

1. As a web-based journal, we are able to compile statistics on our readership numbers and their countries of origin. We would like to thank the tens of thousands of readers who have visited our journal site to date, and we want to share with you that in the last month alone we have had visitors from 22 countries around the globe.
2. Congratulations to the winner of this year's "Bernard Dickens Student Award for Writing in Mental Health Ethics". He is Daniel L. Ambrosini, PhD candidate at the Mental Health and Law Laboratory, McGill University's Department of Psychiatry. His article entitled "Perceptions of Psychiatric Advance Directives Among Legal and Mental Health Professionals in Ontario and Quebec" was published in the November 2008 issue of the Journal. The award is given each year to a deserving student whose article demonstrates the qualities of writing that best exemplifies the focus of the Journal.
3. We have introduced a new section to this issue called "Research Reflections". On occasion, we have received submissions that highlight research challenges, or represent reflections on research in progress or planned research directions. While not meeting criteria for our regular article category, we felt that some of these pieces raised interesting questions or ideas that are worth sharing with our readers. Accordingly, we may from time to time publish pieces under the "Research Reflections" heading that have not been subject to blind peer review but that our Editorial Committee felt merited broader exposure to our frontline audience.
4. In addition to the professional literature indexes that already list the Journal of Ethics in Mental Health, it is a pleasure to announce that JEMH is now indexed in Medline.
5. We regret that the planned special theme issue articles on the relationship between the pharmaceutical industry and psychiatry have been unexpectedly delayed. These will be published shortly as a special theme supplement.

Enjoy this issue of JEMH. We would be pleased to receive your comments and suggestions. Your articles are always welcome.

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Rethinking Compassion Fatigue as Moral Stress

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ABSTRACT

Health and social services professionals often interact with individuals who are economically and socially marginalized because of age, race and/or disability. Providing services to these individuals involves complex emotional and ethical reasoning. As a consequence, these professionals are subject to compassion fatigue and also, moral stress. While the professional literature recognizes compassion fatigue and moral stress as distinct concepts, this paper demonstrates that a more complete understanding of compassion fatigue includes a previously ignored moral component and proposes that compassion fatigue is more correctly understood as a form of moral stress.

Key words:

Compassion Fatigue, Moral Stress, Marginalized Populations

Introduction

Health and social services professionals often provide services to individuals who are socially and economically marginalized because of age, race and/or the presence of some form of physical, mental or emotional impairment. Providing services to these individuals involves complex emotional and ethical reasoning. Consequently, professionals experience both compassion fatigue and also, moral stress. While the professional literature recognizes compassion fatigue and moral stress as distinct concepts, this paper demonstrates that a more complete understanding of compassion fatigue includes a previously ignored moral component and proposes that compassion fatigue is more correctly understood as a form of moral stress.

Compassion Fatigue

Compassion fatigue is an emotional response which occurs within the professional and in response to the clinical material presented by clients. Najjar et al (2009) reviewed recent research on compassion fatigue and concluded that the term is generally used when referring to the secondary trauma experienced by

a professional as he/she engages with the traumatic stories of clients. They suggest that it is the act of providing empathy, understood as entering or projecting oneself into the worldview of the client, which is the source of the trauma. As Sabo (2006) notes, it is the exposure to suffering in another person which leads to compassion fatigue. In this way, compassion fatigue is distinguished from post-traumatic stress disorder in which the individual is directly exposed to the traumatic event (Sabo, 2006). This view of compassion fatigue is supported by many authors working in this area including Bride, Radey and Figley (2007) and also, Siebert (2004).

Figley (2002) distinguishes between compassion fatigue and compassion stress. Compassion stress is the precursor to compassion fatigue and is defined as the emotional residue left behind after the provision of empathy and the ongoing demand to relieve the suffering of others. According to Figley, when compassion stress builds over time, it leads to compassion fatigue. The professional who experiences compassion fatigue experiences a reduction in the ability to bear the suffering of others and is often left feeling confused, helpless and isolated from peers. Figley (2002) and Najjar et al (2009) make further distinctions between compassion fatigue and burnout. While compassion fatigue can develop quickly and in response to the suffering of others, burnout builds gradually through continued exposure to emotional and organizational demands. Burnout leads to mental, physical and physical exhaustion in the professional (Najjar et al 2009, Figley, 2002).

Taking a closer look at the word 'compassion' both supports and challenges current understandings regarding compassion fatigue. As the dictionary defines compassion, it is sympathetic pity and concern for the suffering of others (Soanes, 2001). Current uses of the word 'compassion' tend to focus on the role of sympathy and empathy (Schantz, 2007; Nussbaum, 2001). While both empathy and sympathy refer to feeling states, they are distinguished by the prefix indicators 'em' and 'sym'. Consequently, 'sym' means that sympathy is a state of being in which an individual is simultaneously affected with the same feeling as someone else while the prefix 'em' or 'in' suggests the word empathy refers to the ability to enter into, but not share, the feelings states of another person. Therefore, sympathy is the experience of shared states or feelings and empathy is the act of imaginatively reconstructing the circumstances of another person without the shared experience of pain or suffering (Davies, 2001; Nussbaum 2001). As these concepts are applied to clinical relationships,

professionals are encouraged to provide empathy and discouraged from the experience of sympathy (Schantz, 2007; Nussbaum, 2001). According to Schantz (2007), empathy is viewed as more valuable to the clinician because it supports a more detached and observational role for the professional.

Compassion is a complex response generated by the suffering of others. It is meant to be translated into compassionate behaviour. This move from response to behaviour is mediated by several factors. According to Nussbaum (2001), compassionate behaviour is motivated by the recognition that there is suffering in another person and that this suffering is serious. Therefore, circumstances which require a compassionate response are not trivial or minor in nature; there is a magnitude or severity to the situation. In addition to magnitude, there is some recognition that the suffering is not deserved. Compassion occurs in response to bad luck or circumstances that are beyond one's control; it is not a response to actions which might be blameworthy or consequences which are the direct result of risk taking or personal negligence. Degrees of innocence or magnitude are subject to evaluative processes mediated by ethical frames of reference. Consequently, each compassionate response can be traced to a foundation in ethics.

The preceding discussion regarding compassion and compassionate behaviour draws attention to a missing element in current approaches to compassion fatigue. As discussed by Nussbaum (2001), all compassionate behaviour is informed by value judgments. The definition of compassion fatigue as the reduced response to suffering in another person neglects the ethical foundations of this experience. Having established that value judgments play a role in compassionate behaviour, it is arguable that compassion fatigue is both an emotional and ethical experience. Through its discussion of moral stress, the next section highlights some unexplored connections between moral stress and compassion fatigue.

Moral Stress

Professionals are exposed to, and expected to resolve, ethical conflicts on a regular basis. Generally speaking, when presented with an ethical dilemma, the professional lists possible choices of action, uses ethical codes of conduct to identify the most appropriate course of action and then, follows through with this action. According to Gibson (2003), most ethical conflicts include competing demands between an individual, his/her employer and professional ethics. However, through the careful consideration of ethical codes of conduct, the professional eventually arrives at what would be described as either the least harmful or the right course of action.

While ethical conflicts can be resolved through the application of ethical codes of conduct, moral stress occurs in response to a unique type of ethical conflict. Lütznén et al (2003) distinguish between moral distress and moral stress. More specifically, moral distress is the impact that moral decision making has over time on the professional while moral stress refers to the awareness that competing values are at play and that they cannot be resolved due to external constraints. As Raines (cited in Kälvemarm et al., 2004) uses the term, moral stress refers to situations in which the professional knows the right thing to do but is prevented, for

various reasons, from engaging in what he/she has defined as the right course of action. As such, moral dilemmas are recognizable because they are experienced by the professional as 'no-win' situations. Adding to the view that there is a moral quality to health care work, Lütznén et al (2006) argue that moral values are at play in clinical decision making and that moral sensitivity encourages awareness of the role that values play in the workplace. When health care workers are repeatedly exposed to these 'no-win' conflicts between moral values, they experience moral stress or burden (Lütznén et al, 2006).

The concept of moral stress is gaining recognition within the healthcare literature. While Lütznén et al (2006) acknowledge the benevolent sentiment which motivates moral behaviour; they do not want moral stress reduced to an emotional or cognitive experience. However, Greenfield (2007) proposes that the role of emotions should not be downplayed as discomfort, stemming from emotions like guilt and contempt, gives the professional an early indication that an ethical conflict is occurring. In addition, Tessman (2005) suggests that continued exposure to moral conflicts and decision making have emotional consequences which cannot be ignored.

Tessman (2005) is primarily concerned with moral conflicts and the impact that these have on those who work with people who are marginalized due to race, age or disability. She is particularly concerned with tragic dilemmas, those dilemmas which are not resolvable due to external constraints and which are referred to as 'no-win' situations within the moral stress literature. Lütznén et al (2006) believe that these dilemmas lead to a moral burden in the professional while Tessman defines the impact as a moral trace or remainder. However, Tessman goes beyond recognizing the moral impact on the professional. She argues that professionals working with those who are marginalized, due to race, age or disability, are emotionally affected by their work. More specifically, professionals may need to use anger when advocating on behalf of clients in order to assist them in accessing social and financial resources. While the strategic use of emotions is recognized within the literature on emotional labour (James, 1992; Brotheridge and Grandey, 2002; Zapf, 2002), Tessman believes that the professional who continues to respond to suffering, over time, must choose between indifference and anguish. Professionals who are morally burdened may also experience emotional exhaustion, confusion and hopelessness. Although Tessman does not use the word compassion fatigue to describe the accumulation of these stresses, her description of the impact on the professional is very similar to that provided by those writing in the area of compassion fatigue.

According to Tessman (2005), the professional who responds compassionately to the suffering of others, over time, will experience either indifference or anguish. As outlined by Figley (2002), "compassion fatigue, like any other kind of fatigue, reduces our capacity or our interest in bearing the suffering of others" (p. 1434). Mathieu (2007) also describes compassion fatigue as an emotional experience which is characterized by emotional exhaustion. Compassion fatigue experienced as emotional exhaustion is further supported by Najjar et al (2009). The consequences of compassion fatigue are described using very similar terms and these similarities lead one to question the distinctions between compassion fatigue and moral stress. Furthermore, the work done by Nussbaum (2001), in which she

outlines the ethical foundations to compassionate behaviour, lends further credibility to the argument that compassion fatigue is a form of moral stress.

The links between compassion fatigue and moral stress indicate that compassion fatigue is a complex concept. The following section provides a case vignette which illustrates compassion fatigue as moral stress. The vignette provides a foundation for the discussion of clinical implications associated with these arguments.

Case Vignette

Jen is a counselor working for a local community mental health agency. This agency integrates individuals with mental health challenges back into the community after hospitalization. Recently, Jen finds her energy lacking. She is worrying more about her vulnerable female clients who, due to lack of financial resources, are forced to live in rougher parts of the city. She notices that she is becoming far more aggressive in her approach to lobbying for increased financial supports to her clients. Upon her return home at the end of the day, Jen needs to take long showers before she can 'switch gears' and reconnect with her family and their concerns. Jen seeks out the services of her Employee Assistance Program. Her EAP counselor suggests she has compassion fatigue and gives her emotional awareness exercises as homework. Jen uses the strategies but doesn't feel much better. She just cannot let go of the guilt and anger she feels about her clients and their living conditions. When Jen finally speaks to her supervisor, she is encouraged to think of her fatigue and its moral foundations. Jen comes to understand that her ability to respond compassionately is affected by her judgments about a variety of issues. She sees her clients as victims whose suffering is worsened by strict government policies. The anger she feels at this injustice and the anger she uses to mobilize government services on behalf of her clients are hard to let go of at the end of the day. She concludes that her fatigue is a complex interaction between emotions and judgments and that she needs to take a different approach to her compassion fatigue.

Discussion

Through the case vignette, we see a client who is exposed to two different ways of thinking about compassion fatigue. Viewing compassion fatigue as emotional exhaustion due to vicarious trauma means that Jen is encouraged to develop her emotional awareness skills. Other strategies which come out of this approach include the recommendation that Jen discuss the issue with colleagues, seek out debriefing when necessary and, finally, develop her awareness and capacity to respond when experiencing the early warning signs of compassion fatigue (Mathieu, 2007). Bride, Radey and Figley (2007) would also recommend that Jen focus on developing her intellectual, social and physical resources in order to manage her stress while implementing self-care strategies which promote optimism, happiness and positive attitudes. While viewing compassion fatigue as vicarious trauma leads to a focus on emotional and self-care as well as stress management in Jen, the introduction of a moral element would mean encouraging her to educate herself regarding the contributions that morals and value judgments have made to her experience of compassion fatigue.

Kirschner et al (2001) propose that professionals like Jen need more than brief training in ethical behaviour to cope with the impact of moral stress. Ethical training is considered inadequate as the content of ethical dilemmas will change over time and providing this kind of training may lead some professionals to conclude that all ethical conflicts can be resolved through the standardized application of codes of conduct. Gibson (2003) suggests that training in moral awareness is a more appropriate approach. This means encouraging the professional to accept that conflicts are a part of life and that the role of the professional includes making difficult choices under complicated circumstances. Through promoting moral awareness and also, autonomy in thinking and decision making, professionals are better able to discern which dilemmas are resolvable through the application of codes of ethics and which require more independent thinking and problem solving. Taylor and Bentley (2005) also encourage professionals to learn more about existentialism. The professional would learn that anxiety and guilt are inevitable consequences of decisions made in the face of difficult situations both at work and at home. Jen, the professional in the case vignette, would be encouraged to understand that she will have unresolved emotions about her difficult cases and that she will carry some residual anxiety and guilt home with her at the end of the day. She will gain further insight into and support for her 'cleansing rituals' and realize that these are important tools for switching gears at the end of the day. Finally, as Tessman (2005) suggests, professionals like Jen can reduce the impact of moral stress through recognizing that suffering and sadness can co-exist with more positive emotions like joy. In other words, professionals need to strive for emotional equilibrium in order to buffer themselves from the consequences of exposure to suffering in others.

Conclusion

The current literature on compassion fatigue presents an incomplete definition of the problem. A closer look at compassion, compassionate behaviour and moral stress reveals previously unidentified connections between these concepts. While the implications of these connections require more detailed discussion and debate, they provide justification for the argument that compassion fatigue is a form of moral stress.

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Restraint to facilitate treatment: Is it compatible with least restraint principles?

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In a 2008 decision, *S.M.T. v. Abouelnasr*,² the Superior Court of Ontario (Canada) considered for the first time whether restraint could be construed as “treatment” under the *Health Care Consent Act* (“HCCA”). The case was an appeal by S.M.T., an involuntarily admitted psychiatric patient who had applied to the Consent and Capacity Board (“CCB”) for a review of his involuntary status and capacity to consent to treatment. When the CCB confirmed both matters, the patient appealed the decisions to the Superior Court. On appeal, the patient challenged the constitutionality of the use of restraints for the purpose of administering treatment to incapable persons, on whose behalf a Substitute Decision Maker (“SDM”) had consented.

History of case

By way of background, the patient had been involved in a serious motor vehicle accident in 1987.³ As a result, the patient acquired a brain injury, which in turn gave rise to a significant change in personality, a Psychotic Disorder and cognitive impairment. Since the motor vehicle accident, he had had several contacts with various psychiatric facilities.

In 2001, the patient was charged with several criminal offences, in relation to which he was found unfit to stand trial. As a consequence, he was ordered detained at a forensic psychiatric facility and subject to annual review by the Ontario Review Board.

In November 2005, the patient’s then attending psychiatrist had determined he was incapable with respect to treatment with anti-psychotic medication, mood stabilizers and anti-depressants. This determination was confirmed by the CCB on November 28, 2005. The decision was not appealed and a member of the patient’s family began to act as his SDM. In February 2006, the patient was acquitted of the criminal charges following a *prima facie* inquiry under s. 672.33 of the *Criminal Code*. At that point, the SDM consented to his continued admission at the facility (so that he then became what is referred to as an informal patient).

During the informal admission, the patient was treated pursuant to the SDM’s consent with some clinical improvement in his condition noted. In June of 2007, a new attending psychiatrist assumed care of the patient. He determined that the patient remained incapable

with respect to anti-psychotic medication. Due to the patient’s non-compliance with the oral anti-psychotic medications and consequent deterioration, the physician also determined that the patient would benefit from a long-acting anti-psychotic medication to be delivered intramuscularly by injection. The SDM’s consent to the treatment was obtained and a consent form was signed.

The consent form confirmed that the SDM has also consented to:

“such additional diagnostic or treatment procedures which, in the opinion of the staff providing the above-noted treatment, are considered incidental to the procedure or immediately necessary and vital to the patient’s health and/or life.”

When the patient was advised that the SDM had consented to the IM injection, he became aggressive and threatening towards staff. It was determined that the patient could not be continued as an informal patient and his status was changed to involuntary, as provided for in the *Mental Health Act*. The same day, the attending physician administered an intramuscular injection of anti-psychotic medication. Due to the patient’s forceful resistance to the medication, he was restrained during the administration of the treatment.

A week later, the patient applied to the CCB to review his involuntary status and the finding of incapacity. Prior to the date agreed to for the CCB hearing, the patient’s involuntary admission was renewed as required by the timelines mandated by the *Mental Health Act*. The patient also received a second injection of medication, which was consented to by his SDM, as no new treatment had been commenced prior to the application to the CCB. The patient was restrained for the second injection.

The CCB confirmed that the patient met the criteria for involuntary admission as at the time of the hearing, and also confirmed the incapacity finding. The patient appealed the CCB’s decision, and added two grounds of appeal:

- Whether the patient’s constitutional rights were violated by the physician when he administered the intramuscular injections of medication under the SDM’s consent; and

- Whether the HCCA infringed certain sections of the Charter in so far as that legislation permitted the injection, under restraint, of anti-psychotic drugs for the purpose of treating incapable persons.⁴

The Court Decision

As the appellant had raised constitutional issues, the Attorney General of Ontario was provided with notice of the constitutional challenge and obtained leave to intervene to defend the legislation.

The Court first considered the appeal on the merits of the primary issues raised; that is whether the CCB had erred in finding that the patient was incapable with respect to treatment and in finding that the criteria for an involuntary admission had been met at the time of the hearing. The judge found that the Board's decision on these two issues was reasonable and did not allow the appeal on those grounds.

The judge then went on to consider the appellant's argument that the *Health Care Consent Act* provisions which permit the forcible injection of anti-psychotic drugs into incapable persons infringed section 7, 12 or 15 of the Canadian *Charter of Rights and Freedoms*.⁵

Ultimately, the Court held that the scheme set out in the HCCA for the administration of treatment to incapable persons under substitute consent provides sufficient procedural safeguards to protect the rights of incapable patients, as guaranteed by Canadian *Charter of Rights and Freedoms*.

In particular, the Court held that the definition of "treatment" in the Act, which includes "anything that is done for a therapeutic, preventative, palliative, diagnostic, cosmetic or other health-related purpose"⁶, includes by necessary implication the use of restraints, if necessary to administer treatment safely to incapable persons, provided that his or her substitute decision maker has consented to treatment. Madam Justice Lack wrote:

"Since where substitute consent is obtained, treatment may be administered without the personal consent of the patient it is a necessary implication that a health care professional may have to restrain the person in appropriate circumstances in order to administer non-consensual treatment safely. Thus the use of restraint is something for a health related purpose."⁷

The judge, citing *Fleming v. Reid*,⁸ confirmed that the forcible injection of anti-psychotic drugs into one's body on a non-consensual basis engages a person's interests under section 7 of the *Charter*, particularly the right to security of the person; and that any legislation that authorizes such treatment "must comport with the principles of fundamental justice."⁹

In *Fleming v. Reid*, the Court of Appeal had considered the legislative scheme of substitute decision making in force at that time. Under sections of the *Mental Health Act* since repealed, a Review Board could authorize the forcible treatment of an incapable person, over the objection of a substitute decision maker who was in good faith complying with a prior competent wish as required by the same legislation. The Court of Appeal held that

such a scheme violated section 7 of the *Charter*.

The judge in *S.M.T.* noted that the HCCA (enacted some five years after the C.A. decision in *Fleming v. Reid*) sets out rules to guide SDMs in making decisions on behalf of incapable persons, as well as other procedural and substantive safeguards for patients who have been found incapable with respect to treatment. In the result, the judge found that the scheme in the HCCA that governs substitute decision making for incapable patients, including the application of restraint to facilitate treatment of incapable persons; was constitutionally sound and did not violate the Charter under either section 7, 12 or 15.¹⁰

Where do health care providers go from here?

The restraint of psychiatric patients, incapable or otherwise, is understandably a subject of concern to healthcare providers, incapable patients and their SDMS, whether the patient is admitted to a psychiatric facility or in the community. As Justice Robins wrote in *Fleming v. Reid*:

The right to determine what shall or shall not, be done with one's own body, and to be free from non-consensual medical treatment, is a right deeply rooted in our common law. This right underlies the doctrine of informed consent. With very limited exceptions, every person's body is considered inviolate, and accordingly every competent adult has the right to be free from unwanted medical treatment.¹¹

In addition, the enactment of Ontario's *Patient Restraints Minimization Act* ("PRMA") in 2001, as well as a recent Coroner's Inquest that reviewed the circumstances surrounding the death of a forensic psychiatric inpatient while under restraint,¹² has focused attention on creating a culture of least restraint in the provision of health care generally in various settings.

It is important to note that the PRMA does not apply to persons involuntarily detained in psychiatric facilities under the MHA. (13) While certain provisions of the MHA provide for the detention and restraint of persons who meet the criteria for a Form 1 assessment and patients who meet the criteria for an involuntary admission, the Act is clear that nothing *in the Act* authorizes the restraint or detention of an informal or voluntary patient.¹⁴ In other words, health care providers must look elsewhere for the authority to restrain patients who are not involuntary patients.

The HCCA, in addition to providing rules for determining capacity and substitute decision making, expressly preserves the common law duty of a healthcare provider to restrain or confine a person when immediate action is necessary to prevent serious bodily harm to the person or others.¹⁵ In the mental health care context, this common law duty has been resorted to in emergent situations requiring, as the provision suggests, "immediate action." Addressing the refusal of medication by an incapable patient, where the treatment has been consented to by an SDM, generally does not require the kind of immediate action contemplated by the common law duty (although it may in certain circumstances). It is in the non-urgent situation, where the treatment team anticipates difficulty in engaging the incapable patient's cooperation with

treatment, that the *S.M.T.* decision is likely to be most helpful to mental health care providers.

It is generally acknowledged that patients should be encouraged to participate in treatment decisions, whether the patient is capable or not, and consequently, the decision to restrain an incapable patient in order to facilitate treatment under substitute consent may seem counterintuitive to that therapeutic impulse.

The 2008 *S.M.T.* decision allows health care providers to consider and plan for the restraint of the incapable patient, as may be required, in order to facilitate the safe administration of non-consensual treatment, lawfully consented to by an SDM. (16) It is instructive to return to the underlying purposes of the HCCA, as Madam Justice Lack did in her reasons for decision, and note that they include not only promoting the autonomy of capable persons, but also “protecting the welfare of persons who would benefit from treatment, but who are incapable of giving consent.”¹⁷

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2. [2008] O.J. No. 1298 (S.C.J.) [hereinafter cited as *S.M.T.*].
3. The facts set out in this section are taken from the publicly available Reasons for Judgment, *supra* note 2, and in the exhibits that were filed at the Consent and Capacity Board hearing, thus forming part of the record of the appeal.
4. *S.M.T.*, *supra* note 2, at para 11.
5. Part I of the *Constitution Act*, 1982, being Schedule B to the *Canada Act* 1982 (U.K.), 1982, c. 11; Section 7 of the Charter guarantees that a person's interest in “life, liberty and security of the person” shall not be infringed unless such infringement is in accordance with the principles of fundamental justice; Section 12 guarantees a person's right to free of cruel or unusual treatment; and Section 15 guarantees a person's right to equal benefit of and equal protection under the law, without discrimination
6. *Health Care Consent Act*, 1996, S.O. 1996, c. 2, Sch.A, s. 2.
7. *S.M.T.*, *supra* note 2, at para 53.
8. (1991) 4 O.R. (3d) 74 (Ont. C.A.)
9. *S.M.T.*, *supra* note 2, at para 54.
10. *Ibid.*, at paras 56 – 65.
11. *Fleming v. Reid*, *supra* note 8.
12. Inquest into the death of Jeffrey James; verdict October 10, 2008. Recommendations available at: <http://www.mcscs.jus.gov.on.ca/stellent/groups/public/@mcscs/@www/@com/documents/webasset/ec070944.pdf>
13. *Patient Restraints Minimization Act*, S.O.2001, s. 2(2): “This Act does not apply in circumstances in which the Mental Health Act governs the use of restraints on patients or other persons in psychiatric facilities.”
14. *Mental Health Act*, R.S.O, 1990, c. M.7, s. 14.
15. *HCCA*, *supra* note 6, s. 7.
16. *S.M.T.*, *supra* note 2, at para. 53.
17. *Ibid.*, at para 57; see also *HCCA*, *supra* note 6, at s. 1.

Is it possible to ethically research the mental health needs of the Somali communities in the UK?

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ABSTRACT

This article summarises ethical issues that arise when researching common mental disorders within the Somali communities in the UK. It addresses the danger of researching these disorders from a Eurocentric perspective which risks overlooking the difference in conceptualisation of mental illness between different cultures in the West and Somalia. An ongoing study exploring Improving Access to Psychological Therapy (IAPT) for Somali people in the UK is presented. The participants' own meaning of mental health and illness as well as their conceptualisation of anxiety and depression are examined. In developing the study, standard research paradigms are critically examined in order to take account of the unique aspects of Somali culture and experience. Focus group method is adopted to uphold both ethical and methodological rigour in the research. A participatory approach for developing ethical protocols within different refugee communities is recommended.

Key words:

Focus groups, research methods, ethics, mental health, depression, Somali.

Background

The United Nations High Commissioner for Refugees (2006) recorded that there are over 301,100 Somali refugees around the world (these figures are from just the nine most developing countries in the world). In the UK, the 2001 census recorded over 43,470 Somali refugees living in the United Kingdom whereas other sources have argued that this figure is over 90,000 (ICAR,

2007; Hopkins, 2006). The large presence of Somalian refugees in the UK is due to the ongoing atrocities, wars, violence, and torture in Somalia (Wilson & Drozdek, 2004) which, according to Home Office's Country of Origin report (2008), continue unabated in Somalia.

Since the collapse of Somali central government in 1991, Somalians in Somalia have not had full access to mental health and psychiatric help (Pumroy, 2008; Tyler, 2008). The World Health Organisation (WHO, 2005, 2006) reported that the whole mental health service set-up within Somalia is based on the efforts of the General Assistance and Volunteer Associations (GAVO) and a local Somali NGO that attempt to provide basic mental health services to psychiatric patients. They also help street children and train primary health care personnel. The report also mentions that the conditions of the three mental health hospitals in Somalia are appalling as there is no psychiatric inpatient service and no specialised drug abuse treatment program. In fact, there is no mental health training facility in the whole country. It appears that most mental health care providers in Somalia lack adequate training and knowledge.

The UK experience

Common mental disorders are highly prevalent within the UK Somali community (Bhui et al., 2006; Warfa et al., 2006; McCrone et al., 2005) and this community is increasingly isolated from the mainstream population (Casciani, 2006)

Social research has consistently reported that Black Minority Ethnic (BME) communities, which include Somalians, are not accessing psychological therapy (Department of Health, 2007; Sainsbury Centre for Mental Health, 2004). In response, the Department of Health has introduced a new initiative called, "Improving Access to Psychological Therapy" (IAPT); part of its

agenda is to help BME communities access psychological therapy through primary mental health services. For this initiative to succeed, research is needed to identify barriers these communities face in accessing mental health services. Given the lack of mental health knowledge, and the taboo and fear surrounding mental illness that is pervasive within the Somali community, this article poses the following question: "How can researchers conduct ethical mental health research within the Somali community?" They are a vulnerable population that can be exploited as they are not familiar with research governance.

Research that specifically investigates Somali mental health issues is scarce (Ellis et al., 2007) and is acutely needed (Leaning, 2001). The IAPT research programme being conducted at Roehampton University in the UK is proceeding with careful consideration of the ethical and cultural sensitivity requirements of this unique research undertaking. This project has three goals. Firstly, IAPT aims to improve the Somali service user's and their carers' experience and satisfaction, while at the same time giving them more choice and access to clinically effective psychological therapy services. Secondly, IAPT aims to improve inclusion and employment status which Somali people desperately need (Khan et al., 2003; Bloch, 2002; 2004; Sare, 2008). Thirdly, research findings can be proactively disseminated among those working closely with the Somali community whilst also ensuring that the results will be put into practice (BPS, 2006, p. 5).

Key ethical and methodological issues

Psychologists conducting research in this area are trying to eliminate the recognised lack of equality in access to psychological therapies within the BME community in the UK (see Health Commission, 2007; Fernando, 2005; Bhui et al., 2003; Sashidharan, 2003). They are attempting to understand why the Somali community members in the UK are not accessing psychological therapy in the first place. In particular, they are trying to understand how this community conceptualises common mental disorders and not presume that they experience depression and anxiety the same way as people in the west do.

One of the most important early research observations is that participants do not have any idea about what common mental disorders are. It is unclear whether members of the Somali community can actually differentiate common mental disorders from their everyday struggles and suffering. For instance, it is very difficult to describe what anxiety means in Somali language. Anxiety is understood as just a fleeting situational discomfort that passes away; it is not conceptualized as a potentially chronic or persistent state. Furthermore, an anxiety disorder is difficult to diagnose because most mental disorders manifest as physical symptoms or states within this culture; Somalians are not likely to reflect or report on their distress in psychological terms (Bhugra & Flick, 2005). Researchers, then, have to be open to the complex and unique ways that mental disorders express and manifest themselves within this community; one way of achieving this is to talk to the community members and find out what they make of their life experiences, challenges and struggles in the UK.

Most Somalians have a categorical rather than a dimensional view about mental illness; one is either sane or insane (Guerine, Guerine, Omar, Yates, 2004). Additionally, the common belief is that mental illness entails violent behaviour. Such a conceptualisation of mental illness makes it unlikely that Somalians would seek help from mental health professionals. It also makes it difficult to conduct mental health research within Somalian immigrant communities around the world. Immigrants fear having mental illness or being labelled with it, and there is a great and enduring cultural taboo surrounding mental illness (Guerin et al., 2004; Schuchman, 2004; Palmer, 2007; Warfa et al., 2006; McCrone et al., 2005; Bhui et al., 2003).

Appropriate mental health services

We know there is a high prevalence of mental illness within this community (Warfa et al., 2006) and that Somalis have a great reluctance to access any sort of psychological therapy. The Somali community sees such services as inappropriate for their needs. Even when these services are made available to them, there is an inherent lack of knowledge about these services. Fear, shame and scepticism about mental illness leads to concealment (Whittaker et al., 2005) and rejection of service options. Of note, Somali males might not access CBT and other bona fide psychotherapy treatments (Stiles et al., 2006, 2008) because they see this sort of therapy as 'feminising'.

CBT (cognitive behavioural therapy) is already available to Somalians through the National Health Service. Insofar as CBT might challenge the belief system and thought patterns of the Somali patient, he or she might feel that their religious, cultural and spiritual belief system is being challenged; this might cause unintended harm. To date, most research on CBT has been carried out with only Western participants (Beck et al., 2003; Chorpita, Plummer, & Moffitt, 2000; Cook et al., 2004; Joiner & Lonigan, 2002; Ollendick et al., 2002, see also Brown et al., 1998; Burns & Eidelson, 1998), or suffers methodological shortcomings such as the use of students only (Joiner et al., 1999); it does not take cultural background into account.

There are no treatment protocols that are empirically supported as specifically helpful for Somali service users. This work needs to be done or we run the risk of offering ineffective treatment and undermining trust.

Additional barriers to research

Given their social history, suffering, and displacement, most Somalians remain vulnerable and are still fearful of authorities. This, more often than not, will lead study subjects to worry about discussing mental illness with researchers. There is a risk, too, that if research participation is discovered by their community, they might be ostracised. What these participants need, therefore, is reassurance and trust, that must be protected and reciprocated.

When researchers first establish contact with this community great power attributed to them. Researchers are seen as having special

knowledge of insanity, as well as great authority and status as representatives of health authorities. Thus, they find themselves in a position of great responsibility as they are trusted by a community that respectfully 'puts them first'. Psychologists (Loewenthal, 2006, Fisher, Fried & Mast, 2008) and philosophers (Levinas, 1961; 1985) have written about 'putting the other first' as a way guiding ethical choice. 'Putting the other first' is a critical value determinant for Somalians who may engage in research because they hope their participation will make a meaningful difference for their loved ones. In Somali culture, loved ones are always put first.

Researchers have to be careful not to abuse their inherent power; this can be achieved by respecting the cultural and ethical norm of 'putting the other first' (i.e. the research subject). Furthermore, the Somali community may think that researchers coming into their community will help them solve their problems. Therefore, researchers need to consider not just obtaining data from these participants, but also gaining knowledge and insight about the expectations this community has of them.

Appropriate research tools

As highlighted by Ellis et al., (2007), there are yet to be specifically devised, reliable and psychometrically validated psychological measures for the Somali community. (Note: we have translated IAPT outcome measures into Somali, and they are currently being validated.) Accordingly, focus groups were selected by the IAPT researchers as an ethical way of eliciting necessary service provision needs and suitability information.

Focus group methods are the most appropriate way of investigating marginalised groups with inadequate literacy and or language in the dominant culture which prohibits participation in traditional research methods using validated research instruments (Clark et al., 2003). The distinctive feature about this method is that it generates interactive data. Research shows that focus groups are the most appropriate and ethical way of investigating this community (Green & Thorogood (2004); Garvais, 2008; Halcomb et al., 2007) as it gives participants the chance to express their unique experiences from their own point of view while providing rich descriptions of the meanings that are attached to how common mental disorders are conceptualised and experienced within this community (Warfa, 2006). Further, the oral nature of the Somali culture makes focus groups the most suitable and comfortable research method, which is why previous Somali mental health research has been thus adapted (Warfa et al., 2005; Upvall, Mohammed, Dogde, 2008; Herrel et al., 2004; Straus, McEwen & Hussein, in press; Finnstrom & Soderhamn; 2006). An important proviso is that researchers must be familiar with clan divisions within the Somali community for successful group composition.

Informed consent

Mackenzie, McDowell & Pittawell (2007) have recently argued that getting formal informed consent from a refugee is not enough because it is very difficult to construct a valid or authentic ethical consent process with people who have experienced conflict and

crisis. This precisely describes the Somali community who have been through considerable trauma (Ellis et al., 2008; Jaranson et al., 2004; Braken, Giller & Summerfield, 1995). MacKenzie and Colleagues (2007) argue that genuine informed consent is needed from these communities and the only way to achieve this is to take fully into account, and respond to, refugee participants' potentially altered capacity for autonomy. These authors argue that researchers should make a concerted effort not to just minimise harm but to design and conduct research projects that aim to bring reciprocal benefits for the refugee participants and/or to the community in question. This actually means that research psychologists should think about what positive impact their research is going to have on the people that they are researching.

It is not just sufficient to ask these communities to participate in research projects without ethically and critically evaluating what is in it for them. Both Ellis et al., (2007) and Leaning (2001) have highlighted this. Getting informed consent is an extremely delicate process which impacts on the Somali community in a unique way because Somali people are not used to being asked for informed consent; they are used to dictators and coercive governments which makes it difficult for them to say no to external demands. Furthermore, the collectivist nature of the Somalian culture (see Triandis, 1994; Hofsted, 2001) can hinder individual informed consent (Leaning, 2001). Somalians value social and familial support because, for Somalians, the family is the source of all the resources one needs to progress in life. The Somalian person views the world from a collectivist perspective which researchers need to consider if they want to gain valid informed consent. For example, if a male Somalian person marries, he is still part of the original family that makes important decisions for him, but he is also responsible for his spouse's decision making process (Wiklund, 2000, p.110). This makes it difficult for researchers to gain direct face to face informed consent, and it also makes it hard for Somali participants to give informed consent autonomously as their decision making process is dependent on not just themselves but on family members, spouses and faith leaders. This means that the western notions of autonomy and self-determination might not be applicable to them and researchers need to be very mindful about this. One way of achieving this mindfulness, therefore, is to acquire extensive background information and familiarity in understanding the circumstances that Somalians have been through, which include stress, acculturation, loss of employment (Palmer, 2007), torture, bereavement, and forced separation (Mollica et al., 1992; Miller et al., 1992). Knowing about these problems allows the researcher to empathise with their participants and, as a result, will help them to ethically conduct their research.

A Pilot Project

The IAPT researchers contacted Community Officers (CO) working voluntarily with the Somali community in Wandsworth. Once researchers and COs established face-to-face contact, informal conversation provided insight into the community's perspectives about mental illness and access to psychological therapy. The researchers also provided information about the aims of the research project and invited the COs and the community leaders to attend a research advisory board at the university. The aim of this board was to address research issues relating to the project

and the invitation was a way of giving voice to the community so that they could have input into the project.

Initial set up of the focus groups has been completed and now the second stage is to collect the data qualitatively by audio recording of these discussions and transcribing them. Thematic analysis will follow.

Participants will be given ample opportunity to understand the nature, purpose and the anticipated consequences of this research project so they can give free consent to the extent that their capabilities allow. The consent process will be recorded so that researchers can check to see if consent appears genuine and informed.

Community consultation

To evaluate the risk and benefits of the project and to provide additional review of the project, consultation was made with the Pan Somali group (a Charity Organisation in Lambeth, London) and members of the community who determined the benefits of the research. This also added a social value to the study as both the 'experts' of the community as well as the real participants were asked to give feedback on the study. The forum was firstly sceptical about the study as they questioned the need to conduct this study at all. Secondly, they had great concerns about the way information from the study would be used. They commented that it was typical for researchers to extract data from the community, take it, use it for their purposes and then leave without giving anything back to the community. This is the reason that some researchers call the Somalian community the 'invisible community' because they like to keep to themselves by not participating in research. The forum was reassured that the data will be used to gain knowledge about the barriers that prevent Somalians from accessing psychological therapy. Once the data interpretation is complete it will be verified with them and once the findings are published, it will help and encourage the National Health Service to modify and improve the services provided to this community. The results of this research will also be directly sent to the COs who educate and inform the Somali community.

Next steps

We look forward to reporting on the results of this research endeavour, and we hope that it will serve the Somali community well.

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The Doctor Who Hears Voices

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I recently saw the drama-documentary “The Doctor Who Hears Voices” by Rufus May, a clinical psychologist. I saw this film through a public film theater program that is run by a biopsychiatrist and that presents monthly films on psychosocial issues. After the film was shown, the psychiatrist directed a discussion with audience members. The dynamic of the interaction that ensued troubled me; and brought to mind the extreme relevance of ethical theory and of ethical theorists in illuminating psychosocial issues.

The film is about a junior doctor, Ruth, who is suspended from her job after telling her superiors that she is hearing a voice that wants her to kill herself, and Rufus, who treats her using an innovative interpersonal approach instead of with impersonal, drug-based treatment. Rufus adopts a humane, caring attitude toward Ruth. He tells her not to take medication and to try to find meaning in her stressful experience. We see him meeting her in non-clinical settings, such as by a river, on the street, in a restaurant, and trying persistently to engage with her and the voice. At one point he believes the voice may in some way be related to the tragic loss of her brother who died suddenly when she was young; and he gets her to write a letter to the dead brother. Later in the film Ruth connects the voice to a bully she had in the past. The voice is quieted and she is eventually able to return to work. In the final scene we see her talking to a supportive Rufus in his car. Perhaps the most heartwarming scene is of the two at the water where Ruth drenches her head and Rufus follows suit, joining in “the craziness,” a kind of mutual baptism of absolute equals.

The psychiatrist who directed the discussion about the film, claimed that Rufus had behaved very recklessly and unprofessionally, and talked in detailed clinical terms about Ruth’s “condition.” No members of the audience, however, expressed agreement with him, but rather voiced their own personal complaints about the destructive paternalism of psychiatry. Nonetheless, they continued to look to the psychiatrist for guidance and help in better understanding psychosocial issues. One person asked about alternatives to psychiatric medicine, such as yoga and art therapy, and the psychiatrist answered very confidently that no other treatment had been proved to have the same effectiveness as medication. The audience accepted this response with deference; and I was alarmed, as if the psychiatrist was at that moment putting a pill under their too pliable tongues. People asked him what was wrong with Ruth and why she had behaved as she did; and he answered mostly with references to psychiatric terminology, and with little reference to events and relationships in her life. When someone asked whether Ruth could have been suffering from post-traumatic stress related to the loss of her brother, he said confidently

that this was very unlikely. His responses to me seemed not only grossly one-sided but also irresponsible, in failing to address the concerns about psychiatric paternalism.

It is helpful to apply care ethical theory and its emphasis on the importance of healthy relationships to the situation of Ruth. If we see the stressful situation of Ruth as not being so much a product of “mental disease” but rather, in terms of inadequate or failed relationships, we can ask about relationships around her. For instance, we never heard anything about her parents or about how the family had coped with the tragic loss of a young child. Had the family taken part in any kind of healing ritual or process? How did the loss affect the relationships between family members? Was there any unhelpful behaviour or behaviour reflecting denial of the serious loss? Was it a family in which denial became a way of handling other serious losses or misfortunes, as can happen, especially when a family lacks outside support. Ruth talked about being bullied. Did her parents offer support around this or fall into denial of her suffering? Did members of the larger community around her also fall into denial of this problem, perhaps also lacking in strategies for handling bullying? Further, being a junior doctor and starting a career can be very stressful. Was her supervisor giving her adequate direction and support? Was this relationship strong and positive? Was the social environment of the workplace in general supportive? In the film Rufus and Ruth seemed to be very much isolated; and I wondered what kind of support Rufus was receiving for forging this caring relationship. Was he getting adequate support? Care ethics doesn’t give us a clear explanation for Ruth’s behaviour but at least it gives us good direction for where we can look for answers. In the case of biopsychiatry, both the questions and answers are too simple, framed in the narrow terms of medical diagnosis and not, more flexibly, in an attempt to arrive at a meaningful life narrative.

The film made me think about tragic losses that I suffered in my own family. Rufus’ attitude would have been so much more helpful rather than the punitive attitudes of biopsychiatrists attacking my “grief structure” with drugs and demoralizing labels. For many years, through my childhood and twenties, I was beset by chronic suicidal ideation. I came to experience this as simply a normal, however intensely unpleasant, state of mind. When I told a psychologist about it I remember feeling very surprised when she said it was not something that most people experienced. I have since learned, though, that chronic suicidal ideation is a common state in people who have suffered chronic trauma. It’s something we simply have learned to adapt to while maintaining jobs and continuing on with our lives. Psychiatry, however, casts all suicidal ideation as indicative of possible incompetence. I’m

lucky that I didn't tell more people about the morbid droning; as I surely would have had even more obstacles in my life than I have had already. And one biopsychiatrist in the film gave a wonderful piece of wisdom, as someone who understands the full power of the tools of his trade; which is that people with psychiatric diagnoses should never disclose these to a potential employer lest they should be judged incompetent.

There are many alternative ways to address and manage grief; and many kinds of healers and knowledgeable people to turn to for direction and help. Drugs can play a role in healing but it can never be a leading role, as medication cannot address what are essentially crises in meaning and relationships. For these questions, experts in the humanities and social sciences are much better prepared and biopsychiatrists should not attempt to lead and direct people, putting them at risk for chronic dependence, demoralization and despair.

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Futility

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A story that illustrates a discussion about futility...

This story concerns a patient, a youngish man who has a diagnosis of ALS (or Lou Gehrig's disease.) ALS is fatal, the only real unknown is how long it will take for the patient to die. The patient was a part of a large ALS treatment programme at a major Canadian centre. This centre's ALS treatment programme had a policy (or perhaps a practice) of not offering ventilator support to ALS patients at the end stages of the disease. (Ventilator support would be offered in the earlier stages of the disease with the expectation that the patient would be weaned from the ventilator. Terminal ventilation was not offered.) Well, you can imagine what happened. The patient reached the end stages of the disease and requested (demanded) that he be put on a ventilator. The team refused, "it is against our policy" (practice), they said.

At this stage we held an ethics case consultation, which was attended by most of the staff of the ALS programme and many representatives of the ICU. We are not going to offer a ventilator, said the head of the ALS treatment programme, "no" agreed the head of the ICU, "It's futile."

It is here that I will offer a word or two on the role of the ethicist. Often you can do all that needs to be done by putting your hand up and looking puzzled – or, as in this case, repeating the last word of the previous sentence:

"Futile?"

"Well, yes," they said, "it's futile, it won't cure his ALS."

"No it won't, but will it keep him alive?"

"Oh yes, it will keep him alive."

So, the treatment or intervention, in this case a ventilator, is not "futile", or more precisely, it is not medically futile. It will bring about the effect for which it was intended: it will serve to keep this patient alive. The members of the team understood the power dynamic of the judgment of futility. They knew that the judgment that a treatment was or was not futile was theirs to make, they just misapplied the concept in this case. But the discussion continued.

"We won't put him on a ventilator, it won't do him any good, his quality of life will be awful."

So let us go back to our dynamic of health care decision-making. If a treatment is available and has been offered to a patient the decision about whether or not that treatment is, from the patient's perspective, worth having, is of course, up to the patient. It is up to the patient to decide if the quality of life that would be available with the treatment is something that he or she wants. At the risk of confusing the language a little, the patient has to decide if the treatment is "futile" from his or her perspective. Is there a point to the treatment from the outlook of the person concerned? This, though, is a judgement of "personal futility" not "medical futility." Of course the information that is brought by the care team concerning the experiences of others and their perceptions of the quality of life that would be available with the treatment are very important. In most cases the care giving team will have far greater familiarity with patients who have experience of the treatment concerned and they will know the reports of those patients and they will know what it is like to care for a person under those conditions – this information will be crucial to the patient as she makes her or his decision. However, the care giving team has not lived that experience themselves, and, in any event the authority to make that choice lies with the patient.

So, to go back to our story. We soon established that the decision concerning whether the quality of life with the treatment would be worth having belongs to the patient. But the patient had made his position clear, he wanted the ventilator.

Finally, the head of the ICU said: "That's not what my ventilators are for." Now, perhaps there are other ways of putting this idea, but the concept is crucially important. What the head of the ICU was saying was that he only had a limited number of ventilators. If this patient got one of the ventilators then he would use it for months or possibly years. And then the outcome for that patient would be death. On the other hand if that patient did not use the ventilator for that extended period of time it would be available to help many other people, who could benefit from the ventilator, recover and go home. Given the scarcity of the resource, the head of the ICU wanted to use it in the most productive way he could.

Health care professionals are faced with this type of decision all of the time. Given a scarce resource, how do we share it out – fairly and productively? Given the scarcity of resources, health care resource allocation is a “zero-sum game.” If one person gets “this” then “that” is not available for someone else. This is always and inevitably true. This is one area where the “futility” debate gets confused. A better way of thinking about this issue of resource allocation, rather than “futility”, is to think instead of social “utility.” Is this benefit one that we, as a community, ought, or want to fund? The word “futile,” mistakenly and confusingly in my view, sometimes gets used in this context. Sometimes it is said that a treatment is “futile” if it brings only a very minor benefit, or if the benefit is very unlikely, or if the cost of providing the treatment is somehow disproportionate to any benefits that might accrue. In these cases the treatment is not “medically futile,” though it may well be the case that it is inappropriate, inadvisable or ought not to be offered.

Let’s finish this story with a look at who gets to decide what – and on what grounds. The care giving team, and the physician are responsible for deciding which treatments might be effective, and if those treatments are available they can be offered to the patient. The patient then gets to decide whether or not he or she wants to receive any of those treatments or refuse all of them. But who decides what treatments are available? To go back to our story, who should decide whether or not ventilator support at the end stages of life is something that should be made available to Canadian patients should they want it? Is that the role of the treating physician at the bedside? I would say no. We want physicians at the bedside to be advocates for their patients – to seek the best possible treatment and the widest range of options available. We compromise that advocacy role if we expect the physician at the bedside to be a resource allocator who might have to decide, on value rather than medical grounds, that this patient ought not to receive this treatment because someone else could benefit from it more. The decision that a treatment ought not to be offered to a class of patients (rather than any particular individual) properly belongs to the community. Those who pay for the treatments need to decide what treatments they are prepared to pay for. This should be an informed debate, one that draws on the best evidence, both of effectiveness and cost effectiveness; it should be a compassionate debate, realising exactly what the stakes are, but ultimately it must be a rational debate where people of good will seek and give the best possible reasons and work towards the best possible outcomes.

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BOOK AND MEDIA REVIEWS

Building a Mental Health Ethics Film Series, Building Mental Health Ethics Literacy

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ABSTRACT

Building mental health ethics literacy can be understood as fostering recognition and discernment, critical reflection and assessment, of the mores that inform our understandings of mental health conditions and how these translate into treatment practices. Given the public impact of film as mirror and shaper of our (cultural) understandings of mental health, what better way to build mental health ethics literacy than to: (i) start (at the local level) a film series with panel discussions on mental health ethics issues; and (ii) build critical commentary on mental health ethics issues in and through film with relevant scholarly writing?

Key words:

Ethics, mental health, education, ethics literacy, film, moral imagination

Introduction

In 1997, A.F. Jorm and colleagues introduced the term “mental health literacy”, defining it as “knowledge and beliefs about mental disorders which aid their recognition, management or prevention” (Jorm et al., 1997). Presumably the relevant beliefs that stand to aid—or, as the case may be, hinder—the recognition, management, or prevention of mental health conditions are importantly structured by social and cultural mores (norms and values) (cf. Hoagwood et al., 1996; Surgeon General & (DHHS), 2001). This being the case, mental health literacy should be expanded to include a critical awareness of the mores (norms and values) operative in mental health in our society. The practice of holding up our social attitudes and cultural mores to critical scrutiny and mining them for standards to give us guidance for determining how we ought to treat one another (and on some theories, how we aim to live together) is part of the business of *doing* ethics. Building mental health ethics literacy, among other things (Ballantyne, 2008), can be understood as fostering recognition and

discernment, critical reflection and assessment, of the mores that inform our understandings of mental health conditions and how these translate into treatment practices. Most basically, this process can begin by listening to the voices of users (of mental health services) and having those voices count towards the treatment they receive (cf. Faulkner & Layzell, 2000; Rose & Sainsbury Centre for Mental Health, 2001). In this regard, to make real listening possible involves unpacking those aspects of our culture that both facilitate and block us from hearing with understanding. Given the public interest in film (Croteau & Hoynes, 2006), and given the public impact of film (Giroux, 2002; cf. Street, 1997)—including the capacity of films to sometimes mirror and sometimes shape our cultural understandings of mental health (Grainger-Monsen & Karetzky, 2006; Wolff et al., 1996)—what better way to build mental health ethics literacy than to: (i) start (at the local level) a film series with panel discussions on mental health ethics issues; and (ii) initiate a devoted column in this journal to engage critical commentary on mental health ethics issues *in* and *through* film? With respect to the latter initiative, please expect a commentary on *The Soloist* (pending its release on April 24th, 2009 for Canada) in the next issue of *JEMH*. The purpose, then, of this commentary is to explain the basic mechanics and components of how to build a film series on mental health ethics.

Finding the purpose

Novel Tech Ethics is an interdisciplinary research team based at Dalhousie University that focuses on a wide range of ethical issues associated with the introduction of novel technologies. Current research addresses the concerns of the individual, the community, and humanity at large in relation to recent advances in neural and genetic technologies, including how these developments are redrawing the face of mental health today. Academic exchanges, public discussion, and collegial debate contribute to our understanding of these issues and inform our contributions to public policy and to public education. In 2007 we hosted *States of Mind*, our first (of now three) film series on the ethics of mental health as a public education initiative to build mental health ethics literacy. [See table 1]

TABLE 1

STATES OF MIND 2007	STATES OF MIND 2008	STATES OF MIND 2009
<i>A Beautiful Mind</i> Universal Pictures	<i>Away from Her</i> The Film Farm	<i>Michael Clayton</i> Warner Brothers
<i>Iris</i> Alliance Atlantis	<i>Awakenings</i> Columbia Pictures	<i>The Savages</i> Fox Searchlight Pictures
<i>The Hours</i> Paramount Pictures	<i>What's Eating Gilbert Grape</i> Paramount Pictures	<i>Music Within</i> Metro Goldwyn Mayer Pictures
<i>Eternal Sunshine of the Spotless Mind</i> Alliance Atlantis	<i>Thumbsucker</i> Sony Pictures Clasics	<i>Charlie Bartlett</i> Metro Goldwyn Mayer Pictures

Broadly speaking, the purpose of the series has been to provide a forum for two-way communication between the academic and medical communities and the general public in an effort to: (i) broaden the dissemination of knowledge of ethics in mental health; and (ii) sound out, listen to, and critically shape the concerns of those who are (and will be) affected by the development and use of novel technologies in this field. In this way we have connected the concerns of our research mandate to a broader public audience that includes both professionals and lay persons. Too often public education is only understood as “informing the public” (Goldie & Knifton, 2007). Arguably, any effort at public engagement should be grounded in conditions for genuine dialogue, involving: (i) open communication and deliberation; and (ii) allowing for the possibility for disagreement and movement—at times, affirming change(s)—through discourse. More specifically, our film series has aimed to open up spaces, as led by a panel of experts, where all stakeholders in mental health can learn from one another by asking questions, sharing relevant information and experiences, awakening interest in, creating awareness of, negotiating through, and critically debating the ethical issues as showcased in the films that profile mental health conditions.

Choosing the program and other pragmatic decisions

Each year since beginning the series, we have featured topical films on a common weekday evening for four consecutive weeks. Each screening is followed by a moderated and panelled discussion. Building such a series is foremost about building relations with people, and knowing your target audience is critical. Our target audience is as diverse as all those who are concerned about mental health ethics issues, and importantly, those who might *come to be* concerned about mental health ethics issues through participation in the film series. Speaking to this diversity of perspectives in a way that can track interests that cut across cultural, socio-economic, and educational boundaries, not to

mention age demographics, is a challenge, but a welcome one. We have purposefully focused (primarily) on mainstream films because they provide a common currency for public interests that traverse many of the aforementioned divides. In focusing on popular films, we also hope to do our part to collaboratively unpack the significance that these films have for driving common norms and values in mental health.

As a means to bridge to the various relevant communities—and especially users (of mental health services) and their own communities—we have purposefully hosted the series away from the centre of the university campus within a theatre (seating capacity 168) at the Queen Elizabeth II Hospital. The early winter (mid-January to the beginning of February) works well for probably a number of reasons. It is reasonable to presume that after the holiday season, people in Nova Scotia are not as busy and (perhaps) looking for something to help the winter pass; addressing mental health issues at this time of year, is also timely, given the prevalence of Seasonal Affective Disorder, commonly known as “winter depression” (Lam, 2001). What is more, at this time of the year there are fewer competing events, and panellists tend to be more available than later on in the year: for instance, those that are academics are at the start (as opposed to the usually busy end) of term. And importantly, the media is more available for coverage, not to mention that many significant film awards ceremonies are also held at this time of the year.

Putting together an effective program for surfacing mental health ethics issues starts with finding a set of films that fit together and that hold the relevant educational potential (i). Dorothy Nyswander’s “watchword, ‘start where the people are’” is as appropriate to mental health ethics education as it is in health education work in general (McDonald et al., 2007:269). Our approach has been to begin public education from what the lay public appears to already be interested in, and then build from this to broaden critical appreciation. Strategically, we have started each year with an academy award winner or nominee: *A Beautiful Mind* in 2007, *Away from Her* in 2008, and *Michael Clayton* in 2009. [See Table 1] One way that we have used to gauge local interest in films—albeit this is a limited indicator—is to see how many holds have been placed on them in the public library system. Not all films chosen have had a direct mental health focus. For instance, both *Michael Clayton* and *What's Eating Gilbert Grape* feature mental health conditions that are neither central to the plot nor a critical factor for the main characters in either film. Even so, both films yielded fertile mental health ethics discussions because they give attention to “lifestyle” and socio-cultural determinants of mental health. In trying to “start where people are at”, we have also selected films that tie into the work of existent community organizations. Since January is Alzheimer’s Awareness month, we chose to screen the film *Iris* (in 2007) and *Away from Her* (in 2008) during that month. We have tried to choose the films in such a way as to give balanced representation of a variety of mental health conditions, selecting some that have not received much media attention (e.g. Encephalitis/Catatonia in *Awakenings*) and others (e.g. Anxiety disorders in *The Hours*) that did not seem to have any major society (or community organization) presence in Halifax at the time of screening. We have also tried with each series to build in programming that features mental health issues across the spectrum of age groups (e.g. adolescents with *Thumbsucker*, *What's Eating Gilbert Grape*, and *Charlie Bartlett*; young adults

with *Eternal Sunshine of the Spotless Mind*, and *Music Within*; middle-aged persons with *The Savages*; seniors with *Iris* and *Away from Her*).

Choosing films with broad public appeal has worked to bring in a diverse audience, but near the end of each series we have included at least one alternative, “Indie-style”, “stretch-your-mind” film that takes an approach to the material that is atypical (e.g. *Eternal Sunshine of the Spotless Mind*, *Thumbsucker*, and *Music Within*). [See table 1] Purposefully, we have positioned these screenings near the end of each series in the event that they might be experienced by some audience members as too alienating (as feedback indicated from *Eternal Sunshine*). Our hope for the future is to grow the series to include more documentaries and art films that have been written, produced, or directed by users (of mental health services) or that feature actors with mental health conditions: to borrow a phrase from *M-POWER*, “Nothing about us, without us!” (M-Power, 2009) At Novel Tech Ethics, we have already begun steps along this path with our other public education events for Brain Awareness Week. These have included a screening and panel discussion of *Rage for Order: Autism* (a documentary by Oliver Sacks), and recently, *The Diving Bell & the Butterfly*. The latter, though hardly an “Indie-film”, is nonetheless stylistically more challenging than many popular films because of its camera work that well captures a first-person perspective of the patient protagonist (a stroke survivor), including his states of distress portrayed from the “inside out”. Both these screenings were staged shortly after the *States of Mind* film series and yielded capacity and well over-capacity crowds.

Assembling an effective panel

The next critical component for building a successful film series on the ethics in mental health is assembling an effective panel. This is probably the most involving task. Given that our emphasis is on ethics, we have opted for a single ethics expert across all four sessions of each series so as to provide an element of continuity for the panel discussion. We always include at least one clinician and one person with direct experience of the relevant mental health condition, most preferably a mental health services user and if not, a family member or someone with close relations to persons with mental health conditions. Besides our ethics anchor (with a few exceptions in our first year), we exchange panelists anew for each session. These have included clinicians, researchers, social workers, educators, a law professor, community representatives, advocates, and users (of mental health services) selected according to their relevant expertise as matched with each film. This is admittedly a lot of work, but the sheer variety and changeover of panelists has helped to keep our programming and the discussions fresh. Again, getting the right expertise and ensuring fair representation on the panel to match with the film is a challenge, but the process has also provided opportunities to grow and connect our research to the various relevant communities and stakeholders. We have had panels as large as five members and as small as three. Having a diversity of perspectives sometimes involves including more members on the panel, but can also mean simply choosing panelists committed to presenting a diversity of perspectives. Smaller panels are more likely to attract the criticism of being unbalanced and lacking in representation. The challenge with larger panels is that

they can more easily become unbalanced as questions directed at more, rather than fewer panelists have a tendency to fall “between” them and tend to receive uneven uptake as a result. We try to remember that expertise can come as well from the “floor” as from the “front” which is in keeping with our attempts through this forum to break down some of the power differentials that still obtain between professionals and other mental health stakeholders (cf. Bracken & Thomas, 2005; Miller & Rose, 1986). Any attempt to stage a public event dealing with mental health is likely to involve political dimensions and to be received as such: it is good to remember that getting a diverse audience and working in ways to maximize audience participation and ownership for the discussion is usually key to providing a balanced and satisfying discussion regardless of how many persons staff the panel.

Reaching the audience

Recruiting a diverse audience means reaching out far and wide. Effective advertising is an important skill and getting expert advice on how to manage this aspect of marketing the film series has been important. Advertising requires investment, and for our series this has meant starting by telephone and making personal contact with various mental health agencies, organizations, and institutions. What is more, having a web posting (of each event) to direct contacts to can save time and make communications more efficient and clear. Our posters for each *States of Mind* series have been downloadable from our website two to three months before the start of each series. A public service announcement for the media (prepared by the university’s Communications Department) is sent out six weeks in advance. Personalized e-mail notices are sent out about six to eight weeks in advance for those recipients who might see fit to post a notice on their website, intranet magazines, or in printed newsletters. Then seven to ten days before the series begins, an e-mail notice is sent out to all on our mailing list with a request that recipients pass the invitation onto anyone they think might be interested. A final reminder notice for each movie is e-mailed the day before, or the day of, each session. At each screening, we also run a slideshow that includes a slide with photos of all the panelists, their names and affiliations; a slide reminding the audience of the remaining films in the series and any other upcoming public education events that Novel Tech Ethics is hosting; a slide directing those interested to our website; a slide thanking our sponsors; and a final slide to remind people to fill out their evaluation forms and their contact information if they would like to be added to our mailing list. Our e-mailing list has grown to over 1700 contacts in just over three years, but almost all of these contacts have come in one subscriber at a time. A communications expert (who was instrumental in designing and managing the very successful Douglas Hospital mental health film series, *Brain Frames*) once told me that her goal in advertising was to always attract new people to each event. One very effective way that we have achieved this is by getting uptake with the local newspapers, radio stations and other media outlets that have run stories in advance of the series in both 2008 and 2009. Indeed, it is on the strength of these inroads with the media that we have been able to make this public education initiative reach out to those not already “plugged into” the various existent channels of communication for ethics and mental health education.

Making an impact and addressing challenges

All the events have resulted in lively and engaging discussions with attendance including users (of mental health services), advocates, community representatives, clinicians, health care providers, researchers, social workers, educators, academics, students, and public officials. Providing time and the right context for addressing mental health stakeholders' ethics concerns is a pressing challenge in a healthcare and social services system that is already seriously taxed (Lützén, 2008). The panel-led discussions provide an opportunity for mental health ethics education to occur outside some of the pressures (and constraints) of clinical settings. Very importantly, almost half of those speaking from the floor are now users (of mental health services or their relatives and friends) relating their stories and experiences that are critically informing the resulting debates and building public understanding. Mental health services users, individually and in partnership, are in significant ways showing that they have many of the ethical answers themselves. Just the very practice of cultivating public listening and providing conditions to empower and capacitate users (of mental health services) to speak out, is assuredly part of building mental health ethics literacy in the community.

Admittedly, one of our main challenges with the discussions—especially at those sessions when the theatre is overflowing—has been to maintain an ethics focus. To do so (as affirmed by audience feedback through our evaluation process), the moderator now includes in the introduction to each session a statement of three or four very basic, orienting, ethics questions that the audience is encouraged to consider while viewing the film. After viewing the film, taking a short break, and then assembling the panel, we now also ask our ethics expert to give a three- to five-minute commentary on the film before asking for questions from the floor. This has proven successful in giving the audience entry points for beginning to think about the relevant mental health ethics issues. The audience is also reminded before leaving that a set of ethics questions, along with film reviews and relevant links to healthcare resource materials (including links to local support services), are to be found on our website. The Halifax Regional Municipality public has proven overwhelmingly responsive and we are committed at Novel Tech Ethics to meet the challenge to continue to communicate with and to build ethics literacy in the broader community into the future.

Broadly speaking the film series is succeeding at:

1. disseminating information to the general public about psychiatric conditions, mental health services, and mental health ethics research;
2. building individual awareness and social concern for mental health ethics issues and how these trace out in our culture through the medium of popular film;
3. providing a platform for users (of mental health services), their friends and families to themselves offer their concerns and ethical guidance to the public (researchers included);
4. deconstructing the misinformation, stereotypes and stigma in our culture that still attach to mental health conditions; and,

5. assisting mental health stakeholders to consider how to pursue better ways to both treat and respond ethically to persons with mental health conditions.

For those who may be new to matters of mental health ethics education, in the words of another festival organizer, “It is hoped that by bringing a film [series] of this nature to both mainstream and fringe audiences a serious attempt [is being] made at educating individuals, encouraging them to either re-evaluate the preconceptions they hold, or to inform them about phenomena which they are not normally exposed to” (Mental Health Media, 2003).

Growing moral imagination through film

Building mental health ethics literacy by engaging with film can provide an opportunity to critique and grow the social imagination implicated in the “geography” of mental health in our society. Whenever we really engage with a story—be it through the film itself, or through the various personal responses we have heard in some of our panel-led, public discussions with the *States of Mind* film series—we are engaging not with abstract or theoretical concepts and moral codes; instead, narrative accounts put us in touch with persons and some of the intricacies of their lives (Anonymous, 2009; cf. McCoppin, 2008). In the case of stories presented in film, the persons we engage with are both the characters in the film story and the implied person that has chosen to portray them that way. As Wayne Booth explains:

Putting that implied author aside for a moment, just think about the characters whom that implied person has chosen to dramatize. They always exhibit, if the story is not just a Sunday School sermon, complex values ... When we join such characters, loving them or hating them, in the virtual world of story, we are inescapably caught up in ethical activity—now taking the word “ethical” as covering ... the whole range of human qualities, good and bad: the virtues, the powers, the habits of mind and heart. (Booth, 1998)

In this way, part of building mental health ethics literacy can be seen to include learning to imagine the complicated life of another person and considering what it would be to have their experiences and to make their choices within the complexities that define their world. Films are an especially good vehicle for allowing this sort of moral reflection and the depth that comes with it to surface (cf. McCoppin, 2008). As an art form that enlists the imagination, then, films have the capacity to give viewers a chance to acquire experience vicariously by dwelling in cultural contexts or “worlds” that may be quite different from that which they normally experience (cf. Posner, 1997:19). This is to say, in viewing films we are given a chance to experience and learn about values and sensibilities in our own or others' cultures and “worlds” that may be different (even very different) from our own, yet not so different as to be unintelligible (McCoppin, 2008:184). Thought-provoking movies thus have the capacity to stimulate our curiosity and sense of wonderment about others, including those with mental health conditions. This sense of wondering and of exploring different points of view, even (perhaps) to the

point of questioning one's own preconceived views and values, is one way to begin to develop an ethical outlook (Anonymous, 2009; Nussbaum, 1995). Well chosen films, like "[l]iterary works that promote identification and emotional reaction, can cut through... self-protective stratagems, requiring us to see and to respond to many things that may be difficult to confront," says Martha Nussbaum(ii) (2000:359). By harnessing the powers of moral imagination, our experience at Novel Tech Ethics is that well chosen movies are effective at building mental health ethics literacy on a public scale.

If you are considering starting a film series or film festival related to issues of mental health, we suggest you contact some of the many established and extremely innovative precedents already available across Canada. These include *Frames of Mind Monthly Mental Health Series* (Vancouver); *Rendezvous with Madness Film Festival* (Toronto); *Imagine Film Festival* (Whitby); *Mind's Eye Film Festival* (Peterborough), *Shadows of the Mind Film Festival* (Sault Saint Marie), *Frames of Mind Film Festival* (Montreal), *ViewFinders - International Film Festival for Youth in partnership with the Sun Life Financial Chair in Adolescent Mental Health*, (Halifax), and *States of Mind: A Film Series on the Ethics of Mental Health* (Halifax). There are also some very interesting international mental health film initiatives: namely, *The Scottish Mental Health and Film Festival* and the *New York City Mental Health Film Festival*.

Endnotes

i) It is also important to seek expert legal advice on how to obtain permission to publicly screen any film as per the relevant restrictions of copyright.

ii) I do not herein mean to imply that cultivating moral imagination is sufficient for securing normative competence, only that it provides an entry point for building ethics literacy which can be one part of normative competency. For a very insightful discussion of issues of narrative and normative competency, see Hilde Lindemann Nelson, *Damaged Identities, Narrative Repair* (2001), especially chapter 2 "Narrative Approaches to Ethics".

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