

Mental Health Ethics: The New Reality

Welcome to the first edition of the Journal of Ethics in Mental Health (JEMH). This international journal offers new perspectives on mental health ethical issues from around the world. JEMH aspires to contribute to knowledge and clinical practice and to be a unique forum for discussion and debate of ethical issues affecting individuals with mental illness.

The prominence of ethical issues in mental health is undeniable. Increasingly, mental health practitioners, consumers of mental health services and their families, law makers, legal representatives, advocates, community service providers and other experts have recognized the importance of ethical principles and actions in clinical practice. Although there remains wide variation across the globe with respect to the role of ethics in mental health, there is an emerging consensus that the rise of the consumer voice has been the principal contributing factor to this new reality.

But the developmental path of an ethical focus in mental health has been incremental rather than dramatic or rapid. Differences between the integration of ethics into medical practice in general and psychiatry in particular have been significant with a key factor being the role of capacity in patients. Historically, mental health ethics has taken a back seat to bioethics and this is evident when one surveys the professional literature for articles on mental health ethics. There are relatively few articles on mental health ethics and they are widely dispersed.

For many practitioners the difficulty in having open, ethical debates on mental health issues remains a barrier, although decreasingly so. Understandably ethical discussions can be difficult, often acrimonious. Many practitioners fear repercussions from peers and managers or perceive pressure to maintain the status quo. There is also a reluctance to destabilize the balance of power. Within this context, the Journal of Ethics in Mental Health was born. The journal provides a forum for discussion of ethical issues affecting all persons living or working with individuals who are experiencing mental health difficulties in order to promote the awareness and understanding of ethics in mental health. The aim is to develop JEMH as the principal journal featuring mental health ethical issues in the world.

JEMH will publish an international, peer-reviewed, web-based journal and electronic forum for the exchange of ideas worldwide, free of charge, three times annually. An important goal is to increase awareness of ethical issues in mental health and to provide a place where professionals, consumers, family members, academics and advocates can voice their perspectives and experiences related to mental health ethical issues. Equally important for our new journal is to ensure that the voice of the consumer is featured prominently in articles and other sections of the journal. The journal is targeting relevance and applicability to mental health practice where day to day ethical issues are so crucial.

JEMH will re-evaluate old ideas and approaches, will strive for positive change through increased awareness and dialogue, will

evoke change in practice in the care of persons with mental illness, will contribute to policy development and will reflect honestly and factually on key issues for consumers and their families, health care professionals and other professionals. We encourage a diversity of perspectives and exploration of new and innovative ideas.

Complementing the publication of the journal, JEMH will sponsor an ethics conference every two years. The inaugural conference was held in May of this year in Toronto and proved to be very successful in bringing together a wide range of individuals and perspectives from across the globe. Thanks to Whitby Mental Health Centre, the Centre for Addiction and Mental Health and McMaster University for their invaluable assistance in this endeavour. Based on the conference evaluations, the program was exceptionally well-received by those in attendance. A number of the presentations at the conference are featured in this edition of the journal. Conference audio files can be accessed on the JEMH website (<http://www.jemh.ca>).

JEMH, as a non-profit organization, is managed by an Editorial Committee composed of leaders in mental health and law in Canada. A prominent International Editorial Board has been established and their rich and valuable input to date is most appreciated. Both the Editorial Committee and Editorial Board have consumer representation, an important priority for JEMH.

We trust you will enjoy our new journal. Your active participation and contributions will ensure that JEMH thrives and our goal of developing a forum for healthy academic and policy debate on a wide range of topics is achieved with clear relevance to, and interest for, consumers, families, service providers and professionals.

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Patterns of Practice: A Useful Notion in Medical Ethics?

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ABSTRACT

This paper introduces the notion of patterns of practice and shows the extent to which it is useful at the level of practice and at a profound philosophical level. The notion makes deep connections with ideas in the realm of the philosophy of language and thought and, in addition, it connects to virtue ethics. Using the example of whether or not to admit someone using compulsory powers or whether to treat them in the community, the notion of patterns of practice can be used to demonstrate the internal and external coherence of decisions in psychiatric care and thus to offer clinical and ethical justification.

Introduction

My aim is to suggest that the notion of patterns of practice might provide a useful way to think about ethical decision making. An immediate point to note is that, if this is so, patterns of practice might be useful not only in the clinical field, but wherever ethical decisions have to be made: in political life or in the financial world for instance. It is also only honest to acknowledge that this aim should, in large measure, be fairly easily achieved. Our ethical decision making, whether in clinical, financial or political settings, will sit within some pattern of practice or other. At least, most ethical decisions will be describable in terms of a pattern of practice. Only highly idiosyncratic or aberrant decisions are likely not to conform to some pattern or other; and, even then, their idiosyncratic or aberrant nature is likely to reflect the precise fact that they stand outside normal patterns of practice. So, of course patterns of practice – as a notion – can provide a way to think about ethical decision making! My aim, however, is easily achieved only *in large measure*. The more interesting point is *the extent to which* the notion of pattern of practice is *useful*. My suggestion is that it is useful at the level of practice and at a profound philosophical level. Indeed it is a notion that brings these levels together.

What are Patterns of Practice?

Patterns of practice are ubiquitous and pervasive. At a superficial level, we can hardly escape the extent to which our lives are patterned. Our routine behaviours, eating and sleeping say, tend to conform to patterns and we suffer when the behaviours are too radically disturbed. Social behaviour is also deeply reliant upon patterns of practice: safe driving, for instance. Even good manners are a matter of accepting certain patterns of practice and it is disconcerting when such codes of practice are ignored. Cultural patterns of practice can be observed in sporting arenas around the world, or in concert halls, with subtle and not so subtle differences depending on the precise type of sport or brand of music.

At a deeper level, perhaps, in the case of religions we speak of patterns of prayer or worship. There is an obvious philosophical debate to be had concerning whether such patterns merely reflect different socio-cultural traditions, or whether the practices themselves are in some deeper sense constitutive of religious belief. To be of a particular religion is to engage in (and with) its patterns of worship. To fail to go to Mass on Sundays is to be a lapsed Catholic. Like other religions, Islam dictates certain practices: "Recite from the Koran as many verses as you are able... Attend to your prayers, render the alms levy... Implore God to forgive you..." (Dawood 1956, p. 410). To disregard the precepts of any religion wilfully and persistently would be incompatible with the practice of the religion.

Something very similar can be said about clinical practice. Medical practice is full of patterned responses. We learn to take and report a history in a standard way. Particular routines for the examination of a patient are pursued. Particular symptoms and signs trigger certain investigations. One set of complaints triggers immediate admission to hospital; different complaints might prompt a referral to social services. Although there may be regional variations and occasional innovations in precise practice, if the pattern of practice is woefully wrong the doctor risks losing his or her licence to practice. Clinical patterns of practice also pervade how we communicate with patients and carers, how we think of them (e.g., as cases or as people) and ultimately how we treat them.

So far I have: (a) shown the extent to which our personal and social lives are patterned; (b) gestured at the possibility that patterns of practice might not just reflect our beliefs, but might play a constitutive role in them; and (c) indicated how clinical practice is also

patterned in a pervasive and ubiquitous fashion. Before moving on to consider the extent to which the notion of patterns of practice might be useful, I shall pause to consider two particular ways in which the idea of practice proves profound: first, in the context of the philosophy of thought and language; secondly, in connection with virtue ethics. In both cases I shall be drawing on the work of philosophers, which I can neither emulate nor adequately describe, but which helps to underpin my suggestion about the extent of the usefulness of patterns of practice in medical ethics.

Patterned Language

To say that language is patterned might be to make a purely linguistic point about the structure of language. Wittgenstein's claim that, "To understand a language means to be master of a technique" (Wittgenstein 1953, §199) might be taken simply at this linguistic level. But Wittgenstein's interest was in philosophical issues to do with meaning. In this regard, in his famous discussion of rule-following, he pointed to the normative nature of our descriptions of mental states. In other words, when I say that I understand something it entails that certain things are or will be the case. The mental state seems to exert its normative constraints over things which are not even now in existence; for if the content of the mental state is to have meaning, certain things in the world must be or will be true. Mental states with content – that is, my true beliefs, thoughts, wishes and so on – just like rules (which govern the future), are similar in that they exhibit this normativity.

"A wish seems already to know what will or would satisfy it; a proposition, a thought, what makes it true – even when that thing is not there at all! Whence this determining of what is not yet there? This despotic demand?"

(Wittgenstein 1953, §4 37).

The conclusion of Wittgenstein's famous rule-following discussion "is that understanding cannot be further explained other than as an ability to enact a practice..." (Thornton 1998, p. 35).

According to Wittgenstein: "... there is a way of grasping a rule which is not an interpretation, but which is exhibited in what we call "obeying the rule" and "going against it" in actual cases. ... And hence "obeying a rule" is a practice" (Wittgenstein 1953, §§201-2).

In the course of presenting his interpretation of Wittgenstein, Thornton puts it thus:

"When one comes to understand the meaning of a word, one acquires an ability to use it correctly which cannot be further explained. One simply masters a practice or technique... Understanding a meaning is a piece of "know-how", a practical ability. One way of putting this is to say that meanings and rules are individuated by practices and that understanding a meaning or a rule is thus individuated by the practice over which one has mastery"

(Thornton 1998, p. 90).

When Wittgenstein himself is talking about how he might justify following a rule in the way that he does, he says:

"If I have exhausted the justifications I have reached bedrock, and my spade is turned. Then I am inclined to say:

"This is simply what I do!"

(Wittgenstein 1953, §217).

In this adumbrated account we see that certain types of mental state (understanding, remembering, meaning and the like), represented by linguistic practices, are rule-governed. Their rule-governed nature manifests an essential normativity, but what this boils down to is a matter of practice. There are, of course, alternative interpretations of normativity (cf. Thornton 1998), but on the one being considered here the normativity of mental states amounts, somewhat shockingly, to a mere practice: "This is simply what I do".

Those aspects of our life that seem so essential to our make up as human beings – our ability to think, understand, believe, hope, remember – turn out on this interpretation to be practices, things that we do in a particular way simply because we are thus. These patterns of practice reflect our standing as agents of this type in the world. This is simply how we act in the world. The important point is that we act normatively. As Luntley says:

"... our thinking lies in the pattern of our actions, where actions are causal encounters with the world. The normativity of thought is the normativity of the pattern/structure of our causal encounters... We say that the patterns of our causal encounters with the world are irreducibly normative... Some of the patterns that physical things, like us, get into are normative patterns"

(Luntley 1999, p. 345).

The argument I have been wishing to imply, therefore, is this: language and thought is essentially normative; normativity is a matter of practice; thus, at heart our lives as embodied agents are situated in a realm of practices (Hughes 2001). Hence, the notion of patterns of practice makes a profound link with our standing as human beings of this sort (with minds and language) in the world. These patterns of practice involve (constitutively) normative constraints, the despotic demand that we live thus and so, because this is how we are. In other words, there is an essential link between our actions, what we do, and how we have to be as human beings in the world. Elsewhere Luntley has said:

"The moral world has its being in, it rests upon, what we do and how we act. It is in our actions and the way we treat one another that values come into being and are preserved in being"

(Luntley 1995, p. 218).

With this thought I shall turn to a connection between patterns of practice and the virtues.

Patterns and Virtues

The emphasis on action and practices might, at first blush, seem to sit uncomfortably with virtue ethics where the emphasis is more on the agent than the action. Whilst it is true that virtue ethics stresses what the person *becomes* by acting this way or that (rather than, say, the consequences of actions), it is also true that virtue ethics is concerned with actions themselves inasmuch as these are specified by the virtues. As Hursthouse (1999) says, "Not only does each virtue generate a prescription – do what is honest,

charitable, generous – but each vice a prohibition – do not do what is dishonest, uncharitable, mean” (p. 36). To these prescriptions and prohibitions virtue ethics adds a corrective by focussing attention on how the action is performed. The right action, done badly, might be as harmful as the wrong decision.

Hursthouse (1999) went on to argue that, even if virtue ethics can generate action guides (i.e., “do this” or “don’t do that”), there are reasons to pull back and consider *the agent* in our judgements of moral action. For one thing, she argues, this allows room for regret, even if the right action has been performed. With explicit reference to medical practice she contends: “... if someone dies, or suffers, or undergoes frightful humiliation as a result of [a doctor’s] decision, even supposing it is unquestionably correct, surely regret is called for. A dose of virtue ethics might make them concentrate more on how they should respond, rather than resting content with the thought that they have made the right decision” (Hursthouse 1999, p. 48).

Hence, the notion of patterns of practice links to virtue ethics not simply because of the way action can comprise a practice, but also because *how* we act – with regret, compassion, integrity and so on – is conveyed by the notion: our patterns of practice include not only actions but also demeanours and dispositions.

There is another subtle way in which a link can be made between virtue ethics and patterns of practice. To those who are not predisposed to virtue ethics as a normative theory this may seem contentious and I suggest the link tentatively. Whilst discussing religious practices I suggested that such practices are in some sense not just reflective of religious beliefs but constitutive of them. Similarly, it might be argued that moral practices do not just reflect ethical beliefs, but play a role in constituting them. There is something heretical in this because the normal presumption in medical ethics is that we use normative ethical theories to judge our actions, whereas I am suggesting that – in some albeit sketchy way – the normative simply emerges from the action. We might say that the normative is immanent.

Virtue ethics, it seems to me, squares with this view because it suggests the importance of what I become by what I do. It is as if we do not need the normative theory first, but rather the actions show us the possibilities for human beings. In an analogous way MacIntyre (1985), in his seminal study *After Virtue*, gave an account of the virtues that proceeded through three stages. The second and third stages considered the narrative unity of a whole life and the importance of an ongoing social tradition. But his account begins with practices. Other moral philosophers start with passions or desires or some conception of duty or goodness. But in such cases MacIntyre suggests, “the discussion is all too apt to be governed from then on by some version of the means-ends distinction according to which all human activities are either conducted as means to already given or decided ends or are simply worthwhile in themselves or perhaps both” (MacIntyre 1985, p. 273). MacIntyre continues:

“What this framework omits from view are those ongoing modes of human activity within which ends have to be discovered and rediscovered, and means devised to pursue them; and it thereby obscures the importance of the ways in which those modes of activity generate new ends and new conceptions of ends”

(MacIntyre 1985, p. 273).

Once again, of importance here is what we become by what we do and the possibility that practices have the potential to enlarge our view of human flourishing. A key feature of the virtues is that they require a prior account of certain aspects of social and moral life in terms of which they can be defined and explained (MacIntyre 1985, p. 186). The concept of a virtue requires a background against which to be made intelligible. The notion of a practice, which forms the first stage of the background, is defined by MacIntyre in a technical way:

“By a “practice” I am going to mean any coherent and complex form of socially established cooperative human activity through which goods internal to that form of activity are realised in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity, with the result that human powers to achieve excellence, and human conceptions of the ends and goods involved, are systematically extended” (MacIntyre 1985, p. 187).

The idea here is that in order to pursue certain human goods, which help to constitute human flourishing, we have to engage in practices, where a practice itself aims at what is excellent for human beings. Football, chess, architecture, history and medicine would all be examples of practices in this sense. Furthermore, according to this definition, such practices are patterned in a way that allows the possibility that they will reveal to us new and perhaps unexpected ways to flourish as human beings. From this virtue ethics perspective, the immanence of normativity is seen in the way that, within patterns of practice, conceptions of human goods are discovered and rediscovered through the actions of agents and by what they thereby become. Once a framework or pattern of practice is adopted there is a normative constraint on how things should go. The success or otherwise of a particular person engaged in a specific practice is not something that is open to subjective fiat. There is a normative constraint on what counts as an excellence in a particular pattern of practice; but this constraint is internal to the practice; the normativity is quintessential despite ultimately depending on what people ‘simply do’.

Thus, the notion of patterns of practice can be employed to do some difficult philosophical work in connection with thought and language as well as in the sphere of morals. I want now to come back to clinical practice and psychiatric practice in particular. The ethical question will always concern why one pattern of practice is better or worse than another. How do we justify community treatment over against in-patient admission? I do not intend to deal with this particular issue in detail, but merely to indicate the form of the argument. In order to do this I require an overview of how patterns of practice are justified.

Justifying Patterns of Practice

The clinical problem is this: there may be different patterns of practice with respect to particular decisions. One community mental health team (CMHT) might try very hard to keep people in the community in their own homes for as long as possible. Whilst this sounds laudable – it is what clients tend to say they would want and, therefore, it respects their autonomy – it does impose a good deal of stress on some family carers and there is always the risk that something will go wrong. The risk of self-harm is harder

to contain in the community. Contrariwise, another CMHT tends to admit people very readily to an in-patient assessment ward. There are obvious concerns about this tendency in terms of cost, stigma, institutionalisation, lack of respect for autonomy, the possibility of worsening behaviour learned from other in-patients and dependence, not to mention the loss of liberty, especially if compulsion is required under mental health legislation. But, on the other hand, the admission might instantly de-escalate a tense situation for all concerned in the community and reduce the risk of violence towards self or others.

So there are two patterns of practice. Whilst I have said that the *clinical* problem is deciding between them, it is also an *ethical* problem: which pattern of practice is from both the clinical and the ethical points of view to be preferred? How do we justify one over the other? In passing it is worth noting that one way in which the notion of patterns of practice might be useful is *precisely because it brings together the clinical and the ethical*; and in addition it brings in the legal, the psychological, the social, the spiritual and any number of other potential aspects of a practice. Recall that MacIntyre (1985) defined a practice, in part, as a “complex form of socially established co-operative human activity”. Whereas it is all too easy for there to be a discontinuity between clinical practice and ethical theory, or at best the latter is imposed on the former, the notion of patterns of practice inherently involves the complexity of clinical practice, whereby biological, psychological and social considerations do not exhaust the possible levels of human involvement, which are likely also to involve ethical, spiritual, legal dimensions and so on.

The other word used by MacIntyre (1985) in his definition of practice was ‘coherent’. I would argue that the coherence of a pattern of practice is the way in which it must be justified. This is to recommend a coherentist account of justification, which is often pitted against a foundationalist account. But recall that Wittgenstein spoke of “bedrock”, suggesting foundations, and then promptly appealed to a practice: “this is simply what I do”. It might be that we do not need to enter further into this dispute: perhaps patterns of practice can be foundational too, but they also require a mixture of internal and external coherence. Whether there is some “ultimate” pattern of practice on which others rest and against which, therefore, judgements can be made when other patterns of practice clash, needs further consideration (Hughes 1995). But it is worth noting what Wittgenstein says in response to a question he puts to himself about judging the rightness of an action (where he is talking about obeying an order). He asks us to imagine ourselves as explorers in an unknown country with a strange language. He asks how in that country you would be able to judge whether orders were being given, understood, obeyed and so on. Then he states:

“The common behaviour of mankind is the system of reference by means of which we interpret an unknown language”
(Wittgenstein 1953, §206).

This brings to my mind a picture of patterns of practice around particular words or phrases, with broadening patterns of practice as we expand to language and, finally, “the common behaviour of mankind” when we start to think of language itself. And why should this picture not have some sort of application in the moral field? There may be local justifications for calling a particular practice virtuous, but in the end we need something common:

shared beliefs about what constitutes human flourishing.

Leaving the broader debate in favour of coherentism aside, I suggested above that there is a need for internal and external coherence. The first CMHT would be indulging in an internally incoherent pattern of practice if they strove to keep people in the community unless they lived in houses with yellow doors. The pattern of practice would be incoherent because it lacks consistency. If there were a good reason to discriminate against people in houses with yellow doors – if it signified a strange sect with a propensity to violence for instance – then this consideration would need to be built into the complexity of the pattern of practice, which would thereby retain its coherence. Or, there could be different patterns of practice for people with yellow and non-yellow doors. More seriously, there might be different patterns of practice, because of resources, depending on whether the crisis occurs on a weekday or over a weekend. This in turn raises the question about external coherence. Is the pattern of practice of the first CMHT better than that of the second? And is the weekend or weekday pattern of practice to be preferred?

Well, before moving away from these particular patterns of practice it might still be worthwhile to consider their internal coherence. MacIntyre (1985) spoke of “co-operative human activity through which goods internal to that form of activity are realized”. The first CMHT needs to ask itself what the internal goods are at which its pattern of practice aims. The aim might be delineated by the virtue of respectfulness, in which case the CMHT would need to assure itself that variations in its pattern of practice (e.g., in response to weekends or yellow doors) still conveyed appropriate respect towards the person. If we imagine that they have to admit that they simply cannot strive towards respect at weekends, then to this extent they lack internal coherence. This internal incoherence will need to be weighed up against the putative coherence of the second CMHT, who always aim at both benevolence and fidelity: doing good and staying true to their patients. Of course, it can be questioned whether you always do good to people by pursuing a pattern of practice that inevitably leads to in-patient admission. But this is again to stress internal coherence. But here I have been gesturing at the possibility of external comparisons of internal coherence.

True external coherence comes when we ask how this particular pattern of practice squares with our other patterns of practice or with the patterns of others. We must judge coherence within a broadening field, finally against something akin to “the common behaviour of mankind”. For instance a pattern of practice that encouraged compulsory admission would have to be squared with those other practices that valued liberty and autonomy. A pattern of practice that compelled psychiatric admission and treatment on those with political views at variance with the state would have to cohere with those patterns of practice that foster democratic rights and justice or show them to be incoherent. By implication there is a connection – made by the interconnecting and overlapping of our patterns of practice – between an inclination to admit someone to a ward against their wishes and the pattern of practice embodied in our politically democratic institutions. Obviously there is no easy way to compel a regime (or a person) to check its own patterns of practice against others, but this refusal to openness itself represents a pattern of practice that would be repudiated by other human practices. The iterative process of checking our patterns

of practice for internal and external coherence might itself be regarded as a manifestation of human flourishing.

For the sake of external coherence the inclination to use compulsory treatment should be modulated by our libertarian values. The weighing up of these different values can occur as an overt comparison between patterns of practice. More likely the process of balancing and assessing occurs naturally within the broad patterns of practice that constitute our clinical and ethical lives. When values are shared between patterns of practice, there is no incoherence; but when values are diverse, we have to look elsewhere in order to figure how our patterns of practice might cohere. Thus, the business of assessing coherence between patterns of practice aligns with values-based practice (Fulford 2004): both reflect how in real life we must deal with diversity.

Clinical practice inevitably involves negotiating between values and navigating between patterns of practice. The aim is to find a way through and, according to the line I have been pushing, the form of the argument will always involve looking at patterns of practice for internal coherence and checking that any particular practice coheres with our broader patterns of behaviour and demeanour. In short, we justify particular cases by reference to our broader forms of life. And, inasmuch as these broader patterns of practice constitutively express the aims and aspirations of human beings generally, inasmuch as they manifest an essential normativity, they can be regarded as embodying something given for human beings like us.

“What has to be accepted, the given, is – so one could say – forms of life”

(Wittgenstein 1953, p. 226).

Conclusion

I have suggested that the notion of patterns of practice provides a useful way to think about ethical decision making. I have suggested that this notion is useful both as a way to justify particular practices and as a way to uncover the connections between moral decisions and deeper philosophical concerns about the constitutive nature of normativity in our lives. Not only, therefore, might patterns of practice be clinically useful as a way of situating our ethical decisions and judging them for coherence, but also, through reflecting on patterns of practice, our ordinary clinico-ethical decisions are located in the broader patterns of human life.

Funding and Support: *There is no specific funding for this paper, although I continue to be supported by my National Health Service Trust: Northumbria Healthcare NHS Trust.*

Competing Interests: *None*

Acknowledgements: *None*

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Key Words: *coherentism, community treatment, compulsory admission, justification, normativity, patterns of practice, rules, values, virtue ethics, Wittgenstein.*

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The Ethics of “Ethics”: Black and White or Shades of Grey

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In historical understanding, ethics is an aspect of morality or a normative branch of moral philosophy. Morality concerns contrasts between right and wrong conduct, and because many of the world's religions tend to express themselves in these terms, morality is often approached by reference to religious beliefs and authorities. However, the rise of modern ethics concerned with developments in biology, particularly human biology and health care, known as bioethics, is essentially fact-based, rather than faith-based, and non-religious in that it excludes reasoning based on supernatural or divine agency.

Modern bioethics, which includes the ethics of mental health care, is old enough to have a history, but young enough that many whose initiatives and writings founded the field of bioethics are still contributing to its literature. In 1999, Warren Reich, an observer of the evolution of bioethics, recorded how in the 1960s the Vatican invited Catholic theologians and philosophers to consider church teaching on contraception, sterilization and abortion. Their proposals for liberalizing reform were rejected, however, since in 1870 the Catholic Church voted to approve the doctrine of papal infallibility, meaning that no papal pronouncement delivered ex cathedra could later be faulted or contradicted. Reich noted that “The theologians, who were the first ethicists working in bioethics, cut their teeth on contraception/sterilization and abortion debates and in a very real sense, much of the great energy that was turned toward bioethics around 1970/71 was energy that was diverted from the then-increasingly futile church debates on fertility control” (Reich, 1999).

Modern bioethics, unlike religious doctrine, is secular, pluralistic, empirical and argumentative, rejecting narrow orthodoxy and duties of obedience to authority. Bioethics often embraces a spectrum of approaches, on acceptance that there can be different ways of reaching decisions by reference to the priority given to competing ethical principles and levels of ethical analysis. These range from person-to-person ethics (microethics) to group or population-based ethics (macroethics), including administrative or bureaucratic ethics (mesoethics), and may transcend national or jurisdictional boundaries to consider wider environmental or ecological concerns (metaethics/megaethics). Bioethical discourse has flourished to such an extent that proponents of religious preferences have come to claim participation under the guise of advancing bioethics, making their religiosity of approach and appeals to emotion and supernatural influence under the name of bioethics, as the existing U.S. President's Council on Bioethics does.

The tension in ethics comes from the need to maintain sound ethical principles and also to endorse practices that work well. Sometimes, effective practices require compromises of principle and consistent applications of principle can be at the cost of efficient or effective practices. For instance, medications to treat schizophrenia can produce wanted effects, but eligible patients may decline to take them regularly. Medications' effects of maintaining patients' functioning in their communities may be gained by compromising patients' autonomy of choice on taking them. Respect for the principle of patient autonomy in consumption of medications may entail patients' periodic involuntary admission to care because they do not take appropriate medications and present an apparent danger to themselves or others.

This tension raises the issue of whether there are practices that are overwhelmingly correct and should never be compromised, that is, whether some principles present black and white options, and whether there can be ethically legitimate compromises of principle to produce desirable, protective effects. That is, whether the part-black, part-white application of principles produces shades of grey.

Black and White

A key ethical practice that should always be observed and never allowed to be violated, which emerges from the ethical principle of respect for persons, is non-discrimination. Recipients of mental health care warrant the same respect due to other persons. They should not suffer disadvantage such as stigma, because of their past, present and/or prospective mental health status and treatment. This is a principle of practice that is sadly often violated as amply illustrated in the findings and narratives presented in the Final Report of the Standing Committee on Social Affairs, Science and Technology of the Senate of Canada (the Kirby Committee Report) “Out of the Shadows at Last,” released in May 2006.

A history of demeaning abuse of patients with mental illness, such as was once expressed in involuntary sterilization, has not ended. Its modern expression is in the lack of these patients' equal access to employment, community housing and even health care itself. The Kirby Report publicizes the voices of mental health service consumers and their family caregivers who explain the lack of respect and the unequal, discriminatory treatment and stigma that patients with mental illness and their families suffer in access to

both private and public services, including institutional and community services, schools, homes for the aged, and in, for instance, police and prison care.

Discrimination against mental health patients is a clear violation of ethical principles, not only of respect for persons but also of the duty to do good (beneficence) and to avoid harm (non-maleficence, or Do No Harm), and of the duty to act justly. It is also a violation of human rights, expressed in the laws of many countries and in leading international human rights treaties. Attitudes and practices that discriminate against and stigmatize mental health service recipients show the clear distinction between unethical and ethical conduct.

Shades of Grey

Medical treatment, at both the clinical and public health or population levels, often requires judgement to be exercised in assessment of benefit-to-risk ratios. At times, the prospect of achieving wanted results is offset by the risk of causing inadvertent harm. For instance, the confidentiality of health care patients is important to preserve and beneficial in that it encourages patients to make the full disclosures to health service providers that allow providers to identify optimal treatments and care strategies for patients. Where patients present risks of causing injury to others or to themselves, however, strict observance of their confidentiality may expose others, and the patients themselves, to avoidable harm.

Warning others, such as family members, of mental health patients' liability to cause harm to others or to themselves, is not discriminatory. For instance, persons unfit to drive motor vehicles, and those liable to spread contagious infections, are liable to suffer comparable restrictions that limit their rights to confidentiality. Persons who live alone and are mentally disposed to neglect themselves, for instance in nutrition or hygiene, or to attempt self-injury or suicide, may have others appropriately warned of their disposition. The price of added safety is the compromise of confidentiality, but this trade-off may be ethically acceptable.

Consent to treatment can similarly present difficult ethical trade-offs. Courts applying non-discrimination principles have ruled that when mentally competent patients who declined to take particular medications become incompetent, they cannot be forced to take the medications they refused when competent. That is, they have the same rights to autonomy and physical or bodily integrity as mentally competent individuals. One price of this respect for their autonomy may be a loss of their physical liberty, if their decisions to refuse medication have the result of making them appear dangerous to themselves or others. Concerns are acute, however, when adolescents suffer from anorexia and refuse to eat or to be fed. Parental decision-makers may approve forms of treatment, such as by nutritional interventions, adolescents previously refused. It is a grey area of ethical choice whether involuntary feeding is justifiable when lack of nutrition endangers adolescents' health and lives.

Capacity to consent raises the ethical and often legal concern of whether the same test of capacity applies to decisions to accept recommended care and to refuse it, or whether capacity

is asymmetrical in that there is a lower threshold of capacity to accept advised treatment than to refuse it. If adult patients agree to medically advised care, it seems dysfunctional to assess them incompetent to decide and then seek the decision of guardians or substitute decision-makers whose duty to act in dependent persons' best interests requires them to consent to medically advised care. If adult patients refuse such care, it seems self-serving and manipulative of caregivers to assess them as incompetent to decide and seek the decisions of guardians whose duty is to consent to advised care. However, if capacity is specific to function, the decision to refuse advised care is more serious than the decision to accept advised care and capacity to refuse may have to be assessed by more critical criteria.

A further grey area of ethical choice concerns research. It is a black and white issue that individuals with mental impairment should not be recruited as subjects of research when unimpaired people would serve the scientific purpose. However, research into mental impairment, such as by application of unproven drugs, may be possible only by recruitment of those affected by the impairment under study. Whether affected individuals can provide adequately informed and free consent to participate can be ethically challenging. Clearly no pressure or coercion can be applied to condition their consent, but they may be induced to participate by the promise of relief of symptoms, or the need to appear agreeable to their care providers. A benefit-to-risk ratio has to be struck. Their uncritical recruitment into studies may expose them to risks, such as, consuming unproven products or forgoing their regular medications, but their exclusion may result in improvement in their treatment being forfeited. The ethical principles of promoting good, by improving treatment, and of avoiding harm, by not exposing dependent persons to risks, are in conflict. Promotion of one principle subordinates the other and striking a balance may not be a clear-cut, black or white issue.

Conclusion

The ethics of acting ethically are less complex when an issue presents a "right" or "wrong", black or white solution. In the many grey areas, however, prioritization of one ethical value over another requires reflection and discussion. Reasonable people may differ without finding that preferences that differ from their own ethical conclusions are unethical. That is, in the grey areas where part-white, part-black decisions have to be made, there can be different ways of acting ethically. More important than the individual conclusion is the process of ethical evaluation of competing principles and values that shape it.

International experience, including judicial assessments, poses the contrast. In 2001 in Erwadi, in the Indian state of Tamil Nadu, 28 women patients who were shackled in a hut were burned to death when a kerosene lamp overturned. The Supreme Court of India found the conditions in which they were maintained to be a human rights abuse and condemned the state government for its apathy regarding care of patients with mental health needs. Patients suffering other conditions are not usually shackled in their places of accommodation. This discriminatory management seems ethically indefensible.

In contrast in 2003, the U.S. Eighth Circuit Court of Appeal, in the Arkansas case of *Singleton v. Morris*, upheld legality of mandatory medication over the objection of a schizophrenic prisoner whose execution for brutal murder could not proceed while he remained mentally disordered. His condition manifested itself while he was awaiting execution. The court considered that medically indicated care would be required to be administered to any other prisoner and that a mentally disordered patient was no different even if he would be liable to execution when fit. Other prisoners, not being free to control conditions of their detention, cannot voluntarily remain ill. Whether a psychiatrist would act ethically to provide such treatment is a matter on which there can be legitimate disagreement, even accepting that American Medical Association professional ethics forbid participation in capital punishment. The ethical grey area is whether restoring a prisoner to his usual health is “participation” in his sentence, or showing respect for his human right to health care.

Competing Interests: None

Acknowledgements: None

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Ethical and Clinical Issues in Cardiopulmonary Resuscitation (CPR) in the Frail Elderly with Dementia: A Jewish Perspective

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ABSTRACT

Few clinical situations arouse more emotion and drama and lead to more conflict in decision-making than cardio-pulmonary resuscitation (CPR). The procedure was described as potentially beneficial more than 40 years ago. However, its efficacy and place in the care of the frail elderly have taken a long time to be established. In the world of secular medical practice, there are many situations when CPR may be provided to elderly, frail and cognitively compromised individuals for whom its clinical benefit is questionable. In those patients suffering from dementia, surrogates are responsible for decision-making, which complicates the process. When the clinical uncertainty is coupled with strong cultural and religious influences, as within Orthodox Judaism, the development of an acceptable approach to cardiac arrest is more challenging. A clinically sound, ethically defensible and religiously sensitive approach to CPR requires a deep understanding of all the factors involved in the decision-making process and may require periodic re-evaluation not only by clinicians but by religious scholars and leaders.

Dementia is one of the main factors that require families to choose a long-term care environment for their loved one. The frail elderly suffering from dementia are a group of individuals for whom institutional long-term care may become necessary. As a group they face many special clinical needs, which may pose unique challenges in emergency situations. The ethical challenges, especially in the realm of end-of-life decisions or potentially life-ending events such as cardiac arrest are of special interest (Conroy, 2006; Gordon, 1995, 2001; Gordon & Singer, 1995). During the past 30 years, in much of the Western world, and certainly in North America, a good deal of ethical deliberation has been based on secular values, as described by Beauchamps and Childress (2001) in their development of Principlism. This framework is used in many clinical scenarios (Adams, 2004). However, in many Western nations, there is an increasing number of citizens with strong ethnic and religious beliefs, which may provide a counter-balance to traditional or secular values and discourse as a basis of ethical decision-making in complex clinical situations.

For those elders with special ethnic or religious views or beliefs, health care professionals should try and understand the meaning of these values in the decision-making process, especially when issues of life and death are in question. In those societies that have a multicultural and varied religious make-up of their populations, the situation becomes complicated because of the impact on decision-making that religious views may engender among family members, patients and health care professionals (Markwell, 2001; Daar & Khitany, 2001; Goldsand, 2001).

Health Care Decisions and *Halacha*

For the Jewish elderly whether abroad or in Israel, health care decision issues, especially those at the end of life may be affected by *Halachic* interpretations depending on the degree of orthodoxy of the patient and the involved family (Jakobovits, 1995; Weingarten, 2002; Freedman, 1999; Steinberg, 1994; Novak, 1990; Friedman, 1993; Grodin, 1995). *Halacha* is Jewish Law. As it pertains to the practice of medicine it has a long history of development, interpretation and re-interpretation. For Jews, even those who are not Orthodox, it often has a substantial impact on medical deliberation and clinical decision-making especially in end of life or potentially life-ending situations.

For those who follow Judaic practices and principles, *Halachic* interpretations and advice from scholars and rabbis responsible for interpreting Jewish Law may be of great importance when difficult clinical decisions, as when life and death hang in the balance, are being contemplated. There are often situations where the values, local laws and decision-making options of individuals conflict with *Halacha* and may result in tensions and controversies in treatment. Institutional policies may result in potential conflicts depending on how secular or religious-based the policy appears to be and how it affects individuals across the spectrum of Jewish religious belief.

In medical emergencies, there is usually an overriding obligation to save the life potentially at risk. This is congruent with most secular principles as well as with the *Halachic* value of *pevuach nefesh* (saving of a life because all life is sacred). Cardiopulmonary resuscitation (CPR) is an example: The normal clinical obligation in response to a cardiac arrest is generally to initiate immediate CPR. This is done with the hope that by restoring the heart and lung function it may be possible to prevent what otherwise

would be imminent death and reverse the underlying condition that caused the cardiac arrest in the first place. Currently, in most Western countries, unless there is a specific refusal to have CPR performed through a “Do Not Resuscitate” (DNR) order, physicians and nurses are obligated to undertake CPR until success or failure occurs.

During the past few years, the data related to CPR in the elderly frail population, who live in long-term care facilities in which a large percentage suffer from dementia at various levels of severity, suggests that perhaps the standard paradigm of CPR, unless refused through a DNR order, may not be clinically and ethically applicable. This is related to the dismal outcomes that have been found in this population. Perhaps the obligatory application of CPR, which is a common occurrence in the emergency room (ER), is not potentially beneficial in a defined group of frail elderly long-term care patients that suffer from many concurrent illnesses including end stage dementia that compromise their ability to survive CPR. This might be so, not because they have no intrinsic “human value”, but because they do not have the biological reserve to withstand CPR or because the cardiac event is really the final common pathway for death from their multiple co-morbidities. If this is the case, perhaps the *Halachic* principle, which would support CPR in anyone with a cardiac arrest, might benefit from a review by *Halachic* scholars and rabbis of its applicability in the face of the circumstances and well-documented dismal clinical outcomes that surround this frail, elderly long-term care population.

Outcomes of Cardiopulmonary Resuscitation (CPR) in the Frail Elderly

In order to understand the potential place and benefit of CPR in the frail elderly that live permanently, often because of severe dementia among other chronic illnesses, in long-term care facilities (nursing homes and chronic care hospitals or units) a review of the relevant literature is necessary. In this population, CPR has been shown to offer little if anything in terms of survival (Gordon, 1995; Gordon, 2001; Zweig, 1998; Stein, 1996; Ditillo, 1996; Benkendorf, 1997; Zweig, 1997). Even under the conditions where arrest “teams” are readily available, which is rare and limited to a very few large academic facilities that may have on-site medical interns and residents immediately available, the outcomes from CPR are at best grim. Most long-term care facilities do not have 24-hour round-the-clock full CPR capability. Rather, they depend on emergency response services and rapid transfer to an ER for further emergency care, which results in substantial delay in full CPR to patients whose clinically determined likelihood of survival is minuscule.

A 1990 study demonstrated that when resuscitation was performed on residents who had suffered cardiac arrest in a nursing home, only two of 117 (1.7%) patients survived to hospital discharge (Applebaum, 1990). One of those survivors spent 30 days in the hospital and died eight months after returning to the nursing home demented, cachectic and with a large sacral pressure sore. In a review by Gordon (1995), in more than 100

cases there were no survivors of CPR using 100 days post-arrest as the outcome measure. There were in fact very few immediate survivors and these studies reflected settings where there was 24-hour on-site maximum resuscitative capability, a situation that does not exist in the vast majority of long-term care facilities in most countries. In a 1997 study, it was reported that there were no survivors when CPR was applied to 182 elderly nursing home residents out of a total of 2348 out-of-hospital cardiac arrests (Benkendorf, 1997). More recent studies substantiate previous observations (Conroy, 2006; Fidler, 2006).

With this evidence from the medical literature, why is it still often the norm to provide CPR as the *modus exitus* to this very frail elderly population? It seems that both the secular and *Halachic* justification for CPR reflects the idea of saving a life (*pecuach nefesh*), which is a powerful treatment motivation. But, the contemporary secular and religious model of “salvage” is actually based on populations for whom CPR offers some semblance for survival. But, in geriatric long-term care patients, such a beneficial outcome is far less likely than for younger patients or the many relatively healthy elderly population that do not require long-term care because of the complexity of their medical and cognitive status. The need and usual criteria for admission for permanent long-term care is a good marker for multiple complex physical and cognitive problems and frailty and the dismal outcomes from attempted CPR (Gordon, 1995).

In many long-term care facilities, attempts are made to obtain do-not-resuscitate (DNR) orders in order to avoid the implementation of CPR, which is unlikely to confer any clinical benefit. However, for many reasons, DNR orders may not have been obtained or some people for personal or religious reasons may be opposed to the provision of a DNR order. This may be the case for observant Jews for whom the agreement to sacrifice even a moment of life may be in conflict with their *Halachic* commitment to the sanctity of life. When a DNR order has not been obtained, certain necessary protocols and policies must be implemented in order to avoid inappropriate CPR. There are two minimal criteria which should be in place before CPR is initiated: that the event is witnessed; and that it is unexpected. A CPR policy that spells out these criteria in detail would be a reasonable administrative approach to those who do not have a DNR order in place (Gordon, 2003). The vast majority of people in long-term care are “found” dead rather than in the throes of dying or with a true “cardiac arrest”. The initiation of CPR would therefore be unlikely if these two criteria were used as the basis of implementing CPR.

Attempting on-site CPR even when the capability, staff-wise, exists or sending such patients via ambulance to an ER seems to be an inappropriate transfer of clinical and ethical responsibility. The transfer is from those who know the patient and family and can make such judgements to forgo CPR to an ER staff that would feel obligated to carry out what will in all likelihood be ineffectual CPR. Families should be told by physicians and other health care providers about the limited benefits to be gained from CPR (Gordon, 2001, 2003). They should be informed that even in the absence of a DNR order, CPR might not be attempted other than in very limited and well-defined and circumscribed circumstances.

Within Judaism, the Concept of Goses and CPR

An important tenet of Judaism which should be considered in a deliberation of the CPR process is the respect for a Goses (Shema Yisrael; Eisenberg, 1999). A Goses refers to the ancient Talmudic criteria by which a person who is in the throes of dying is identified and treated in a way that respects the state of events and the inevitability of immediately foreseeable death and does nothing to interfere with the dying process. In modern terms, it is a way of trying to define the trajectory of dying as one might in a terminal patient undergoing palliative care. In ancient times, when the concept of the Goses was developed, it was defined as one to three days or less. This prognostic ability often exists even in an era of modern medical technology and should be based on the clinical situation and the known and expected outcomes of any possible clinical interventions. It is hard to determine from literature, how many of these patients in long-term care who receive CPR survive and how many of the few immediate responders may have survived more than the traditional three days that is usually used when describing the Goses status. Most patients who die, do so within the first few moments, hours or days, often experiencing failed attempts at CPR or efforts to maintain them on life-support systems.

The important concept of allowing a person to die, for whom there is virtually no chance for living and respecting the process so that it is dignified and uninterrupted, is difficult to resist within a secular framework. The concept of the Goses appears to be the Halachic basis for such a respectful approach as well. Its conceptual framework was described in the tenth century by Rabbi Moshe Isserles and as noted by Washofsky (2005) prohibits “...anything which constitutes a hindrance to the departure of the soul such as chattering noise or salt upon his tongue [attempting to revive him]...since such acts involve no active hastening of death, but only the removal of the impediment”.

This very humane principle helps form the foundational understanding of the Goses. It suggests that perhaps attempting CPR on Jewish, elderly, frail, long-term care individuals, many of whom suffer from dementia and who have experienced a “cardiac arrest”, and for whom the likelihood of immediate or even short-term survival is virtually non-existent, is an affront to the concept of the Goses. If this is so, it may be that what should be done for this well-defined population is to treat “cardiac arrests” as a stage in imminent dying. Therefore, instead of attempting ineffectual CPR, which is clearly undignified and intrusive to the dying process, treat the person as a Goses and allow them to die peaceably with no impediments to that process.

It would not be surprising to hear some Halachic scholars suggest that even in the face of those overwhelming odds, CPR should be provided to this population in any event because some elderly patients do survive. To deny the opportunity for those lives to be saved would be in conflict with the over-riding Halachic duty to save lives. The question becomes, just how likely is CPR to be of benefit in this population and whether the rare occasional success merits the more frequent occurrence of violating the concept of the dying process as exemplified in the

concept of the Goses. In the geriatric long-term care population survival from “cardiac arrests” is extremely rare (Gordon, 1995; Gordon, 2001; Zweig, 1998; Stein, 1996; Ditillo, 2002; Benken-dorf, 1997; Zweig, 1997). In view of the long history that promotes CPR, despite its poor results, it may be worth re-considering the CPR-dying-Goses paradigm specifically when it comes to the very frail geriatric long-term care population. Perhaps the Halachic principles that govern how such clinical situations are approached should be re-examined in the face of the evidence about lack of survival. Ideally, it might be of value for each case to be reviewed by Halachic scholars (poseks) so that individuals at risk of receiving ineffectual CPR might implement a timely DNR discussion and order. However, the likelihood of most long-term care facilities that have frail, chronically ill elderly Jewish residents, being able to mobilize the number of Halachic scholars to address the needs of all the potential CPR candidates on a one-to-one basis, would make such an approach unrealistic. Rather, Halachic scholars, interested in the field should confer with the clinical experts to determine if the contemporary interpretation of the implications of the status of a Goses and its relationship to likely ineffectual attempts at CPR can be further examined. If so, perhaps the emphasis should be changed to forgo CPR and to allow death to occur without interventions that would be in conflict with the concept of the Goses.

In some ways, what is being proposed to Halachic scholars is to frame the situation as one might when an individual is deemed suitable for the late stages of palliative care, where terminal symptom management is the focus of treatment. In such situations, it would be a rare occurrence that those responsible for care would consider CPR as an option if the patient appeared to succumb to the illness for which palliative care was being provided, even if it were prior to the anticipated time of death. It is not saying that elderly individuals requiring long-term care are necessarily comparable to those in a palliative care program. Many have long periods of potentially satisfying and fruitful lives ahead of them and deserve full and respectful care. But, because of their underlying medical frailty, a “cardiac arrest” is tantamount to the very terminal stage of an individual receiving palliative care and should not be treated by CPR.

It is a challenge to physicians involved in the care of the frail Jewish elderly to provide optimal clinical and religiously and culturally respectful care. Similar challenges occur in other religious and ethnocultural groups whose elderly frail members reside in long-term care facilities. When physicians are dealing with families who are acting as surrogates, because of the cognitive impairment or dementia of their family members, it might be apparent that the family’s views may or may not accurately or completely reflect those of the patient they represent. For those of the Jewish faith who are observant and struggling to follow Halacha while at the same time wishing to avoid unnecessary dramatic interventions and suffering, the struggle between the saving of a life and the respect for a Goses can be most disquieting. A careful reconsideration of the evidence and outcomes of CPR in this population might result in fewer frail, chronically ill long-term patients being sent to the ER via an ambulance for ineffectual CPR because they have suffered a life-ending cardiac arrest. Rather, they would be allowed to die peacefully and in a dignified fashion and within the framework meant for a Goses, in the place that was their home.

Conclusion

Physicians and Halachic scholars should revisit the discussion of the relationship and obligation to save a life and the obligation to respect the Goses. If the position that is proposed is acceptable to rabbis and Halachic scholars, it could change the way the very frail elderly, Jewish long-term care residents are approached during the last period of their lives. In place of considering the dying event in a "medically emergent" manner, and exposing frail elders to an undignified and physically intrusive and, at times, apparently painful last few moments of life, it could revert to one of an uninterrupted, peaceful and Halachacally sound transition from life to death.

This article has been peer reviewed.

Competing Interests: None

Acknowledgements: None

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Key Words: CPR, DNR, elderly, ethics, nursing homes, Jewish, Halacha, Goses

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Restraint Use and Autonomy in Psychiatric Care

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ABSTRACT

The use of four-point physical restraints has long been controversial in psychiatry. But the most common objections against these restraints hinges on the idea that they would be imposed against patients. In light of the trend towards giving patients access to Advance Directives, why not allow patients to use such legal documents to arrange for restraints being used against them? Patients might do this if they feared an inability to make competent decisions in the future. Proper oversight over the requests and the restraint-use would help psychiatric patients plan for their own care. Clearly, not all patients would qualify for such an expansion of their autonomy. Many would be unable to give adequately informed consent. Still, for the patients who could consent, being able to draw up such a "Ulysses Contract" could provide an improved balance of risks and benefits.

Of the means of physically controlling patients in psychiatric institutions, the most controversial is the 4-point restraint (4PR). Use of the 4PR involves a patient being "placed on a bed, which is bolted to the floor, and both of his/her ankles and wrists are secured in leather restraints. Two additional leather straps are [then] placed over the patient's legs and chest" (Schreiner, Crofton and Sevin, 2004, p. 451). From advocates for patient rights to scholars on healthcare law, virtually everyone seems to agree that the less 4PRs are used, the better (Sullivan, et al., 2005).

This strong stand against the 4PR derives primarily from the reasonable belief that "being treated involuntarily in psychiatric care" is a threat to "the integrity of the patient," and that this way of treating patients is among the worst (Johansson and Lundman, 2002, p. 646). Critics also cite the dark history of restraint use in psychiatry and the fact that in industrialized nations the rules governing the use of physical restraints are becoming stricter (Grob, 1994). In some European countries the use of 4PRs is almost unheard of (Fairman and Happ, 1998). Mindful of these trends, critics urge an end to the use of 4PRs (Tumeinski, 2005; Weiner, Tabak and Bergman, 2003).

A possibility rarely considered, however, is that a patient might arrange for the restraints to be used. Such arrangements would be in keeping with the general move towards giving patients more

say in the risks that they take. There are already provisions for Advance Directives (ADs) in psychiatry, as there are in medicine overall (Brock, 1993; Matthews, 2000; and VanWillingenburg, 2005). These contracts give patients in a psychiatric institution greater control over their own therapy, mainly by spelling out legal arrangements that are to take effect if the patients become unable to make competent decisions. Although the usage of the AD is more common in emergency medicine, the documents could be designed around the idea that a psychiatric patient might not be able to adequately communicate his or her preferences regarding the 4PR.

Humiliation and Autonomy

The main objection against this would be paternalistic, that the 4PR is beyond the pale, and that institutions have an obligation to prevent patients from choosing something that will lead to their own humiliation and possible mistreatment. According to one critic, the "most important point . . . is that tying someone spread-eagled to a bed is very degrading" (Saks, 2002, p. 162). In Saks' opinion, "it is hard to imagine a more humiliating intervention" than the 4PR. For this reason, Saks would allow patients to ask for a helmet "in a padded cell" if they posed a threat to themselves, but insists that a request for "more drastic forms of mechanical restraint should never be honored" (Saks, p. 162).

Objections of this sort are flawed, inasmuch as they simply declare the 4PR humiliating and then move to the claim that patients should not be allowed to request it. Such reasoning can easily take a logical shortcut and gloss over several important points. First, there are varieties of paternalism, with some interventions on behalf of the patient being more easily defended than others. Second, there is no clear, agreed-upon account of humiliation or the moral relevance that the potential for humiliation should have. Taken together, these points suggest that any proposal for the AD must show that these legal arrangements will cater to the interests of the patients and that the imposition will be consistent with limitations that the patient him or herself can accept while able to give consent in advance.

This way of establishing the groundwork for the proposal concedes that there are very real risks associated with the 4PR, including the heavy psychological and emotional costs to everyone involved with the restraining process (Singh, et al., 1999). There are also physical risks that would be present any time someone is forced into the restraints. But whatever else humiliation is, it seems to

be a cluster of reactions that we can only gauge from reports or statements that the person being humiliated might give. This means that humiliation might be what the affected person says it is, rather than what an observer would predict. It also means that we should be skeptical of second-hand predictions of what patients might or might not experience.

Where our primary basis for narrowing the range of patient choice is a state of humiliation that we presume that the patients will experience, our restriction looks arbitrary. Some patients might find restraints of any kind humiliating, just as many will have strong reservations against the 4PR. But this may not tell us much, since, as the 4PR is one of the most extreme forms of restraint used in institutional settings, it is understandable that some patients might have very negative opinions about its use.

As tempting as it might be to think that one patient at risk of humiliation is one patient too many, a large slice of human experience is concerned with our trying to adjust our response to situations or outcomes that we believe might lead to some type of humiliation. In these instances, humiliation or fear is not always sufficient reason to avoid the situation entirely. Medical care involves routine trade-offs between benefit and potential embarrassment. Visits to the clinic can involve catheters, bedpans, frank discussions about bodily secretions, nakedness in front of strangers and so on. An urologist's patient can consent to having a nurse hold his penis while the urologist pushes a flexible microscope through the patient's urethra with technicians, medical students and others possibly looking on. It is odd to not let that patient also consent to a possible 4PR out of concern over embarrassment.

The best course would be to determine if the 4PR offers an acceptable balance of risks and benefits for patients who would draw up the AD and, in some cases, for those with the status of substitute decision-maker. The patients who qualify for the AD will hardly look forward to being restrained; the intent of the proposal is not to "sell" patients on the virtues of being strapped to a bed. Rather, the point is to allow a mechanism for certain patients that will let them derive some value from their increased ability to take an active role in determining when and how this treatment will come about.

This needn't amount to a system whereby the patient would invite humiliation. An assumption at the core of the proposal is that there will be an absence of malice or the other harmful intentions that we ordinarily associate with something like humiliation. The premise behind questions about whether patients ought to be able to negotiate for a period of humiliation are thus difficult to accept. Humiliation may well occur, but that outcome would not have to represent a lack of social skills or moral competency in the patients. Even if reform of personal character is accepted as one of the goals of psychiatry, limiting the responsibility that patients can take for their own care seems a poor way to achieve it. Proper oversight could ensure that patients arrange for a 4PR only when this will help restore a sense of dignity, self-control, and self-respect.

Informed Consent

There are legitimate concerns about whether, given a possibly diminished emotional and cognitive state, patients rationally mull over the request for a 4PR. A similar objection is often made to

allowing prisoners to consent to medical research. The presumption is that they would be all too willing to accept treatment that non-prisoners would find abhorrent. Might the AD prove to be an "offer" that some patients would not be able to refuse? (Slomka, et al., 1998).

Fortunately, medical institutions are used to dealing with moral quandaries about access to treatment. Because of wide variation in decision-making capacity, the 4PR would clearly not be appropriate for every patient. Some patients might present inadequate reasons for wanting to be restrained, for instance. But it would be wrong to therefore deny all patients access to an AD out of concern for such possibilities. The more promising course would be to treat the decision to contract for the 4PR as we would any other that the patient might make, or that a patient might make in conjunction with proxies and substitute decision-makers.

To this end, one commentator tells of a patient who would insist on receiving the liquid medications that he saw other patients receiving; staff responded to this behavior by giving the patient "fruit punch whenever the others were receiving their supplements" (Donat, 2005, p. 1106). Granting the differences between the types of treatment and recognizing that the presumption would be against associating deception with the 4PR, the point is that staff can find ways around inappropriate patient requests. There is no justification for arranging to subdue a patient because he or she desires physical contact, for instance, and oversight committees can assess these and others reasons that patients might give for wanting the 4PR. They committee members can do this, that is, just as they assess other aspects of the patients' care.

The idea behind the AD is that "one clear advantage to respecting autonomy is that people tend to know best their own value structure, for example, what they are willing to endure, and generally have a good sense of the basis of their own well being" (DeMarco, 2002, p. 241). But the paternalist might allege that consenting to the AD requires patients making judgments about their future well-being in a way that many would be incapable of doing. The patients can, after all, misjudge their own thresholds of embarrassment or discomfort, and there is some question of which patient we would restrain, the one who requests the AD one week, or the one who fights against it a week later (Olsen, 2003).

Shortcomings in human judgment, along with ambiguities over moral personhood, do bear on the ethical question. Under consideration are "Ulysses Contracts," which will stipulate the restraints to be provided, and will tell staff to ignore the patient's opposition to that treatment. The common usage of the term "Ulysses" in this context can be a bit misleading. The general idea is based on the idea that Ulysses asked his men to restrain him, aware that he would at a future time tell them to do otherwise. As a specialized form of the AD, a Ulysses Contract would, in effect, tell the staff to disregard any objections the patient makes in the future, when certain conditions exist.

As unconventional as this might sound, there is nothing mysterious about the possibility that patients will change their minds or that they might want someone to over-rule their later decisions. Patients who opt for the AD expect to change their minds, otherwise they would not be requesting that the staff ignore their protests later. This suggests that, if anything, we should puzzle over patients who

arrange for the AD and do not find the restraints offensive. Such a patient would likely not need restraining.

The sort of uncertainty in contention here is a feature of any request that the patient might make. There is no reason to rule out the Ulysses Contract when we do allow patients to make similar judgments that project their interests into the future, as they would with the AD. Philosophical quandaries like these reinforce the notion that such a contract would not be appropriate for all patients (Miller, 1998). Advocacy of the Ulysses Contract needn't side-step these quandaries; all should recognize that the case for these arrangements will inherit all of the moral uncertainty typically linked to the use of an AD. Indeed, one of the reasons that the AD might not enjoy wide application is that the freedom to choose, and the understanding of the choices, would have very different significance for each patient (Kukla, 2005; Thomas and Cahill, 2004). But this fact only reinforces the need to ensure that patients understand the dimension of choice that they would be gaining and relinquishing, to be eligible for the AD.

A related criticism would hold that the situation in the psychiatric institute might be grave enough that some patients could consent to things that they would not outside of that setting. But this is a misleading objection. Procedures like the 4PR have little use to anyone who was not in such a setting to begin with, so it is difficult to compare the selection of the AD with a choice that one might make in another context. Perhaps the real issue is whether the influences on the patient's decision-making would be so great as to amount to coercion. That matter is best settled with empirical evidence and individual counseling, however.

The mere possibility of strong influences on the patient's thinking should not invalidate decisions about the Contract. Guidelines can give patients the benefit of the doubt to decide against certain medical treatments, like chemotherapy, if they feel that the risks outweigh the benefits. Patients retain this right, even when their refusal can be expected to hasten death, and with doubts concerning the influences on their decisions. Laws that allow adult patients to refuse necessary blood transfusions illustrate this same dimension of autonomy. These points force the paternalist to show why it is acceptable in some cases to respect a choice that will almost certainly lead to a patient's death, without assuming that influence equals coercion, yet deny that same patient the ability to sign a 4PR directive.

Again, no one should pretend that consent will eliminate ambiguity in this context any more than it can in others. It is certainly true that consent will not preclude some patients from getting themselves into situations radically different from what is expected or needed. The argument here is only that consent would be a step towards meeting the patient's needs, and the prospect of misjudgment has to be set against the positive features of the AD. Not the least of those advantages is the fact that the restraints would be temporary and, unlike other procedures, the 4PR would not pose a risk of lasting emotional or physical harm.

The 4PR As Medical Treatment

Critics (e.g., Tannsjö, 2004) might question how detailed clinicians

could be when giving eligible patients an account of the risks and benefits. Reliable data on the 4PR is scarce, some allege, making the act of subduing patients "experimental" medicine, not standard care (Moss and La Puma, 1991). Others add that there is currently insufficient evidence about the effectiveness of ADs of any kind in psychiatry (e.g., Varekamp, 2004).

One could reply, however, that this too is an empirical question. Why not tentatively introduce the ADs, and examine the role that this and other Ulysses Contracts might play in psychiatry? Institutional guidelines now let patients participate in clinical research. Patients can now consent to similar research, or they can consent by way of family members and proxies. Significantly, some experimental treatments pose long-term health risks, which the 4PR would not. We can look on the restraints as experimental and simply devise protocols around the 4PR with all of the safeguards that such a categorization usually involves.

In other words, treating the restraint procedure as research would only be a good thing if this adds a layer of oversight. Rules could allow for patients to consent only when they can show that they understand the comparative lack of clinical evidence for the efficacy of the restraints. Guidelines could give patients, family members and others a way to monitor the choices that the patient would be making if this was deemed necessary.

Increasing our knowledge of the effectiveness of the AD could also clarify the role that it plays in the patient's care. There are many ways to describe or defend something done to or for the patient, depending on the particular orientation towards therapy. It might be true that the color of the paint in the patient's room is to some extent part of the type or quality of care, but this is not the same as saying that wall color is itself medical treatment. Institutional guidelines for the AD might help clarify the distinctions between a purported therapeutic use of the restraints, as something to directly benefit the patient, and a use of the restraints in therapy, as something useful for facilitating other aspects of their care.

Would Consent be a Hollow Gesture?

In the end, might the AD seem like a redundant legal device? Institutional regulations could already permit staff to impose whatever restraint is necessary to maintain control over patients who pose immediate threats to themselves or others. This could make obtaining a signed Contract look like a pointless ritual, in light of what is bound to happen regardless of how the patient decides. A critic might add that the goal should be the elimination of the restraints, not a facade of consent for them.

The concern in this objection is important, but misplaced. If the 4PR will be used regardless of what some patients want, this supports giving them a greater sense of control over how the restraints are used. A measured approach to using the Ulysses Contract could offer real benefits to patients, families and staff. This would not continue the legacy of mistreating patients with the restraints. Both patient and provider would have to understand the importance of managing aggressive or disruptive behavior, ideally without restraints, in order for the potential use of the 4PR to be justified.

Where there are gaps in the communication of this nature, and where oversight leaves room for workplace sadism, the institution is facing a problem with its personnel, not an inherent defect in the use of the 4PR. Mandatory monitoring of the restraining process, along with documentation and additional training, could go hand-in-hand with a level of choice that would not be merely symbolic. Any informed consent procedure has its ritualistic qualities, but far from being a strike against the proposal for the AD, this serves as one reason why patients are better off with such routines. The symbolic leveling of authority and privilege enhances the moral significance of the compromise that doctor and patient can make about interests and resources.

Giving patients this power of consent would, in addition, not have to be part of an attempt to bring the restraints into the ethical mainstream. There are good reasons to work towards a system of care that involves the least invasive form of restraints possible, if only because of the dark history of restraint use. If critics are right, however, some degree of reform is in the interim warranted. Not only that, the potential for patients and their advocates to take part in dialogue about how and when the AD should be implemented would mark a positive turn in the history of psychiatric care. Finally, barring access to Ulysses Contracts will not resolve problems related to the possibility that the 4PR will be used whether patients give prior approval or not.

This article has been peer reviewed.

Competing Interests: None

Acknowledgements: None

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Key Words: *autonomy, Advance Directives, Ulysses Contract, restraints*

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Assertive Community Treatment (ACT): 23 Cases

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THE CASES

These short cases are intended to stimulate thought or perhaps serve as a useful tool in a classroom or discussion group setting. The cases have been modified to protect confidentiality but do represent real life elements and situations that have been encountered by ACT team staff. Many or most case situations presented may be familiar to ACT Team staff members. Will all ACT team members view each of these as ethical problems? Were others aware that all of these things happen within the clinical milieu of assertive community treatment?

For those who are unfamiliar with Assertive Community Treatment Teams...

- small multidisciplinary teams (10 staff) doing community based interventions
- they provide rapid and intensive responses with flexible, all inclusive care
- they have long-term and full clinical responsibility for individuals with serious and persistent mental illness
- there are low staff: client ratios (often 1: 8 to 10)
- ACT is often a program of last resort—the alternative is frequent or permanent hospitalization
- ACT may produce better outcomes than case management for those who are seriously ill
- ACT teams are cost effective because they keep clients out of hospital and because the in-house concentration of multidisciplinary services provides smooth and efficient continuity of care

Our Three Part Presentation Format:

The Case: (a real/composite case)

The Question: (e.g., “What should be done?”)

A Comment: (e.g., “When in doubt don’t do it”)

Family/Caregiver Issues

Case 1: Beverley is a 25 year old capable woman with schizophrenia who lacks insight and lives at home with her parents. Every few months she starts to go without sleep and then decompensates. Her mother secretly puts lorazepam into her food when she sees a change in sleep pattern and this corrects the problem. The mother told the ACT team what she is doing and how this has kept her daughter out of hospital.

The Question: Should ACT staff try to stop this practice?

A Comment: The mother knows it is assault and deception but believes that it is her right as a parent to do so. The ACT team has remained silent on this matter with the client.

Case 2: The parents of a 33 year old male with schizophrenia do everything for him and he has no chores or responsibilities while living with them. The mother explains that in her culture this is the way it should be. The client is quite happy with this but the ACT team has trouble motivating the client to accomplish any rehab goals.

The Question: Should the ACT team try to educate the family about how they believe their efforts are being undermined by the family system?

A Comment: Cultural sensitivity should not be confused with family dynamics that are actually harmful to the client. Tact and modeling are critical.

Confidentiality Issues

Case 3: Lois is adamant that she does not want one ACT team member to know a particular bit of information about her; the information has clinical but not safety significance.

The Question: Should you risk splitting, fragmented care, or inconsistency of approach by allowing or fostering selective disclosure?

A Comment: No. Open sharing of information is the acceptable price of team care, and it is particularly necessary where safety is

a factor. This operational mode must be explained up front. Nonetheless selective disclosure occurs and we must trust the discretion and judgment of our fellow clinicians as they, and we, inevitably filter the information flow.

Case 4: The law in our jurisdiction requires mandatory disclosure of NCR (“not criminally responsible”) status to a potential employer by the client or the ACT team. Susan really wants a particular job and begs the team to not disclose her NCR status because the law is unfair. She was charged with uttering threats to a family member (while manic) but she has no criminal record or history of violence otherwise. She is fine on meds and is happily compliant.

The Question: Should staff withhold the information in the client’s best interest?

A Comment: No. The law should be respected but seeking the patient’s permission for fuller disclosure (i.e., the context of the events and how well she is doing now) may serve to allay an employer’s concerns in this instance.

Case 5: The landlord calls to say that Bill has been suggesting he would like to have a barbeque in the hallway of his large apartment building. The landlord demands to know if Bill has caused fires in the past. (The client hasn’t; the barbeque comment is most likely an awkward attempt at conversation). He will be evicted unless there is a response. The paranoid client refuses to give permission for staff to talk with the landlord.

The Question: Do you tell the landlord the client is not a safety concern?

A Comment: Maybe. The ‘letter of confidentiality law’ should not violate the spirit, which aims at protecting best interests. Homelessness is a serious consequence.

Case 6: The streets are your office; team members regularly meet clients on sidewalks and in coffee shops for assessments.

The Question: If the client wants this, should the team go along with it?

A Comment: Yes. If best efforts at discretion are maintained and the client is not put at risk with public disclosure of status.

Case 7: ACT staff ask neighbours how a client is doing and if they have any concerns about him. The excuse is that everyone in town knows that he is followed by a mental health team.

The Question: Is there a breach in confidentiality?

A Comment: Yes. But if the information is volunteered unsolicited it can be accepted.

Care Issues

Case 8: Joanne enjoys wearing brightly coloured, oddly matched clothes that will make her stand out in any crowd. She is unconcerned about appearance. A particular ACT clinician always makes her dress more “appropriately” before allowing her to come out on her outing.

The Question: Is this demand to change acceptable?

A Comment: Some of what is justified under a therapeutic guise may be about clinician comfort or over-protectiveness.

Case 9: Alice is a 54 year old female who has a 25 year history of schizophrenia. She lives on a disability pension in an apartment with three cats and two dogs. Her apartment reeks of urine and her chairs are always wet and sticky. She has no concerns about hygiene, and never has visitors except for ACT staff?

The Question: Should ACT staff force her to clean as a condition of involvement?

A Comment: Health reasons prompt the need for cleaning but beyond that, staff comfort is not the issue, although the impact of cleanliness on personal relationships is a legitimate therapeutic and rehab concern.

Case 10: Mike always agrees to any suggested medication or dose change. He has persistent delusions that an electronic chip is in his brain preparing him to be transformed into Jesus. He takes the meds happily because they can have no effect on someone with his special powers. The psychiatrist has not declared him incapable and the team never raises this question at client reviews.

The Question: Should he be declared incapable and a substitute decision-maker sought?

A Comment: Yes. However, the reality (as on inpatient wards) is that it is easier to hide behind the presumption of capacity as long as treatment plans are followed.

Case 11: Fred has severe paranoia and has had extremely serious suicide attempts when ill. He does extremely well and is able to work and maintain relationships when on his depot medication. He completely lacks insight. Every two weeks he refuses his injection, is then told by the psychiatrist that his substitute decision-maker has authorized it, he in turn says he will leave the country to escape “evil psychiatrists”, and finally the psychiatrist says he must accept the injection or the police will be called and he will be taken to the hospital where he will get it anyway. He complies.

The Question: Is this repeated exchange acceptable?

A Comment: He keeps coming back and hasn’t left the country. Is each return motivated by fear or is it an expression of subconscious recognition of the benefits of the injection?

Case 12: Ed’s bipolar disorder is fairly well controlled on meds. He

has burned down two houses when manic in the past. He is competent when taking his meds but refuses monitoring bloodwork. The psychiatrist refuses to keep prescribing meds without being able to monitor kidney and liver function every 3-6 months. He says he is aware of the (low) risks of possible lethal organ failure and will take his chances.

The Question: Should the ACT team discharge him?

A Comment: Not sure. After two years of trying to obtain bloodwork they did because the team psychiatrist refused to keep prescribing the meds.

Case 13: Judy, age 53, decompensates within several hours when she drinks. She has a history of grabbing young children off the street and taking them home because she believes they are her own. Staff see her twice a day. She wouldn't let them into her apartment building one afternoon but she answered the phone with slurred speech, all the while denying any alcohol consumption. The team member called the psychiatrist to her apartment. In order to certify her the law requires she be seen by the psychiatrist in person. When she refuses to let the psychiatrist in, he lies to her and says the intercom has so much static he can't understand her. She then buzzes him in and lets him up to the apartment, whereupon she is certified.

The Question: Was it acceptable for the psychiatrist to lie?

A Comment: No, but... if it were your child abducted would the question of lying even matter to you?

Case 14: Mark is required to follow a jointly prepared budget, but staff imposed a budget because he overspends on junk food and cigarettes. Although financially capable, staff controls his weekly spending money. He wants more spending money and he resents this tremendously.

The Question: Should the team interfere in a financially capable person's decisions in this way?

A Comment: Yes, if his rent and basic necessities are not being covered. However, how many people in the real world actually make a monthly budget in such a formalized way?

Case 15: Staff buy cheap cigarettes for clients from the native reserve store. Sometimes groups of clients are taken on "country drives" to the same store.

The Question: Should staff do this?

A Comment: No. It's a clear health issue. However, it is not really this simple. Savings may be spent on better food and thereby lead to an improvement in health.

Case 16: Margaret, an artist, wants to give her favourite team member a small, beautiful watercolour painting as an expression of gratitude. She says it is important to her that it be accepted.

The Question: Should it be accepted?

A Comment: Substantial gifts are always refused. Small, inexpensive gifts might be accepted only if they can be given to the whole team (e.g., this was explained to Margaret and the painting was displayed on the ACT office wall). The safer course may be absolute refusal of all gifts by all staff.

Case 17: Jimmy, a 22 year old with schizophrenia, has a calendar with pictures of naked women displayed on his living room wall. This has upset some female staff who asked him to move it to his bedroom where it will be out of site during visits. Jimmy grew up in a family where pornography was displayed openly in the house. He tells staff to mind their own business and "just get over it". These particular staff feel they should not have to see him now because of their discomfort. (He has no history of violence or inappropriate sexual behaviour.)

The Question: Have team members overstepped their bounds?

A Comment: Yes. Education about sexism should be done, but he is free to adorn his apartment with legal material.

Case 18: A 27 year old Caucasian with stable schizophrenia remarked to a staff member that "those brown people are different". He further relates with open approval how some "brown people" were harassed to the point they left his small village. At a family meeting his mother is openly and proudly racist. When challenged on their views they are disgusted by the ACT team members' "big city stupidity". Thereafter, staff never talk with the mother.

The Question: Should any staff of color have to see this client (he doesn't want to see them)?

A Comment: Staff comfort should be considered because countertransference may be blinding and diminish therapeutic efficacy. Some will argue the possibility of a corrective experience should not be avoided. Whatever the course, the decision for involvement is not the client's but the team's.

Case 19: Clinicians regularly do the laundry and clean the house of some clients "who will never do it themselves and won't do it even if you directly help them". The clinical issues are dependency and disempowerment and they are reviewed case by case.

The Question: Is this even an ethical issue (enabling vs disabling)?

A Comment: Sometimes it feels like an ethical issue and sometimes it doesn't which may reflect projections, intuitions, or suspicions about a fellow clinician's motivation. It is easier at times to clean for someone rather than with them, especially if they "never do a good enough job". This is an issue that is a source of resentment and splitting. "I do cleaning work for clients and so should you".

Case 20: Staff donate food, old TVs, their used computers, etc. for clients. Most on the team feel these items should be passed on with

the explanation that they have been received from anonymous donors. Some staff members say this is silly and that it is just common decency and kindness to give gifts, and they insist on identifying themselves as the source to the respective clients.

The Question: Is revealing yourself as the source simply self-serving?

A Comment: Yes. It meets your need and further sets up an “us and them” demarcation and barrier.

Case 21: A 33 year old client is on a government disability (which everyone on the team agrees is barely a subsistence allowance). If he works, an amount equivalent to his wages is deducted from his disability income. He is working under the table in construction.

The Question: Is the team duty bound to report this income, especially if doing so means the client will simply stop working?

A Comment: No. We are not required to report illegal activity if no one is harmed. (Some argue, cogently and correctly, that the underground economy is broadly harmful to society as a whole and unfairly burdens tax paying citizens.)

Case 22: Joe is 34 years old and has a history of significant substance abuse, with repeated visits to the ER with delirium and intoxication. He always ingests all pills in his possession. With this client it was agreed that he would only have access to his medications through twice daily visits to the pharmacy for a one time dose on each visit. This is a huge demand on his time.

The Question: Is this acceptable?

A Comment: In the alternative, he overdoses repeatedly.

Team Dynamics

Case 23: At a team meeting it was agreed that staff would stop lending clients money (up to \$20 had been lent at various times). There was apparent agreement that it was a boundary crossing that should stop. Subsequently, some team members just kept doing it because they thought the team decision was wrong and punitive. Even after being confronted, the particular team members argued that their professional college or conscience did not prohibit the lending of money.

The Question: Must they go along with the majority view?

A Comment: Don't soil your own nest. Collective wisdom should be trusted; “buy-in” and follow through for decisions should not be passive-aggressive or lukewarm.

Competing Interests: *None*

Acknowledgements: *None*

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John Has Hepatitis and Schizophrenia

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John's History:

John is a 52 year old man who is currently hospitalized with a diagnosis of schizophrenia and hepatitis caused by chronic infection with hepatitis C virus. He has a hepatic encephalopathy that is partially controlled with lactulose which lowers ammonia levels in his blood, but does not affect the progression of his hepatitis. His schizophrenic symptoms have been resistant to treatment by a variety of anti-psychotic medications alone and in combination, including clozapine. Despite treatment he remains delusional believing that he is extremely wealthy, and that he does not have either liver disease or mental illness. He does not appear to experience distress as a result of these delusions, although is angry and upset that he is held in a psychiatric facility against his will. He denies symptoms of depression or anxiety and does not demonstrate significant agitation.

Under the legal framework within which he currently resides and receives treatment, he is hospitalized involuntarily, and has been for a long time in order to prevent substantial mental or physical deterioration, as he is unlikely to follow the treatment plan necessary to minimize the possibility that he will require re-admission. In this jurisdiction, as he is admitted involuntarily under the mental health act, and as he is deemed incompetent to consent with respect to his psychiatric treatment, he can receive psychiatric treatment against his will at the decision of his treating team, but not medical care. He does not have contact with any family members at all, being completely estranged from his siblings, and having never married or had children. Application for consent for medical care can be made to the public guardian who can provide substitute decision making and consent for his medical treatment.

Currently, his liver disease is progressing and it is estimated that, untreated, he will die of liver failure within 2-5 years. Treatment with interferon and ribavirin has a substantial chance of slowing the progression of his hepatitis, and even eradicating the infection and hence arresting the progression of his illness, although it would not improve his liver function from its current level. It remains likely given his stage of progression of liver failure that he will nonetheless die of this, but treatment could significantly prolong his life. Improvement of his psychiatric symptoms could arise either as a result of some improvement in his hepatic encephalopathy, or in liver function that would allow then more aggressive treatment of his symptoms with medication, previously limited by the fact that many anti-psychotics are metabolized by the liver and hence

toxicity can develop in people with liver illness. This is unlikely though as treatment at its best usually only stabilizes liver function, although some resolution of acute infection could result in a modest improvement in liver function.

Standard treatment with interferon and ribavirin for hepatitis C, depending on viral genotype, is generally 48 weeks requiring daily medication and weekly injections. There is a significant risk of worsening of John's psychotic symptoms during the treatment, as well as other mental and physical side effects including depression, anxiety and irritability, insomnia, myalgia (muscle pain), rash, arthralgia (joint pain), nausea, vomiting, anorexia and flu like symptoms such as rigors (shaking chills). These are not easy medications to take. Given that his psychotic symptoms even now can only be partially controlled, exacerbation of these symptoms could be significant and quite disturbing to John.

At this point, providing treatment would be contrary to his currently expressed refusal to accept any such medical treatment on the grounds that he believes he does not have hepatitis, as a result of his psychiatric illness and consequent delusions. We have no evidence to indicate what his wishes would have been when he was well and able to consider the options. Treatment would expose him to significant side effects that could cause marked distress and discomfort, which could be alleviated only by stopping his anti-viral treatment although other measures would be tried before that. In the end the ultimate outcome would not be changed, as he would still likely die as a result of his liver illness. His psychiatric illness is likely to remain unchanged regardless of the success of his liver treatment, and so he may continue to require psychiatric hospitalization or care in a secure environment in the community for many years, limiting his freedom. At the same time, failing to provide the treatment on the basis of not having previously expressed wishes one way or the other, and the lack of capacity to consent, would mean that he will die sooner than otherwise of his liver failure, and it could be seen as providing less than optimal care of his medical illness on the basis only of his also having a mental illness, which would be a form of discrimination.

* Brief commentaries in response to this case were written at the invitation of the editors of JEMH.

1. Joint Commentary on “John” by:

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Sidney Bloch MB PhD

Department of Psychiatry and Centre for Health and Society, University of Melbourne, Australia

One could not encounter a more tragic situation than that of John, a middle-aged man afflicted by two horrific illnesses, compounded by the fact that each is resistant to treatment.

We are often tempted to view patients with severe chronic mental illness and physical co-morbidity differently from those who are only affected by the latter, namely, that it is not as worthwhile treating a physical condition in an individual like John as is the case in treating someone not suffering from an intractable mental illness. Such a view is tantamount to discrimination and a violation of a basic right to “good enough” health care. Our first caveat, therefore, is that John not be treated dissimilarly to any other patient with a progressive physical disease.

How then should we proceed to treat him? Given that his loss of insight is both complete and likely to endure, and that we have no indication of his previous preferences in any dimension of his life, we have no option but to adopt the principle of beneficence; attempting to identify any residual sphere of autonomy seems utterly futile.

In acting paternalistically we face the awesome task of trying to ascertain both what are likely to be in John’s best interests and what he himself would perceive in that regard. As we are so often reminded, the first value here is *primum non nocere*—not to cause him harm. This is easier said than done in that any decision taken regarding his health care will have profound repercussions for his overall quality of life. Moreover, we are hamstrung in not being able to determine the medical decisions that would promote John’s best interests. For example, we have little idea of the potential adverse effects of the treatment for his hepatitis, nor how John would wish to deal with them. On the other hand we do know that the effects of both his illnesses and the interferon treatment for his hepatitis will severely diminish his quality of life. We therefore face the uncomfortable conclusion that we have no choice but to assume responsibility for his fate; specifically, our line of reasoning supports not treating his physical illness.

Our position has revolved primarily around principle-based ethics, but we should not lose sight of the potential role of care ethics. We mean by this paying attention to the contribution mental health professionals are obliged to make in being empathically attuned to John’s needs as a human being for sensi-

tive and compassionate care. (1) As Annette Baier (2) has so poignantly expressed it, “There but for the grace of God go I”.

Competing Interests: None

Acknowledgements: None

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2. Commentary on “John” by:

Walter Glannon, PhD

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Because John lacks decisional capacity due to his psychiatric illness, he can be given antipsychotic medication against his will. What complicates this case is that legally he cannot be forced to take treatment for his liver disease, even though he has been deemed incompetent and treatment for this condition is medically indicated. His hepatic encephalopathy may exacerbate his psychiatric symptoms and treating his hepatitis C might alleviate these symptoms. The efficacy of treatment would depend on the viral genotype. If it is likely to be effective, then John’s physicians have at least a prima facie obligation to prevent harm to and benefit him by treating both diseases. This would be consistent with the medical ethical principles of nonmaleficence and beneficence, though it would mean overriding John’s expressed refusal of treatment. Yet it is not an autonomous refusal given his delusional state. John’s health care providers have a professional duty to act in John’s best interests, and he does not know what is in his best interests, or the consequences of not treating his hepatitis C. Treating his liver disease would appear to violate his freedom from interference with his body. But treatment could free him from the pain and suffering caused by the combination of his two conditions.

Still, treating John against his wishes can be ethically justified only if: (1) his delusional state completely undermines his decisional capacity; and (2) his medical conditions entail a significant risk of harm to him. The fact that John does not believe he has liver disease or mental illness indicates that he lacks decisional capacity. Moreover, the likelihood of a shorter life span from hepatitis C and a worsening of his psychiatric symptoms constitute a significant risk of harm to him. For these reasons, treating John for both medical conditions can be ethically justified. With respect to benefit, therapeutic intervention can be justified not only with a view to increasing the quantity of his life years, but also to improving his quality of life. For both quantitative and qualitative reasons, treating both psychiatric and hepatic conditions can prevent harm to and benefit an incompetent patient.

Competing Interests: None

Acknowledgements: None

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ANALYSIS

Actual Case Outcome

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Upon review of the opinions provided with respect to John's care, the treatment team was left with a decision to make regarding next steps. We did apply to the Public Guardian who is legally empowered in our province to provide substitute decision making for individuals such as John who are unable to provide consent, and who do not have alternate SDMs available (John is completely estranged from his family). The Public Guardian did provide substitute consent for hepatitis treatment.

Following the reasoning provided in support of treatment under the principle of beneficence, we then addressed the practical issue of treatment. In the case of treatment with ribavirin and interferon, administration requires both daily oral capsules and weekly intramuscular injections. For the medication to be effective, they need to be received at least 80% of the time. John is extremely resistant to taking medications, especially oral medications. He is able to detect any attempt to provide medication in food or other liquids and will refuse anything he detects as altered in any way. This extends to medications of all kinds, whether for comfort, minor medical problems or psychiatric medications. He is more accepting of injections as long as they are infrequent and so his psychiatric medications are provided now by depot intra-muscular agents. This step has improved his quality of life in that he avoids daily struggles with nurses trying to convince him to take medication and he has both a greater sense of freedom and autonomy as a result, as well as being able to avoid experiences of conflict and argument. Thus despite the fact that we had substitute consent, we felt that the lack of sufficient assent by John was such a barrier to being able to provide effective hepatitis treatment that we would not proceed with such treatment. Should John's experience of his illness change, such that he is more willing to assent to oral medications, we would then be prepared to address this issue again.

The opinions provided illustrate the difficult balancing act that clinical teams need to perform in trying to balance principles that are often in conflict. With the difficulty inherent in providing this particular treatment for this particular individual, we felt that the balance between beneficence and *primum non nocere* was further tipped to the side of not causing harm, as forced oral treatment would be so destructive to the therapeutic environment in which John has to continue to live and would be so prolonged (often up to 48 weeks) that it would have a significantly negative impact on his quality of life as well as reducing significantly the likelihood of efficacy of the treatment for his

hepatitis due to problems in ensuring sufficient medication actually enters his system to be effective. Although it is impossible to know what decision John would make were he able to provide informed consent, his resolute refusal of any and all oral medications, regardless of indication, and the improvement we have seen in his overall sense of well being and comfort when we stopped other oral medications provide us with a sense at least that the decision we are making for John, even if forced by practical issues of medication delivery, may in fact be consistent with what he would have wished even if he were able to more clearly appreciate his current situation.

So in the end, one might ask if an ethical consultation was of any use, if we are just in fact choosing the answer we would have chosen any way. Ethical decision making is never free of bias in the decision maker but, at least by analyzing the principles involved, we can be more conscious of the full range of the issues underlying any clinical decision. Having opinions available that conflict is helpful for clinicians at least to ensure that we have fully reflected on a difficult decision and to provide assurance that the discomfort we may feel in making those decisions is honestly derived.

Competing Interests: None

Acknowledgements: None

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Mental Disorder, Diagnosis, Treatment and Ethics

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This short contribution questions the ethics of basing the way we think and act in relation to mental disorder on beliefs and assumptions that are in the view of the author at best, unhelpful and at worst, simply incorrect.

How is it possible to classify mental “disorder” when we have not yet classified mental “order”? It is generally recognised that there is no one “official” definition of “mental health” let alone a “classification”. Cultural differences, subjective assessments and competing professional theories all affect how “mental health” is defined. The World Health Organisation (WHO) defines mental health as “a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.” (<http://www.who.int/mediacentre/factsheets/fs220/en/>).

Each human experience is unique, and whilst there are common elements between people’s experiences, each one of us manages our experiences differently. People who hear voices, whose experience may be classified as “psychotic”, do not all experience voices in the same way and many voice hearers are very able to manage their voices outside of the psychiatric system using a wide range of personal strategies (Bock, 1999). This highlights the fact that the experience of psychosis in the community is significantly greater than identified by people coming into contact with the psychiatric system (Van Os, 2000). Of course there are common elements and themes in the way people experience and/or respond to distress especially those from the same cultural, familial and genetic background. But that does not mean that each person’s experience can be treated in the same way. Each person needs to be treated as a unique being and within our cultural, familial and linguistic worlds.

In July 1990, George Bush Sr. signed the proclamation on the “Decade of the Brain” and significant expectations were raised that biological and genetic causes of “mental disorder” would be identified and solutions achieved. Completion of the human genome led to further expectations that genetic causes of these distressing and damaging disorders would lead to biological solutions. However, despite a decade and a half of investment and expectation, no biological or genetic solutions for mental disorder have materialised although potential advances have been made in relation to identified neurological disorders.

The above beliefs have led to an increasingly singular focus on biological forms of treatment in psychiatry and the development of a plethora of medications over the last 30 years. In the main, these are targeted and marketed by the pharmaceutical industry at specific diagnoses. If you look in any psychiatric journal, the majority of advertising is based around diagnosis. Some adverts even suggest that diagnosis is the key to selecting the most appropriate treatment, that is, of course, medication. Medication becomes equated with treatment. Yet there are arguments that the evidence for the effectiveness of some medications is not as strong as suggested by the industry. Healy (2002) judges that the evidence that the selective serotonin reuptake inhibitors (the SSRIs) and the “atypical” anti-psychotics are superior to older drugs is weak.

This author considers that a singular focus on medication, as the only treatment, is unethical. This is not an argument against the importance of diagnosis or medication, but simply the use of diagnosis to “select the most appropriate treatment (medication)” as a response to people’s distressing mental experiences. It is clear that people who are distressed and challenged by their mental experiences, more often than not, have had the most horrendous life experiences to which their “mental disorder” is a response (Read, 2005). In other words, what we call mental disorder is often the result of people’s inability to cope with “abnormal” life stressors, and if we accept the WHO definition of mental health, then these responses to distressing experiences could even be defined as mentally healthy.

It is considered that if we continue in this singular direction we will journey on around the same old pathologically classified plateau rather than seeing the beauty of the recovery and wellness focused hills and valleys. We should instead be trying to understand the lived experiences of people who can be diagnosed as “mentally ill” and learn about the experiences of people who have overcome their adversities (Journal of Social Issues, Summer 1998). In addition, the connections between mental disorders and artists, poets and other creative people is strong (Jamison, 1994) and it could be argued therefore that the differences provided by the experiences we call mental disorder actually contribute to the richness of our societies. So our thinking needs to change to a focus on people’s narratives and learning how the experience of “mental disorder” can contribute to our lives, our communities and society as is happening with the growing interest in recovery and Wellness Recovery Action Planning (WRAP). This is not just for how it can be used in personally managing mental disorder but many other aspects of people’s lives.

The RISK of not focussing on the richness of recovery and wellness is that we will condemn those diagnosed as mentally ill to a life of chronic illness when “The cause of chronicity, which has long been sought within the individual (biological or psychological characteristics) is not inherent in the illness itself, a part of the natural order, but rather is clearly connected with the person’s life in society” (Topor, 2001).

As John Read states:

“Surveys of public opinion all over the world find that most people believe that emotional problems, including those deemed severe, such as hearing voices, are primarily caused by bad things happening to us rather than by faulty brains or genes. The public also favours psycho-social approaches, such as talking to someone and getting advice, or help finding friends or a job, rather than drugs, electro-shocks or admission to psychiatric hospital.

Some experts, however, dismiss these views as “mental health illiteracy”. They continue to insist that mental illness is an illness like any other, despite many studies showing that the more we adopt this medical model, the more prejudiced and frightened we become.” (<http://www.project-syndicate.org/commentary/read1>)

So let us “add values” (Fulford, 2002) to our thinking in relation to diagnosis. Let us recover diagnostic classification so that it is used correctly/ethically as a common professional language that enables research and professional understanding of a wide range of human psychological experiences. Let us recover the pharmaceutical industry so that they recognise the uniqueness of each person and promote the control of medication being in the power of the recipient rather than promoting treatments based on diagnostic classification.

Competing Interests: None

Acknowledgements: None

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Making the Law Match the Reality; Making the Reality Match the Law

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The purpose of this paper is to discuss the importance of the rule of law in democratic societies. Many of my examples come from Ontario, Canada because that is where my experience lies, but I have spoken to enough people and visited enough places to know that the problems are universal.

In Ontario, decisional capacity for many purposes is defined by legislation and a substitute decision-making regime is set out. Decisions about health care treatment and nursing home admission are both covered by this regime. The law sets out a scheme for determining capacity and clearly states that the starting point is a presumption of capacity. The law also establishes a clear hierarchy for substitute decision-making. In brief, the substitute decision-maker for a person found to be incapable is the highest ranking individual on a list of potential substitutes who is available, willing and capable of making that decision.

The Supreme Court of Canada, the highest court in the land, has stated clearly and unequivocally that the capacity test is to be applied objectively and that a capable person has the right to make a decision for him or herself with which others would disagree. In the case of a substitute decision-maker, there is a legal process that allows the professional to, in effect, appeal the decision of a substitute decision-maker that he or she finds objectionable. The law allows the professional to disqualify a potential substitute on the basis of an objectively reached opinion with regard to a potential substitute's capacity but does not otherwise allow the professional to pick and choose among potential substitutes.

That's the theory, anyway.

According to the reasons for decision in a recent case before the Ontario Consent and Capacity Board, the tribunal charged with adjudication under the legislation, things played out somewhat differently. In those reasons, a health professional was cited as having given evidence to the effect that, quote, "his definition of capacity reflected whether he thought the substitute decision-maker was acting in the best interests of the person who needed to be admitted to a care facility" and "that in his view the legal definition of capacity was irrelevant to the consent process." He guided his approach based upon whether or not consent was given or refused in accordance with what he thought was in the patient's best interests" As he explained, "We try to obtain the best result for the patient."

This is the sort of thinking that I want to talk about today. I will come back to this decision later in my remarks but first permit me to set the stage.

Jurisdictions everywhere have struggled with mental health law since psychiatric institutions were founded. Capacity and substitute decision-making legislation has become an increasingly hot topic as our societies age. One problem with this area of law is that society has never really been clear in its own mind just what it wants to accomplish with this whole area and what it thinks about the people who are subjected to it.

We have never been clear in our own minds if we have psychiatrists, and medications, and programmes, and laws, and institutions to assist our fellow citizens who have tragically fallen prey to illness; or if we are dealing with a group of undeserving people who are somehow damaged or inferior as the result of moral or religious failing, or whether we need to control this group because they threaten our safety and create an unsightly and unpleasant situation in our town squares.

A similar level of complex ambivalence influences our thinking about issues of decisional capacity. Do we want our health care professionals to make decisions for us because they know best and will do the best for us? Do we want to let them determine our fate because that is their right as befits their station in life, or are we committed to informing ourselves and making our own decisions because to do so affirms our independence and autonomy and the right to control our own bodies and fates?

Are we committed to preserving life above all else because of our commitment to a religious or philosophically-rooted belief in the sanctity of life or do we believe the right of the individual to decide when to end suffering and make a dignified exit from a life that has replaced meaning with endless suffering?

And we live in capitalistic societies. Control over one's own property is considered a fundamental right. Transfer of control over property from the owner to a third person is a big deal in our world. We assume that we can only do it to protect the person from him or herself. But historically this was done in order to protect the interests of the sovereign by preserving an incompetent person's assets and estate so that family members would not become charges on the public purse. So here again we see the confusion and ambivalence.

Underneath all of these questions is the more fundamental question of who really owns the health care system and its institutions and for whose benefit it ultimately exists. In plain English, whose turf is it, anyway?

If all this were not enough, we have the cultural issues and assumptions that underlie all of the legislation and practices in question. These cultural challenges exist on several different axes. For example: We have the different world views and languages of the physicians, ethicists, lawyers, policy makers and politicians. Frequently, they don't think like each other, talk like each other or trust each other. The assumptions that underlie their work profoundly differ from one group to the other. And when an area of endeavour, such as this one, involves all of them on the same playing field, things are likely to get messy.

In fact, if I can continue with the playing field metaphor for a moment, we have one team on the field playing basketball, one playing lacrosse and one playing football, all at the same time. No wonder they don't understand each other, interact very well or even respect each other. They can't even agree on the rules, the underlying assumptions, the purpose of the game or even which game they are playing.

But there are other cultural players as well. Both mental health and consent and capacity legislation are laden with cultural assumptions. These assumptions relate to how society is organized, the concept and importance of individual autonomy, the role of family, the way important decisions are made and a host of other issues. Our consent law, for example, presupposes that there are two layers to our society: the individual and the state. Family members are relegated to the role of substitute decision-makers bound by the rules established by the state, and, arguably, nominees of the state. Substitute decision-makers, for example, are bound by statute to take into account the values and beliefs of the patient but forbidden to make reference to their own values and beliefs when making their decision. (As an aside, I am not at all sure how this is even supposed to work unless we introduce robotics into the substitute decision-making scheme.)

Cultural assumptions also underlie our concept of decisional capacity, a construct based on the assumption that you are either fully autonomous or stripped of all control over your affairs in a particular sphere. Nowhere does our model accommodate the ideas of shared decision-making and consensus management that are so fundamental to so many cultures such as Canada's own aboriginal peoples.

For all of the reasons already mentioned, and many more, mental health and capacity law reflect a delicate balance taking competing interests and philosophies into account. Some have referred to the process of creating these laws as an attempt to reconcile the irreconcilable. Mental health law, for example, allows us to apprehend and detain citizens who are not accused of any crime. In Ontario, it does not require court authorization. This is a very unusual authority in a democracy. At the same time, there are extraordinary powers of review and supervision of the committal power. All of this exists because mental health law is about trying to balance the need for safety and treatment, on one hand, with the right of every citizen to liberty, autonomy and self-determination, on the other. What some see as technicalities, others see as necessary protections.

Consent and capacity law allows a health practitioner proposing a treatment to make a legal determination that I am not fit to make my own decisions. This, in turn, allows the professional to seek out a substitute decision-maker who will make decisions for me that are so fundamental as to sometimes determine whether I will live or die. Or whether I will be allowed to return to my own home or have to spend the rest of my days in an institution not of my choosing.

No individual, no matter what his or her education, credentials, or status or standing in the community has the right, without legal authorization, to hold me against my will or interfere with my body in ways or for purposes that I have not consented to. In a democratic society there is only one way to balance all of these competing interests. That is through the rule of law. Outside of judge made law that is designed to deal with certain closely defined emergency situations, there is only one body that can authorize a citizen's detention or treatment against their will. All of these powers, of course, are reserved to the people themselves through their elected representatives in parliament. In the case of Ontario, for example, the parliamentary body in question is our provincial legislature.

We see then, that the family doctor or emergency room physician or psychiatrist who decides to hold me against my will, or sign paperwork to that effect, may only do so under the authority of power granted to him or her by the people through their elected representatives in parliament. Again, with a few minor judicially sanctioned exceptions, there is no other way. And, it stands to reason, that there must be strict limits and appropriate checks and balances in the exercise of such powers. The fundamental principles of democracy demand no less. Just like we oversee the armies and police and jails that deprive people of their liberty and, sometimes their life, against their will and demand strict parameters, oversight and control, so must there be parameters, oversight, and control over those health and helping professionals who, for the most beneficent of reasons, seek to restrict our liberty, control our property, or interfere with our bodies.

I am sure that few would dispute my conclusions to this point in the paper. They are self-evident to anyone weaned on the milk of democracy. But yet no one seems to scream loudly when these fundamental and self-evident principles are not followed. In fact, many of us scream bloody murder when we are not allowed to flaunt these principles in the name of some supposed greater good. At the outset of my remarks I provided one example of a professional who appears to believe that he is not bound by the rule of law in making determinations that will result in the permanent institutionalization of his client. From the remarks, one can safely conclude that he believes that he is morally justified to ignore the rules established by society in order to achieve some greater good for his elderly and vulnerable client. He is not alone. I set out a few more examples below.

Ontario laws have two sets of procedures for making findings of financial incapacity. These findings have the effect of removing control of a property from the person and placing it in the hands of a state official. The usual procedure requires a specially trained fee-for-service professional known as an assessor to attend and examine the person. The assessor is required to explain why he or she is there and the subject is entitled to reject the assessment. This procedure applies to anyone in the province over eighteen years of age.

There is also a much simpler procedure that has the same effect. This procedure is carried out by a physician so there is no need to contact an assessor or wait a few days for the assessor to arrive. There is no direct cost to the individual. And the patient has no right to refuse. The only problem is that this procedure may only be used for a bona fide patient under *the Mental Health Act* in a hospital recognized in law as a psychiatric facility. The law is very clear that only a person who is legally detained in a psychiatric facility against their will or who has given voluntary, informed capable consent to voluntary psychiatric status is considered to be a psychiatric patient. The law could not possibly be any clearer. The fact is, however, that the procedure is routinely used for grannies admitted to orthopaedics after a hip fracture. The fact that this is totally illegal, a terrible violation of personal rights, and, arguably, fraudulent, has apparently not crossed many people's minds. The office of the Public Guardian and Trustee sent out a bulletin a few years ago in an attempt to address the matter. The memo helped a bit but did not stem the tide.

A finding of incapacity to make a nursing home admission decision can have momentous implications for a person. In Ontario, such a finding can be made by any physician, social worker, nurse, psychologist, etc. The effect of such a finding is to remove from the person the right to make their autonomous decision as to where they will spend the rest of their life and transfer the decision-making power to a third party. The authority to make this finding is clearly quasi-judicial although it is never thought of as such. The law sets out a clear definition of capacity that must be followed in conducting the evaluation. The courts, up to our Supreme Court of Canada, have repeatedly made it clear that the process is a very serious one and that objectivity, clear-headedness and proper documentation are the rules of the day. The courts have also made it clear that an appropriate amount of time must be devoted to a capacity evaluation to allow the necessary inquiries to take place and the appropriate persons spoken to.

None of this, however, has stopped the routine use of nurses and social workers employed as hospital discharge planners from performing this function. Many of them are poorly trained in capacity evaluation or not trained at all. A high number of them are told to ask a few pro forma questions and tick off a few boxes on a form instead of conducting a proper capacity evaluation. More troubling is the fact that many of them are in a conflict of interest so serious that they should never be allowed to conduct capacity evaluations in the first place. What I mean by this is that many discharge planners are under enormous pressure to clear hospital beds by moving the elderly out of the door. It is simply inconceivable that anyone subjected to this sort of pressure should be allowed to make a capacity evaluation when the result of that finding may well determine the speed with which the patient will depart the hospital.

A person admitted to a nursing home theoretically has all the rights of any other citizen. But it often doesn't work that way. Their treatment decisions are often made by family members even though no one has even bothered to assess the resident's decisional capacity, let alone make a finding of incapacity. In fact, treatment decisions are frequently made by house physicians who don't bother to get consent from either patients or their families.

In one recent scandalous case, a complaint was made against a

physician who routinely ignored the clear legal obligation to get informed consent before treating nursing home patients. He was, however, successful in defending himself before the profession's self-governing body by arguing that it was standard practice among physicians in nursing homes to ignore the requirement for informed consent to treatment. Now, I understand that if I complain against my doctor for mismanaging my ulcer treatment, she can legitimately and reasonably defend herself by saying that she followed accepted practice. But that is quite different than arguing that a clear violation of legal requirements is excusable on the basis that others are scoffing at the law as well. Then again, maybe we should all adopt that defence. Just imagine. The boys up at the lake who are ticketed for heading out in their boats after drinking five or six beers could just tell the judge, "Your honour, I am innocent 'cause all the guys do it."

And the list goes on.

Our *Mental Health Act* allows the detention of an individual for an assessment of up to seventy-two hours. This assessment must take place in a hospital legally recognized as a psychiatric facility. The individual's rights under the *Canadian Charter of Rights and Freedoms* must be honoured by providing a form that explains his or her status and rights. Anybody outside of a psychiatric facility having custody of such a person must transfer them forthwith to a psychiatric facility. But the fact is that many of the receiving hospitals designated as psychiatric facilities are either full or place such a low priority on mental health that they routinely refuse or are very slow in accepting these individuals from outlying hospitals that are not designated as psychiatric facilities. As a result, our smaller hospitals are faced every day with the dilemma of putting their communities and patients at risk by releasing potentially dangerous individuals into the community or detaining them quite illegally and risking prosecution or suit for false imprisonment.

Once that patient gets to the psychiatric facility, there is no guarantee that fundamental legal rights will be respected. The law is clear that I am either to be kept against my will as an involuntary patient, in which case I get rights advice and the right to an appeal, or I am a voluntary patient and can head out the door at will. Many staff people at psychiatric facilities, however, do not like the idea of having to face a legal review. So they have found a trick that allows them to lock patients up without legal recourse. The attending physician simply notes in the chart "certifiable if tries to leave." This puts the patient into legal limbo. He or she has no legal recourse whatsoever or even access to the rights advisor since they are not technically held against their will. On the other hand everybody knows that they cannot leave. This scandalous situation, this wholesale abuse of human rights, takes place every day across our province.

I should also mention the fraudulent ruse of avoiding the mandatory annual tribunal review of involuntary committal by making the patient voluntary on paper for a brief period and then starting the involuntary status again. Scandalous! I could go on all day but I think that you get the point.

This sad state of affairs is not limited to Ontario. I was recently in Israel, a country with progressive mental health legislation and an engaged bar and bench. And yet I was told of a recent case where the courts ordered the release of a psychiatric patient but

the physicians at the hospital decided that release was not in the patient's best interest so they simply moved her to another unit and ignored the court order.

Hungary is another country that we consider to be progressive. Until recently some patients in Hungary were kept in cages. Specifically, selected patients were kept in a contraption known as a cage bed which is a metal bed frame with bars welded around and on top. Cage beds were made illegal a few years ago. Some hospitals removed them. Others replaced the bars with chicken wire and announced that they no longer had cage beds. Net beds, but not cage beds. And they claim that they are now complying with the law.

So why does all of this matter? In addition to the obvious human rights violations inherent in some of the situations described above, I would argue that this state of affairs is a fundamental affront to democratic principles and that it puts the liberty of all of us at risk. In fact, I would argue that it would be better in many ways not to have any laws at all in these areas than to have laws that are ignored. At least, if we had no laws, we would know that we have not legislated and not fulfilled our responsibility. The way it is right now, we can dupe ourselves into thinking that we have dealt with the issue and solved the problem when, in reality, we have done nothing of the kind.

I think that there is something profoundly frightening in a state of affairs wherein we pass legislation in the glare of publicity but then ignore it or violate it away from the bright lights when dealing with our most vulnerable citizens who rely on the legislation to protect their rights. As I noted at the outset, only parliament has the right to legislate in these areas and that legislation, by definition, reflects the wishes of society and a delicate balance between competing interests and philosophies. It is simply intolerable that anyone would take upon themselves the right to ignore these statutory provisions. And the fact that the rest of society ignores these violations is unfathomable and frightening. And I should make one more point. If the laws are being ignored or violated with impunity and on such a regular basis, should we not be asking ourselves if the law needs changing?

I recently reread a paper that I wrote on this topic about fifteen years ago. In that paper I said much the same thing but in a much more measured and philosophical way. I am no longer philosophical about the issue. I am angry and I am frightened. Not just for the rights of those vulnerable people in our hospitals and nursing homes but for all of us and for the fabric of democracy itself.

We need to write our laws in plain English and to ensure that ongoing educational programmes are offered for health and helping professionals. They are not going to absorb the law by osmosis. Law and ethics must be an integral part of the training of health professionals and an important part of their ongoing training. And we have too many laws. And they are too long. Nobody but a lawyer or policy wonk could understand this stuff. If we are to expect health professionals to know it, we have to produce it in manageable quantities.

Unfortunately, there also has to be some meaningful enforcement of standards so that it is clear to everyone that the law is ignored at your peril. And ethicists need to understand that legal compliance is not optional. Too many times I have heard ethicists discuss the law as simply another available option. Most of all, we need to take every opportunity to ensure that we make knowledge of and compliance with the law an integral part of professional practice.

It is always wrong for those who exercise state-granted power and authority over others to do so in violation of the law. It is particularly odious when the law is violated and ignored routinely by those who do so while caring for the most vulnerable members of our society. If these individuals believe that the law is wrong then they are morally obliged to struggle to change it. They are not entitled, however, to simply ignore the law when it suits them.

Competing Interests: None

Acknowledgements: None

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Reflections from JEMH's Inaugural Conference

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Just before my recent move to Toronto from Edmonton, I worked on a conference organizing committee. I learned first-hand the challenges in selecting a relevant, timely theme, designing an engaging format (panels? paper presentations? workshops?), recruiting leading speakers and presciently choosing from the “call for papers” submissions. In the case of ethics-related conferences, however, three central points in philosopher Walker’s well-known article about hospital-based ethics consultations are especially relevant (Walker, 1993). First, a conference itself can help keep “moral space open.” Second, conference planners act as architects, trying to build much-needed conversations within a protected, albeit limited, time period. Third, planners also act as mediators, trying to balance competing or conflicting issues, perspectives, and types of authority without damaging the conversations. Philosopher-bioethicist Zaner’s demand for mindfulness in ethics consultations applies, too, to these planners (Zaner, 2000). They must attend to the voices not readily heard, regardless of whether such silence comes from belonging to a minority, from being stigmatized or from discomfort with public attention.

It is telling that a large proportion of bioethicists’ consultations are in response to poor conversations, regardless of whether they are between client-family, client-clinician, or clinician-clinician. Clearly there are good and bad conversations. Bad conversations can be monologues that seem dictatorial or too simplistic. Or, round-table conversations that seem chaotic or competitive. Guided by sociologist Frank’s work in clinical ethics, I therefore want to replace “conversation” with “dialogue” in thinking about the important ethical work that a conference can do (Frank, 2000). In the context of ethics-related conferences, Frankian “dialogue” represents presenters and registrants collaboratively examining—with individual integrity and mutual generosity—topics of great complexity, recalcitrant uncertainty and deep human significance (Frank, 2004).

Yet dialogue, according to Zaner, can be risky because participants must remain open and vulnerable to each other. In response to such inescapable risk, people frequently find solace in the seeming certainty and clarity of health-related laws. Laws seem especially helpful when they offer resolute answers to what Frank characterizes as decisions “that people should never have to make” (Frank, 2004, p. 355). But just as there are good and bad conversations, there are good and bad laws. Bad laws, I suggest, dismiss an individual’s plight and silence his or her voice. Good laws qualify as codified ethics if they result from initial worries about vulnerable citizens, nuanced understanding of relevant historical and contextual values, and communal dialogue about meaning and

relationships, all of which resonates with bioethicist Agich’s rich characterization of ethics consultations (Agich, 2005). Thus, it is essential for legislators and lawyers to be invited into the moral space of an ethics-related conference along with clients, families, clinicians, and bioethicists.

These reflections about this conference apply equally to ethics-related journals. During the conference, attendees and the editorial leaders of the *Journal of Ethics in Mental Health* discussed the journal’s purpose, format and mechanisms for broad accessibility. Though the editors may not have conscientiously thought of Walker’s insights, this conference affirmed their efforts to be architects and mediators creating a type of moral space that is credible, sustainable and welcoming to all.

Competing Interests: None

Acknowledgements: None

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Chaos and Grace

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In 1970, when I was about 16 or 17 and in my third year of high school, our entire school was taken on a day trip to the Whitby Psychiatric Hospital.

We were not told where we were going or why. All we knew was that we had the day off. It was one of those days in Ontario, filled with the light green of early spring and the promise of a summer to come. The buses dropped us off in front of what appeared to be a gymnasium and we were instructed to enter. Inside was an auditorium which had obviously seen better days and which had that peculiar smell which I would later come to learn accompanies most health care institutions. I can't remember what was said by our hosts since, as teenagers, our attention was completely focused upon our immediate coterie of friends. It wasn't until we were taken on a tour of the rest of the facility that we began to move a little beyond ourselves.

We were taken first to a workshop where some patients were busily engaged in making various objects which held no interest for us. What struck us most was the distinct feeling that we had now entered a completely different world of social discourse. We did not gawk, they did. We did not speak, they did. And they did so with an abandon that unnerved us. We were not in control here, they were. And what they wanted most was to devour us; to drink us up the way very young children drink up the world. It was their honesty that struck us; not the sort of honesty teenagers lay pretense to, but the sort of naked honesty that only those who have completely stopped caring have. They were not unhappy in any obvious way, but neither were they happy. They were simply what they were and here upon them had descended a group of juvenile apes for their amusement. This honesty frightened us and we couldn't wait to get out of there.

Next they took us by a number of small, neatly kept cottages, within which, we were told, were housed the most dangerous patients; those who dare not be let out for fear of what they might do. What they looked like and what they had done to deserve this imprisonment was left to our imaginations.

Next came the saddest part of the tour; the sadness of a shared ward where people wandered about aimlessly in that half-space between light and dark. This perhaps was the most frightening place of all because this was the place where boredom reigned; where the past and future remained the same.

And then it became clear this is what our teachers meant to show us; they meant to show us the half-life we would inherit if we continued our evil ways of drugs and rock'n'roll and rejection of authority; where we would all end up if we didn't smarten up and do the right thing and give up our highs and obsessive devotion to one another.

But the odd thing is that I don't think any of us came away from this thinking that we would end our evil ways. The most important lesson we came away with that day was that if we, too, were to become mentally ill we would be punished for it. Because that is what we saw; that the mentally ill were not treated with care and compassion and a sense that they could not help themselves, but instead were treated as if they had committed an offence against the rest of us.

It did not help. It did not enlighten us. We were teenagers and all a little mad anyway. We weren't afraid of going crazy; we were afraid we were already crazy. And showing us this place was a little like being shown the instruments of torture by our inquisitors. In spite of whatever official story might be told regarding the purpose of our visit and in spite of what was no doubt the best standard of care provided by caregivers with the best of intentions, it was clear that our teachers thought that the real purpose of this visit was to show us that mental illness was a crime.

But we knew that something else was more true; that, as Nietzsche once put it, "One must still have chaos in oneself to be able to give birth to a dancing star." (Thus Spake Zarathustra, Prologue, Section 5). And it occurs to me today that many of the core issues in psychiatric ethics still stem from our attempt to value that chaos within while avoiding the temptation to punish ourselves for it; that the core question concerning the ethical treatment of psychiatric patients is whether we have correctly distinguished between the chaos which may produce a dancing star and the chaos which produces little more than a life-consuming black hole.

Competing Interests: None

Acknowledgements: None

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BOOK REVIEW

The Ethical Brain By Michael S. Gazzaniga [201 pp. Dana Press, 2005]

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A man stands on trial for assaulting another man in a bar. A neuroscientist takes the stand and the jury are shown a panoply of functional MRI scans and neurophysiological data about the defendant, leading them to the conclusion that his dysfunctional brain made him do it, so he is not responsible for his actions. The jury, dazzled by science, accept the man's arguments and he walks free.

This nearly absurd 21st century manifestation of the old English 'M'Naghten rules' is not so far fetched according to Michael Gazzaniga, in his new book *The Ethical Brain*. In this engaging introduction to the fledgling field of neuroethics, Gazzaniga adumbrates a number of the ethical challenges presented to us by the recent progress in the neurosciences. Best known for his work in the so-called 'split-brain' experiments, Gazzaniga is the director of the Centre of Cognitive Neuroscience at Dartmouth College and sits on President Bush's "Council on Bioethics". Whilst recent discourse in contemporary bioethics has focussed upon dilemmas created by possible technologies in cloning and the stem cell research, these areas are still on the cusp of science fiction. Since the decade of the brain however, the ethical problems arising from the advances in the neurosciences are very much science fact.

The early chapters of *The Ethical Brain* read a little like material from the *New Scientist*. Gazzaniga postulates about the problems posed by the potential identification of genes that code for intelligence and the possibility of the creation of a generation of Nietzschean intellectual ubermenschen. In pondering the prospect for artificial manipulation of the nervous system producing elite athleticism, Gazzaniga speculates that sportspeople will eventually be endorsing biotech and pharmaceutical companies instead of manufacturers of running shoes and sports drinks. This style of writing unfortunately disillusioned the serious reader, and undermines the book's true contribution to moral philosophy, which appears in its later chapters.

The issue of moral responsibility first appeared in the Nichomachean Ethics and has challenged the legal and psychiatric professions since. In a testimony to the sagacity of Aristotle's notion of coercion vitiating responsibility, Gazzaniga's exploration of this area in the context of neuroscience raises questions that are as much about language and ontology as ethics. We are taken through Benjamin Libet's experiments and the implications of the 'readiness potential' for individual responsibility (Libet, 1999). Gazzaniga then outlines how neuroscience currently, and in the near future, is likely to further clarify this issue. Gazzaniga seems to assume a variant of the 'compatibilist' position, which sees a

potential relationship between the free-will of persons and the determinism of the central nervous system. In considering this, Gazzaniga puts it to us that the brain is determined by the physical universe. If the brain determines mind then the mind is therefore determined by the physical universe. Gazzaniga appears to take a materialist position and casts issues such as responsibility and personhood as being social constructs. As such, issues of physical determinism cannot be attributed to non-physical entities. In the conditional proposition put to us, the sufficient condition i.e., the brain determines the mind, is not convincingly affirmed and so the argument is therefore invalid. Gazzaniga thus sees responsibility as an attribute of the socially constructed world. He sees personal responsibility as a public concept existing in a group, not within an individual.

This issue lies at the heart of the philosophical implications of the commissurotomy experiments outlined in Gazzaniga's earlier book, *Nature's Mind* (Gazzaniga 1992). This issue was well developed by other thinkers in this area such as Derek Parfit in Oxford, who defined personhood in terms of the metaphor of 'a club' - no single building, structure or person, but rather a concept which bundles the components together. As Parfit says of the split-brain patient, "the number of persons is none" (Parfit 1987). So too in *The Ethical Brain*, responsibility cannot, in Gazzaniga's thesis, be attributed to an overactive amygdala or a sluggish frontal lobe. Brains are physical entities, persons, and the 'responsibility' for their actions, are social ones.

The book's true contribution to moral philosophy is found in the last few chapters. Ethics, simply defined, is the means of living a life with reference to a conception of the 'good'. Normative ethical theories, particularly those that arose out of the political and rational movements of the Enlightenment, are prescriptive in duties, rights and responsibilities, yet provide these without a coherent or universal conception of the good. Those keen to expostulate against Kant or Mill use this limitation to show how either moral theory could be used as justification of the banal evil of the next Eichmann or Milosevic. Attempts to define the 'good' in terms of eudaemonic happiness, divine command or feminist 'care' (Baier, 1994) have ultimately failed to provide the universalism needed for a comprehensive moral philosophy. *The Ethical Brain* attempts to provide us with the neural substrate that may underlie the elusive good sought by moral philosophers and bioethicists alike. Building upon the tenets of the theory of mind, Gazzaniga describes altruism as emerging from a neurological basis akin to mirror neurons. "Simulation theory", in which the brain's limbic system is activated by the witnessing of the travails of another, provides

us with a neurological basis of empathy, which not only accounts for compassion, but perhaps moral agency. If one is called to moral action by the same limbic drives as that experienced by our fellow species member, whose suffering we witness, then this may be the universal good we have been seeking for millennia. Hume's idea of reason being 'the slave of the passions' and moral agency being predicated on sympathy can now be seen in a new light (Hume, 1998) - the pleasure which motivates moral action is indeed the abolition of the emotional pain we experience when our limbic systems fire in response to this phenomenon. Epicurus and the ethical hedonists were right after all.

In Gazzaniga's thesis, moral agency has an evolutionary advantage. Any behaviour that survives natural selection must have a species preserving or species enhancing function. Here we see more evidence of what Daniel Dennett described as "Darwin's dangerous idea" (Dennett, 1995). Whilst there is great appeal of a plausible universal conception of 'the good', the sense of unease created by the greedy reductionism of Darwinian ideas is equally troubling. In the light of Darwin's theories appearing to dissolve others like an industrial-strength intellectual solvent (or "acid" in Dennett's words), one finds oneself uncomfortably in the proximity of creationism or intelligent design in the process of challenging them.

In grappling with the concept of an ethical good in the last chapters of *The Ethical Brain*, we have certainly transcended Socrates' intellectual gymnastics with Euthypro over the Divine command basis of moral philosophy. We now find ourselves potentially wedded to a molecular conception of 'the good'. Protagoras was not quite right in averring that man is the measure of all things; the synapse may well be. If Gazzaniga is right, we will need to rework the Delphic injunction of 'know thyself' to 'know thy brain'

Competing Interests: None

Acknowledgements: None

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