including his sister. He also told the appellant that all of his behaviour at the hospital had been "staged and planned". She understood him to tell her that he had faked his psychosis. She testified that she took this information with a grain of salt. The appellant concluded on December 4 that Johannes probably did not meet the criteria for an involuntary patient at that time. She decided to meet with Johannes the next day for further discussion.

15 The appellant met Johannes on December 5. Her progress note presents a somewhat mixed picture of the patient:

Patient seen again today. Pleased he is finally released. Good mood, pleasant, co-operative, but inappropriately flirtatious (jokingly insists we go for dinner). Has plans about job, picking up his car, and restarting life. No signs of delusions, paranoid thinking or psychosis. Denies any suicidal or/and homicidal ideas ... (illegible) or plans. Alert and oriented - however remains provocative, ma-

cho and in [sic] the same time angry and fragile.

16 The appellant concluded on December 5, 1996, that Johannes no longer met the criteria to be detained in the hospital as an involuntary patient. She changed his status from involuntary to voluntary under the *Mental Health Act*. In doing so, she considered a number of factors including: the patient's general trend of improvement, his stated intention that he did not plan to harm himself or others, his response to medications, the decision of the Consent and Capacity Review Board, his previous admission to Scarborough General Hospital, consultations with other psychiatrists and conversations with his employer.

17 When the appellant changed Johannes' status to voluntary, she suggested that he remain in the hospital on a voluntary basis but he refused to do so. He also declined to follow the appellant's suggestion that he continue with a psychiatrist whom he had been seeing prior to his admission to Humber Memorial Hospital.

18 When Johannes left the hospital he moved back into his sister's apartment.

19 Johannes returned to Humber Memorial Hospital on more than one occasion to visit a female patient. Such visits were disruptive and he was asked to leave the premises. On one occasion, he was escorted off the premises by the police and spent the night in jail.

20 On January 21, 1997, Johannes attended at the North York General Hospital emergency department. He was assessed by Dr. Weinstein, a psychiatrist. Dr. Weinstein noted that Johannes was depressed. He was also noted as being well dressed and articulate. In response to questions from Dr. Weinstein, Johannes said that he was not capable of hurting himself or others. Dr. Weinstein saw no indication of violence or potential for violence from Johannes on January 21, 1997. Dr. Weinstein concluded that Johannes did not meet the criteria for involuntary admission.

21 On January 22, 1997, Johannes attended at the Toronto General Hospital emergency department where he was seen by Dr. Lee, a Toronto General Hospital resident. Dr. Lee reviewed his medical history, including his involuntary admission at Humber Memorial Hospital. Johannes requested an immediate psychiatric consultation. Dr. Lee declined to order a consultation because at that time she did not regard Johannes as a danger to himself or to others. Dr. Lee assessed Johannes to be stable and opted to go with out-patient care. Dr. Lee concluded, in consultation with her supervisor, Dr. Caravaggio, that Johannes did not meet the criteria for involuntary admission under the *Mental Health Act*.

22 On January 24, 1997, Johannes murdered his sister at her apartment. At the time that he murdered his sister, he was in a floridly psychotic, acutely delusional rage in which he believed that his sister was possessed by the devil.

APPELLATE REVIEW AND THE PRINCIPLE OF “JURY DEFERENCE”

An important aspect of this case – which helps explain if not justify the result – is that it was a trial by judge and jury. The vast majority of civil cases in Ontario are tried by judge alone. In fact, it was thought at one time that cases involving medical malpractice were too complex to be submitted to a jury.¹⁰ More recently, the courts in Canada have rejected this as a general principle and concluded that juries are sufficiently sophisticated to understand the evidence and to deliver a just verdict even if the case involves complex medical issues.¹¹ Nonetheless, jury verdicts in medical malpractice cases are still relatively rare.

In appealing the verdict in this case, Dr. Stefaniu was entitled to only a limited review by the Court of Appeal. An appellate court is limited to questions of law, and to a very limited extent, questions of fact. In reviewing factual findings of a jury, the Appeal Court must accept those findings unless it can be demonstrated that no reasonable jury, properly instructed by the trial judge, would have reached those findings.¹² Similarly, the judge’s charge to a jury will only lead to a verdict being overturned if it can be demonstrated that the charge was inadequate or wrong, and also, that it would have materially affected the jury’s verdict.¹³

In the *Stefaniu* case, Justice Armstrong considered the limitations of an appellate court on several occasions throughout his reasons for judgment. He closely reviewed the evidence of Dr. Hector, the expert witness called by the plaintiff to demonstrate that Dr. Stefaniu breached a reasonable standard of care. Counsel for Dr. Stefaniu had argued that Dr. Hector, in the course of his cross examination, had conceded that Dr. Stefaniu had not been negligent, but rather, had committed an error of judgment. As a matter of law, an error of judgement would not result in a finding of legal liability.¹⁴ However, Justice Armstrong concluded that there is “often a fine line between a mere error in judgment and a failure to meet the professional standard of care.”¹⁵ He concluded that “the jury could find that the line was crossed.”¹⁶ In other words, he was unwilling to conclude that the jury verdict—that Dr. Stefaniu was negligent—was so unreasonable that it ought to be set aside.

The Court was also asked to review the causal relationship between Dr. Stefaniu’s decision to discharge the patient December 5, 1996, and the murder of his sister on January 24, 1997. Dr. Stefaniu’s counsel had argued that even if she was wrong in changing the patient’s status from involuntary to voluntary, which resulted in him being released from the hospital, it was “unreasonable” to conclude that the murder was the result of Dr. Stefaniu’s negligence. Only several days before the murder, the patient had attended at two different hospital where it was determined, following medical assessments, one by a psychiatrist, that he did not meet the criteria for involuntary admission. Her counsel argued that even if the patient’s status had not been changed appropriately on December 5, Dr. Stefaniu, or another psychiatrist, would have changed it, appropriately, days or weeks after December 5, 1996, and before he killed his sister on January 24, 1997. However, Justice Armstrong did not agree. In his view, it was

Open to the jury to find on the basis of the evidence that but for the change in Johannes’ status to a voluntary patient on December 5, the murder of his sister would not have occurred. The jury was entitled to reject

the submission of counsel for the appellant, based on the evidence of the emergency room physicians, that Johannes’ status would have changed in any event prior to the date of the murder on January 25, 1997.¹⁷

This is another way of saying that the Court of Appeal, which was not present at the trial and did not hear the evidence directly, is paying deference to the “trier of fact”¹⁸ This is much different than a judicial finding that Dr. Stefaniu breached the relevant standard of care and was negligent. It is not the Court of Appeal asserting: “This jury was right: Dr. Stefaniu was negligent.” Rather, the Court of Appeal is saying: “You’ve asked us to overturn the verdict of the jury. However, we weren’t at the trial. We didn’t hear the witnesses testify. We’re not saying the jury is right, but unless you can show us that it was clearly wrong, we must, as a matter of law, defer to the verdict the jury reached.”

Implicit in the Court of Appeal’s decision is a message that in another case, even with similar facts, a different judge or a different jury might reach a different conclusion. Accordingly, as a precedent for other similar cases, *Stefaniu* is of limited value. The Court of Appeal decision merely confirms the binding precedent¹⁹ that an appellate court is restricted in its review of a trial decision and cannot overturn the decision unless there is an error of law or unless the finding of the trier of fact is so unreasonable that no properly instructed jury would have reached such a verdict. As experienced appellate counsel know, this is a very heavy onus to discharge and so it is not surprising that the Court of Appeal was unwilling to set aside the trial decision when one considers the limited jurisdiction for it doing so.

Accordingly, the *Stefaniu* decision does not stand for the proposition that the Court of Appeal concluded that Dr. Stefaniu was negligent. It did no such thing. It only concluded that it was not prepared, given its limited jurisdiction, to say the jury was clearly wrong and set aside its verdict.

THE ABSENCE OF REASONS

Even if the Court of Appeal decision does not represent a binding authority in future cases, won’t judges and juries look at the outcome at trial of the *Stefaniu* case in the future and consider it persuasive?

If the reasoning of the Court of Appeal in a particular case contains an analysis of a legal issue and reaches a reasoned conclusion as to the appropriate principle that should apply, this is binding on lower courts and judges. However, the finding of judge at trial in one court, i.e. the Superior Court of Ontario, is not binding on another judge of the Superior Court. It can be, however, “persuasive”. In other words, if a judge considers the reasoning and result in a similar case to be persuasive,²⁰ he or she may decide to “follow that case”. This is consistent with an important common law principle, namely, that it is helpful for the law to be consistent and predictable. To the extent that a judge can “do justice” by following the persuasive reasoning of another judge, this reinforces the principle. To make decisions that ignore other decisions—be they binding or persuasive—is inconsistent with the principles of common law and results in principles of law that are difficult to understand and apply.

Nonetheless, in *Stefaniu*, any persuasive value to the case is quite limited.²¹ Because it is a jury verdict, there are no reasons. Whereas a judge is required to provide a detailed analysis of the evidence and the reasoning that led to the particular result, there is no such obligation on a jury.²² The jury's task is limited to deciding factual issues such as credibility and weight of evidence, along with the finding of liability. There are no "reasons" to persuade a judge in another case. Moreover, if a similar case in the future is tried by a judge and jury, the jury will not consider other verdicts. By definition, the role of the jury is limited to "fact-finding", and therefore, it does not consider, and is not provided with, legal precedents to consider in reaching its own decision. Likewise, the judge, in instructing the jury, would have no reasons or precedent from the trial decision in *Stefaniu* to employ in instructing the jury.

Consequently, not only is the decision of the Court of Appeal of no binding precedential value in determining the standard of care to be applied to mental health professionals in future cases, the trial decision contains no "reasoned decision" that would be persuasive to judges or juries in future cases.

DUTY OF CARE

While the limited import of the Court of Appeal Decision in *Stefaniu* may be reassuring to psychiatrists who are concerned about being sued in similar circumstances, it is a deficient result when one considers that this decision, if "jury deference" is the fundamental principle for which it stands, does little to guide psychiatrists in future cases. What will a court do in a future case? If the purpose of the common law is to provide consistency and predictability to citizens, how does one know how to conduct oneself in the absence of a clear precedent? How should psychiatrists and other mental health professionals measure their legal obligation in discharging patients who may have the propensity to harm themselves or others?

Some guidance to these questions can be found in a somewhat cryptic comment contained in the reasons for judgment of Justice Armstrong. Having set out the specific grounds of appeal advanced by Dr. Stefaniu in challenging the trial verdict, Justice Armstrong, before beginning his analysis, identifies an issue that he will not address.

"It perhaps should be noted that 'duty of care' was not raised as an issue in this appeal."²³

There is a principle of appellate review, similar to the principle that a jury's findings will not be overturned unless unreasonable, in relation to issues that are raised or not raised upon appeal. Unless a party specifically asks the court to address a particular issue, it will not do so on its own motion. It is not clear from Justice Armstrong's reasons whether this was advertent or inadvertent on the part of Dr. Stefaniu and her counsel, but it is clear that "duty of care" is something the court did not consider and was not asked to consider.

"Duty of care" suggests a legal issue and is one in which the Court of Appeal had greater appellate latitude because, as opposed to being a "finding of fact", it is a legal issue upon which the Court of Appeal was unrestricted in second-guessing the trial decision.

Although we cannot know what the Court of Appeal would have decided had it been asked to address the issue of "duty of care", it is instructive to know that this issue was squarely raised by the Australian New South Wales Court of Appeal only a year earlier in the similarly-controversial case of *Hunter Area Health Service & Anor v. Preslend*.²⁴

In that case, a trial judge, who tried the case without a jury, awarded damages to a psychiatric patient for having been improperly discharged. The patient alleged that his psychiatrist had discharged him from a psychiatric facility in circumstances where he was a risk to himself and others as a consequence of mental illness. Six hours after the patient was released from the psychiatric hospital, he had killed the fiancée of his brother. He was subsequently acquitted of the murder of his brother's fiancée on the grounds of mental illness, but was then committed to a psychiatric facility. One of the substantive issues put before the New South Wales Court of Appeal was:

The nature and content of the duty of care owed to patients presented for psychiatric assessment both at common law and under the Mental Health Act, 1900 and whether there was a breach of the duty of care. [Emphasis added]²⁵

In *Preslend*, the facts were unusual in that the patient sought damages he personally sustained as a result of being incarcerated in a psychiatric facility once he had been found to be not criminally responsible for the death of Ms. Laws. All three judges identified "public policy" as a consideration by which the court should be mindful. However, the decision was not unanimous. One of the appeal judges dissented and would have allowed the trial decision to stand. However, he was overruled by the majority. The length and complexity of the reasons delivered by all three judges underscore the difficulty they had in reconciling, on a principled basis, the nature and content of the duty of care in that case. In the *Stefaniu* case there was no similar debate amongst the judges of the Court of Appeal.

CONCLUSION

The response to the *Stefaniu* decision by mental health professionals can be visceral.²⁶ How can it be that Dr. Stefaniu was found civilly responsible for the death of the patient's sister, 59 days after the patient left her facility and after he had been assessed by two other physicians—one of them a psychiatrist—on two separate occasions, several days before the murder, and found not to be a threat to himself or others? The simple, and perhaps trite, answer is that this is the verdict the jury reached after hearing the evidence in that case.

What about the follow up question: does that mean that other mental health professionals in a similar situation will face the same civil responsibility? The answer to that question, in my respectful opinion, is: we don't know yet, but quite possibly, not. This was a jury verdict that has very limited, if any, application to other cases. While the Court of the Appeal considered the case, it did so in a narrow way and specifically stated in its decision that it did not examine the substantive legal issue of "duty of care". If it had done so, it might have reached a different conclusion. In *Preslend*, the Court of Appeal of New South Wales considered this issue, and in

the circumstances of that case concluded that there was no duty of care and overturned the trial decision. An Ontario Court, in a future case, may examine this issue more closely than has occurred to date and reach a similar conclusion. .

Competing Interests: none

Acknowledgements: none

End Notes:

1. I wish to thank Gillian Wilkins, student-at-law, for her assistance in preparing this paper for publication. All errors, of course, are my own.
2. 17 Cal. 3d 425. (Sup. Ct. Cal. 1976).
3. *Supra* at 442
4. Considered in: *Smith v. Jones*, [1999] 1 S.C.R. 455; Referred to in: *Healey v. Lakeridge Health Corp.*, [2006] O.J. No. 4277 (Ont. Sup. C.J.); *Farrows-Shelley v. Canada*, [2003] F.C.J. No. 574 (Fed Ct. (Q.L.)); and *Wenden v. Trikha*, [1991] 116 A.R. 81 (Alta. Q.B.).
5. Douglas M. Smith, "Wenden v. Trikha and Third Party Liability of Doctors and Hospitals: What's Been Happening to Tarasoff", 4 Health L. Rev. No. 2, at 12-25; Jessica Van Exan, "The legal and ethical duty to warn in the practice of psychology", (November, 2004) 18 W.R.L.S.I. at 123, and see also Adam M. Dodek "The Public Safety Exception to Solicitor-Client Privilege: *Smith v. Jones*", (2000) 34 U.B.C.L. Rev. at 293 – 315.
6. *Ahmed v. Stefaniu*, [2006] 275 D.L.R. (4th) 101
7. [2006] S.C.C. No 498
8. Barankin, G., National Review of Medicine, (2005) Vol. 2, No. 20.
9. Justices Gillese and Juriansz concurred in the decision and with Justice Armstrong's reasons.
10. *Gerbracht v. Bingham* (1912), 7 D.L.R. 259 (Ont. H.C.) and *Town v. Archer* (1902), 40 O.L.R. 383. The cases held that the combination of inherent complexity and perceived bias of the jurors towards the patient plaintiff made a jury trial inappropriate.
11. *Soldwisch v. Toronto Western Hospital*, [1983] 43 O.R. (2d) 449.
12. *C.N.R. v. Muller*, [1934] 1 D.L.R. 786 (S.C.C.). The justification for this limitation is that the jury was in a position to see and hear witnesses testify and were in a better position than an appeal court – which must rely upon transcripts and does not hear oral evidence or see witnesses – to make findings of credibility and to weigh and balance contradictory evidence.
13. Error: *Earle v. Smith* (1972), 22 D.L.R. (3d) 34 (N.S.C.A.); *Nielsen v. Fredrikson*, [1983] B.C.J.No. 1315(C.A) (Q.L); *Giurlando* (Litigation Guardian of) *v. Cammalleri* (1999), 30 C.P.C. (4th) 229 (Ont. C.A). Inadequacy: *Katsiroumbas v. Dasilva*; *Katsiroumbas v. Shack* (1982), 132 D.L.R. (3d) 696 (Ont.C.A.)
14. *Elverson v. Doctors Hospital* (1974), 4 O.R. (2d) 748, 49 D.L.R. (3d) 196 (C.A.); affd (1976) 65 D.L.R. (3d) 382n (S.C.C.).
15. paragraph 35.
16. paragraph 35.
17. paragraph 44.
18. The trier of fact may be the judge or the jury who hears the testimony and reviews the evidence to rule on a factual issue. Bryan A. Gardner, ed., *Black's Law Dictionary*, 8th ed. (St. Paul, Minn: West Publishing, 2004).
19. A binding precedent is a principle that a court of equal or lesser jurisdiction must follow. (*R. vs. Smith* (1988) 44 C.C.C. (3) 385 (Ont. H.C.J.)).
20. *R v. Henry*, [2005] 3 S.C.R. 609
21. *Ter Neuzen v. Korn*, [1991] B.C.L.R. (2d) 125 (B.C. Sup.Ct.)
22. *R v. Pan*; *R v. Sawyer*, [2001] 2 S.C.R. 344
23. Paragraph 26.
24. [2005] S.W.C.A. 33.
25. Presland, fn. 24, Headnote.
26. I presented the *Stefaniu* case to a large group, composed mostly of mental health professionals, at the *Mental Health Law Conference* held at Whitby Mental Health Centre on October 24, 2007. At the conclusion of my presentation I asked for a show of hands from those who thought the Court of Appeal got it right, i.e. upheld the decision of the jury, and from those who thought they got it wrong. As may not be surprising, I saw no raised hands in response to the "did they get it right?" question. The thrust and content of the comments and questions that followed this straw poll strongly suggested that the audience found the result highly disturbing.

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Why I am Afraid to Write for this Journal – But Really Should Anyway

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Ethics in mental health is a critical area of our everyday life and work whether we are someone who lives with mental illness, or someone who works with those who do. Issues arise everyday that warrant attention, thought and analysis. With this journal, we now have a venue to discuss and share ideas with each other from a vast diversity of experience. Despite this, those of us who sit on the editorial committee frequently speak to people we know have something important to say, and yet are intimidated by the expectations they feel would need to be met to publish in this journal.

I am a psychiatrist, with an academic position at a University Department of Psychiatry, having been in that business for almost 2 decades, and yet I feel as well that I am unqualified to write intelligently for this journal, feeling that I lack the academic rigour to properly analyze my experiences in a way that would be suitable for publication. From the outside, some may wonder how that can be, but medical faculties now are often made up of people who are increasingly recognized academically for their contribution outside of the traditional publication and research component of the academic mission. At the same time, if I am too intimidated to write for this journal, then who else is similarly excluding themselves from this opportunity to be part of an important forum to advance ideas in mental health ethics?

This journal provides multiple ways to contribute beyond classic academic or research papers, but even something like sharing a case is intimidating for me, as to do so raises the question in my mind as to whether in fact my case will reflect my ignorance and unethical approach to practice. Fear of being wrong, or of making a mistake is recognized as being a major challenge in health care perhaps driven by an increasingly litigious world where mistakes can trigger law suits, but also perhaps because our slow retreat from paternalism as a profession has deprived us of the refuge of “doctor knows best”, even as it has advanced important issues of autonomy and consent, and significantly improved health care in the long run by promoting a shared partnership between a person with an illness and a care provider. The focus on safety in health care^{1,2} recognizes that creating an atmosphere in which errors can be discussed in a non-judgemental way that promotes self reflection can be an important driver in reducing errors in health care. Similarly, ethical practice will surely benefit from an environment in which we all openly discuss the situations that we face as the ethical issues usually best become clear in an open discussion with people from a variety of backgrounds. The biggest challenge for people working in the field, myself

included, then is to risk being seen as less than perfect, talk openly about what we do and the struggles we see, and share and receive feedback in a way that takes joy from the advancement of knowledge that arises from this to and fro discussion. As Peter Falk demonstrated in “Columbo”, the path to truth often requires a muddy and uncertain beginning.

With the tremendous explosion in numbers of journals, and opportunities for publication, as well as conferences at which papers can be presented, one would think that the opportunity to publish would expand proportionately. At the same time however, the desire for increasing academic rigour and the focus on evidence based decision making which values most work that reaches a certain experimental standard, may be leading to the removal of the voice of the clinician and the person with the illness from traditional vehicles for academic discussion. More and more journals require submissions with structured abstracts that fit an experimental model best, but make it difficult for clinicians for example to share their unstructured experience. Even in the midst of planning a revolution with Fidel Castro, Dr. Ernesto (Che) Guevara took time from his small practice in Mexico to present a paper at a conference on allergies, but increasingly conference proceedings in medicine are dominated by research papers that each follow a similar methodology, and are increasingly beyond the means of a single clinician providing front line care.

As a field ethics is somewhat unique at least within health care, in that the material of study is the experiences of all who exist within a system, whether they are people who have a particular illness, their family members or the people who provide care for such individuals. Thus if the only voice is that of the academic who is most equipped with the theoretical and background knowledge that facilitates the writing of a high level analysis of an ethical, the field is potentially deprived of the very material on which any analysis is based – the experience and voices of people from everywhere in the system.

The challenge then for me, and for others who are interested in this area, and who may have already enjoyed this journal, is to take the chance to speak out and say something, whether the language is correct or not, whether there are references or not that can be cited, and to risk being “wrong”. This journal has been founded with a goal of being broadly applicable to people with mental illness, front line clinicians, and more traditional academics, and to reflect all of those voices in the journal.

Competing Interests: None

Acknowledgements: None

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