

## ICU Psychosis and Patient Autonomy: Some Thoughts from the Inside

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*I shall draw on my experience of being an ICU patient to make some practical, ethical, and philosophical points about the care of the critically ill. The recurring theme in this paper is ICU psychosis. I suggest that discharged patients ought to be educated about it; I discuss the obstacles in the way of accurately measuring it; I argue that we must rethink autonomy in light of it; and I suggest that the self disintegrates in the face of it.*

**Keywords:** *autonomy, ICU psychosis, the self*

### I. INTRODUCTION

When I told a philosophy colleague that I had been asked to contribute to a bioethics conference by speaking to my rather grim experience of septic shock, ARDS (acute respiratory distress syndrome), and multiple organ failure, he responded that this was apt, given my “quasi-empiricist” views. His point was that I have argued that it is a mistake to think that the job of the ethicist is to articulate, from abstract principles or frameworks, a set of rules under which we can make correct moral judgement. Rather, the ethicist ought to engage in an experience-driven deliberation that draws upon a diverse store of insights in play in our moral lives. In other words, the way to get at the right solution to some moral quandary is from above and below—from a consideration of a mix of abstract principles and from a consideration of how various answers actually fit with and play out in experience.<sup>1</sup> What this entails for ethics generally is that we must listen to the first-hand experiences of those who encounter injustice, oppression, and the like, and what this entails for bioethics is that we must listen to first-hand

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accounts of how people affected by a disease or an illness experience the medical interventions and policies to which they are subjected. The bioethicist, like any ethicist, must theorize from practice and experience, as well as from the lofty heights of philosophical principle.

So my colleague was right: given my quasi-empiricist views, it is fitting that I try to engage bioethical debates by drawing on my experience of grave illness. What befell me six years ago is fairly general, as far as critical illness goes, but I shall nonetheless try to guard against making unwarranted generalizations. ARDS is a severe lung injury caused by one of a number of things: sepsis, trauma, burns, and so on. It is usually accompanied by multiple organ failure: mechanical ventilation and other forms of life support are required. It is thus a wide-ranging descriptor, catching a significant proportion of long-stay patients in a medical-surgical intensive care unit (hereafter, an "ICU"). By the time I reached the hospital, I was already on death's door. I was put on a ventilator and spent the next few weeks in multiple organ failure and a drug-induced paralytic coma, with minimal chances of survival. My husband was told on two occasions that my lungs were unlikely to carry me through the night and then things managed to get even worse. When I eventually resurfaced, I was emaciated, virtually lungless, and incredibly weak.

There are three kinds of points I want to draw out from my reflections on this set of experiences. I shall make some practical points about how, for instance, our knowledge of the aftermath of critical illness needs improvement and how that requires taking patient experience into account. This gap in our knowledge is being narrowed, as studies are conducted on the long-term effects of ARDS and its associates. So in making this kind of point, I simply will be adding my voice to those "outcomes" researchers who already think that these projects are urgently required.

The second kind of point is more about medical ethics—about the moral duties that are incurred by ICU nurses, physicians, and their hospitals. I will argue, for instance, that the results of the above studies ought to be communicated to patients upon discharge. And I will argue that the principle of patient autonomy—that physicians must respect the intrinsic value of people's capacity to run their lives for themselves, even if there is reason to think that they are making a mistake—needs to be rethought in the critical care context.<sup>2</sup>

The third kind of point, at which I shall merely gesture, is a more resolutely philosophical point about what we might learn about ourselves—and indeed about the very nature of the self—by reflecting on such experiences.

## II. GOING BEYOND COMMON SENSE: LESSONS ABOUT ICU PSYCHOSIS

Some parts of bioethics seem to me to rest solidly on common sense. It does not take a rocket scientist (indeed, not even a social scientist) to figure

out that when a gravely ill patient in an ICU is in a precarious and desperate physical state, kindness and decency from nurses and physicians becomes overwhelmingly important. We can know this merely by imagining ourselves in the position of someone in that precarious and desperate state. But there are some things that can be fully understood only from the inside—by those with the requisite experience. One such thing, I suggest, is the complex phenomenon of ICU psychosis.

There are two sorts of awfulness involved in what the medical profession charmingly calls a serious “insult.” One sort arises from what is physically going on: the pain, the extreme discomfort that comes with mechanical ventilation, and the physical panic induced by the suctioning process and the attendant inability to breathe. Having had my share of garden-variety painful events (a couple of childbirths, a bit of bone surgery, some botched root canals, post-insult rheumatoid arthritis, and the like) I can easily attest to how unusually awful the physical phenomena are.<sup>3</sup>

But there is a second, perhaps even worse, sort of awfulness: that of stepping well over the fuzzy line that separates sanity from madness. Numerous studies have looked at the mental distress experienced by ICU patients with ARDS. Of those surviving patients who remember anything at all, many report harrowing psychotic episodes. These are usually “nightmares often of a bizarre and extremely terrifying nature,” hallucinations, and paranoid delusions—typically of a nurse or a doctor trying to rape, murder, or otherwise harm the patient.<sup>4</sup>

It is not clear what causes this ugly series of delusions or hallucinations. The finger is sometimes pointed at sedatives and neuromuscular blocking agents, sometimes at central nervous system dysfunction, sometimes at the deprivation of normal sleep.<sup>5</sup> Or perhaps it is just that in multiple organ failure, one of the organs that fail is the brain.<sup>6</sup> It is interesting to note that the slide into madness appears not to be associated with other ventilated patients who endure significant pain and anxiety. A large German study looking at ARDS and ICU psychosis had as a control group patients who had undergone maxillofacial surgery:

“This group contained tumour patients, and was selected because it represents sick hospitalised patients who require perioperative intubation and mechanical ventilation but who almost never experience intensive care treatment and rarely report respiratory distress,<sup>7</sup> anxiety, or other potentially traumatic experiences during their hospital course” (Schelling et al., 1998, p. 652).

Whatever the precise cause, the thing that makes these phenomena especially terrifying and insidious is the fact that unlike ordinary nightmares and more like paranoid delusions, they tend to occur in real time and to hook onto slices of external reality. One takes an actual physician or nurse

in the ICU, whips up a violent conspiracy theory around that person, and then has the conspiracy play itself out in the midst of actual conversations and medical procedures. It is the merging of reality and vicious invention that is most confusing and upsetting. One quite literally loses one's grip on what is true and what is false because the true and the false are mixed together in one mess of experience.

Indeed, it has been suggested that it is not "unpleasant memories for real events during critical illness" that are related to the Post-Traumatic Stress Disorder (PTSD) which can follow ICU psychosis: it is the memories of the delusions (Jones, Griffiths, Humphris, & Skirrow, 2001). The more patients remember of the real events (the extreme medical procedures, the horrific drowning sensation when one cannot breathe prior to being put on the respirator, the suctioning, etc.), the less likely they are to later suffer from the symptoms of PTSD (anxiety, avoiding reminders of the ICU, inability to sleep, recurrent nightmares of the ICU, jumpiness, withdrawal from others, etc). Having some memories of what really went on, no matter how terrible that was, seems to be protective against PTSD. I think that this is because having memories of actual events allows the patient to question the reality of the delusions. Indeed, even those who remember nothing at all are at more risk for PTSD and long-term depression than those who remember some actual events. Perhaps they have had the delusions and are experiencing their submerged effects.

My experience very much coheres with the hypothesis that one benefits from knowing that some of the remembered events really did happen: that one was not entirely mad the entire time. I had a large bank of memories and for weeks after coming to consciousness, my central preoccupation was the attempt to sort out which memories were of actual events and which were of imagined events. It was exceedingly important to get this right. I remembered that at one point a woman with a large crucifix around her neck had asked me whether I wanted to see a priest. It seemed to me that this was a friend of mine and I could not understand how she could be in the ICU asking me this question, given that she was Jewish; and living in Paris.

I was thus certain that I was hallucinating, despite my best efforts at the time to be alert and sane. Soon after I came round, I saw this woman in the ICU and pointed to her in my husband's presence. "That's the ICU chaplain," he said. "She looks like Judith, doesn't she?" It was an enormous relief to place that memory in the correct box.

But much of the required sorting had to wait until I was extubated, when I could question others about what happened. I asked my husband whether there really was a Christmas party (this was in April), at which the ICU physicians drank copious quantities of alcohol and proceeded to parade, ridicule, and humiliate the most pathetic patients, myself included, much to the mirth of all. Part of me knew that this could not have

happened, but it seemed so real that part of me could not believe that it did not happen. I think that I will never quite shake that “memory” of being completely wretched, physically restrained, unable to speak, and at the mercy of that band of cruel sadists. Of course, the fact that one has this “memory” of people who so selflessly fought night and day to save one’s life is its own kind of embarrassment.

The most persistent delusion I had began as I first struggled into consciousness and became aware of the whirl and beat of the machines to which I was chained. The pain and discomfort were unspeakable and to make matters much worse, certain of the medical staff were standing over me with the police, trying to bully me to lay charges against a highly problematic student who had been causing me real trouble just before I had become ill. I knew that this student would be taken to be partly responsible for my illness (I was right about that) and the delusion involving the bullying was extremely convincing: so convincing that, once I had properly resurfaced, it was almost impossible for me to discard the belief that a certain physician had tried to make me lay the charge. Again, what is unusual about these delusions is that they are a mix of fact and fiction: I didn’t imagine the distinctive thump of the machines, the pain, the background context, the physicians and nurses (whose individual names and characters figured accurately in the delusions), and the struggle into consciousness, but I certainly imagined the police and the bullying.

It thus strikes me as right when I read that these traumatic experiences in the ICU “may be as emotionally devastating as intra-operative awareness during anaesthesia” (Schelling et al., 1998, p. 658). Both are associated with a highly elevated incidence of PTSD in the weeks and even years after discharge. The most salient difference might well be that, because of the delusional nature of adverse ICU experiences and the implications one thinks such delusions might have for one’s sanity, they are harder to shake off.

Indeed, as the clear-headed thoughts started tumbling in after I came round, the following struck me forcibly. Dying is easy: it is the coming back that is unimaginably difficult. As the literature, both popular and scientific, says, the delusions in near-death experiences are peaceful and pleasant.<sup>8</sup> I also was struck by the explicit and happy realization that it was highly unlikely that I would have to go through that again: another sinking into death was inevitable, but I would have to be horribly “unlucky,” I thought, to come back from it a second time.

It ought to be clear that mental distress of this sort (and I have left out the hideous details from the descriptions of the delusions) has rather severe consequences for the patient-physician relationship. Most importantly, I shall argue, it brings into question just how seriously we ought to take the principle that the competent-seeming patient ought to take part

in decisions about his or her care or be part of the decision-making “team.”

Indeed, a second kind of mental distress in the ICU contributes to the problematic status of the principle of patient autonomy: the incredibly intense and single-minded desire to be extubated and then released, whatever the costs. It must be pretty clear that all intubated patients are champ-ing at the bit, so to speak, to be off the respirator. Trying to rip out the tube lodged in one’s throat is a frequent phenomenon: the technical term is the brilliantly understated “unplanned extubation.” I was so desperate that I had a series of hallucinations during the first couple of days of half-consciousness, in which “the team” went round to each bed and merrily extubated patient after patient, bypassing my bed altogether, despite my imagined frantic waving and pleading.

I managed to communicate this desperation to the nurses and physicians, notwithstanding the fact that I could not speak and was too weak to write even one legible word on the pad I was given for this purpose. I did not want my already-traumatised small children to visit until I looked less frightening (i.e., until I was off the ventilator) and of course I was ferocious in my desire to see them. Various physicians would come round, show me X-rays of my lungs, and explain how they were not ready to go it alone. My glares, however, were eventually persuasive and I was extubated a day or two before it was thought maximally desirable. And then, more seriously, once I was moved to the ward I managed to get released after just two nights, despite all the excellent reasons offered to the contrary.

I was of course most grateful for both of these things. But even at the time I wondered why my desires were being taken into consideration: could they not tell, I wondered, that I was a lunatic? And once I was at home, in an alarmingly fragile state, it was not clear to me or to my family that this was the best outcome.

While the principle of respect for patient autonomy has it that health care professionals, to fulfill their moral duties toward a patient, should always treat the competent-seeming patient (the patient who passes tests of competency) as a full participant on the decision-making team, it seems pretty clear to me that this principle should not always be upheld in critical care medicine. It may well be a trumping principle with respect to end-of-life decision-making and with respect to questions about resuscitation and continuation of life support. But it is not, I suggest, a straightforwardly trumping principle for more routine treatment matters. In order to make this suggestion plausible, I will offer three arguments.

The first is, as Franklin and Rosenbloom (2000) pointed out, that the stakes are higher in critical care medicine: an irrational decision taken by a critically ill patient is likely to be catastrophic. Certainly, no one assessed my competency and then laid out the pros and cons of intubation so that they could get my consent. They told me that they were going to insert a

tube to help me breathe and generally minimized and whitewashed the whole episode. To do otherwise would have been catastrophic.

The other two arguments have to do with the thought that it is far from clear that ICU patients are competent, even when they seem to be. The first of these is the weakest. It is an anecdotal appeal to my own experience and thus cannot be generalized in an unproblematic way. I appeared competent—I was appropriately responsive to questions and I was propped up in bed reading *The Guardian Weekly*, the *London Review of Books*, and a biography of Walter Benjamin. The medical personnel seemed impressed and expressed their surprise at how quickly I was rebounding. I was, however, mostly trying to bounce back and to get on the rails cognitively and emotionally. I was in fact a psychological mess and should not have been taken to be fit to participate in decisions. Despite the fact that the physicians and nurses had done so much for me, I was filled with what I took to be well-concealed fear and loathing for most of my lifesavers and caregivers. And I was overwhelmed by the determination to be extubated and to get out of there.

It is not clear, that is, that competency can be measured only by taking into account present abilities and capacities. It might well be that difficulties in the past are affecting, under the radar screen of the tests, one's functioning in the present. One might be able to complete all the tests with the required accuracy and yet be haunted by what has recently happened.

Now it might well be that I fooled no one or that the decision to extubate me was not driven by the fact that I wanted to be extubated. That is, perhaps the principle of patient autonomy is not doing the work claimed for it here. Although the principle of patient autonomy (expressed by the slogan that the patient is a part of the decision-making team) seems to be omnipresent in today's critical care departments, perhaps other factors drive the decision-making. For instance, I have been told that one thing that went into the decision to extubate me was an assessment of my will to recover, measured by the fact that my vital signs improved when I listened to my children's voices on a tape recorded message. Or perhaps a medical decision was made that it is better to extubate someone who is extreme in her desire to be extubated than to leave her on the ventilator. But if the principle of patient autonomy is in fact operating as a feel-good untruth, then it has to be better (both practically and ethically) for that to be made explicit.

The last argument is what I want to focus upon. It has to do with the tests for psychological well-being in the ICU. Not all ICUs consider psychological well-being a serious matter and test for it. That is the worst-case scenario. But even in those ICUs in which assessment efforts are made, it is not clear that psychological well-being is viewed with questions of competency and autonomy in mind, even though the results of the assessments have a rather significant impact on assessments of competency and autonomy.

Testing for psychological well-being in an ICU is a notoriously opaque business: most patients are ventilated and this renders concurrent assessment

of psychological status very difficult. (See, for instance, Turnock, 1997). It is of course easy to see when a patient is in an agitated or hyperactive sorry mental state—and most ICU patients are at some point agitated (especially as they come to confused consciousness and discover that they are restrained for tube protection). It is also relatively easy to assess a patient who can in some way communicate and who cannot remember the names of her children, does not know that she is in a hospital, and so on. Patients in these states would never be taken to be psychologically sound and they would never be taken to be competent.

But assessments of psychological status are much more difficult in the face of quiet or hypoactive malfunctioning, especially when the patient is having trouble with communication. And they are even more difficult when the quiet malfunctioning is subtle, but nonetheless devastating. Indeed, I want to argue that assessments of this kind of change in mental status are pretty much impossible. Given the prevalence of these kinds of situations, my suggestion is that the principle of patient autonomy in the ICU needs to be rethought.

To appreciate the point I am trying to make, we need to look at the current methods of assessment of psychological status. Much forward-looking work in this pressing area has been conducted recently: E.W. Ely has been its leading champion. His Confusion Assessment Method for the Intensive Care Unit (CAM-ICU) is a method for measuring *delirium*, especially the most commonly missed subtype: hypoactive or non-agitated delirium. He argues that it is unrecognized in 66–84% of patients (Ely, Gautem et al., 2001).<sup>9</sup>

In many ICUs the test for quiet mental distress is informal: finding out whether patients can obey commands and whether they know who they are talking to, the names of their children, where they are, and so on. CAM-ICU allows for a more precise and standardized measure. It is based on the *DSM-IV*—modified for non-verbal (i.e. intubated) patients—and is conducted in less than two minutes, which is considered a virtue.<sup>10</sup> The tester asks the patient to do such things as squeeze his or her hand whenever he recites, say, the letter “A” in a list of 10 recited letters and to indicate which 5 of 10 pictures (of common objects) has been shown earlier in a series.

Like the less formal ways of assessing confusion, the CAM-ICU tests for some minimal degree of clear thinking, recognition, and memory. Indeed, the characterization given of delirium is that a patient’s “ability to receive, process, store, and recall information is *strikingly impaired*” (Ely, Inouye et al., 2001b, p. 2703, emphasis mine). Most of the work on delirium (Ely’s for instance) is aimed at identifying it with the goal to discovering whether delirium contributes to poor outcomes<sup>11</sup> and whether it can be reduced and treated. The CAM-ICU may well be apt for these purposes. But surely delirium is also a primary consideration for competency—whether or not a

patient is delirious will inevitably be a part of any discussion of competency. That is, despite the fact that the CAM-ICU was not developed as a competency instrument, it will be hijacked for this purpose. And it will not serve us well in its new domain.

The problem is this: how can you know when you are accurately measuring quiet and *subtle* mental distress and malfunctioning? There is no going directly to the phenomenon, no possibility of taking a look at the mental state itself, as opposed to the way that mental state is manifesting itself in behavior. Given that you cannot ask complex questions of an intubated patient and get suitably complex answers, the range of behavior available is minimal: only gross behavior (“squeeze my hand, indicate which pictures ...”) is possible. And only simple questions can be answered. Quiet and subtle mental malfunctioning in intubated patients is a most difficult phenomenon to try to measure.

That is, it seems pretty clear that a patient might have a subsyndromal amount of brain dysfunction that could be completely missed by the CAM-ICU and by any other test that could be administered to intubated patients. While the CAM-ICU is designed to pick up a narrow and severe class of brain dysfunction (delirium), it is a broader class of dysfunction that needs to be identified in order to assess competency. The phenomenon which needs studying is not merely over-arching delusional and disorganized states in which the patient is so confused that he or she is unable to respond appropriately to very simple questions, but the whole phenomenon of mental failings caused by critical illness. For that is the phenomenon relevant to the question of competence (and perhaps even to the question of whether mental failings are associated with poor outcomes). This broad kind of mental distress is best described, I think, as a psychosis: an ICU psychosis. But opinion seems to be swinging the other way. It is said that ICU psychosis is a misnomer for the mental failings found in the ICU: ICU psychosis should be reserved for hyperactive delirium that is accompanied by agitation (Bergeron, Skrobik, & Dubois, 2002, p. 181; Ely, Margolin et al., 2001, p. 1370).

The anecdotal argument can be joined to the better argument. It seems clear to me that I would have often scored very well on tests such as the CAM-ICU. The tests given to me were informal: they were questions about where I was, how many children I had, and so on, and I easily passed them. Of course I would have failed such tests during my agitated delusional states, where I was trying desperately to effect an unplanned extubation. But no tests were needed then: it was obvious that I was delusional and incompetent. I cannot remember being tested when I was in the grip of a quiet delusion, but if I was, I may well have folded the tests into the bizarre world in which I was entrenched. I was folding all sorts of actual events into that world. The very nature of ICU delusions is that they are a mix of fact and fiction and it may be possible to respond accurately to simple

questions in the midst of such a mixed state. During my non-delusional, but still very wobbly states, when I was trying to sort out what had been real and what had not been real and when I was trying to determine whether the physicians and nurses were on my side or not, I easily passed the tests. That is, my mental malfunctioning was such that I was completely alert, I appeared perfectly fine, but nonetheless I still had roving bouts of overwhelming suspicions, conspiracy theories, etc.

The tests, that is, are not fine-grained enough to be sensitive to those quiet mixed states and they are not fine-grained enough to be sensitive to those patients who are sane enough to be trying to sort out their confused mental states while trying to maximize their chances of being extubated and then released. Disturbed mental states need not be marked by agitation and they need not even be marked by current hallucination and inattention. Disturbed mental states can persist over time and over the fluctuating course of hallucination and inattention. There remains, as it were, a monkey on one's back. The available tests are tests for minimal mental capacity. A patient might pass them but nonetheless not be competent because he or she is afraid, desperate, tired and traumatized.

My anecdotal observations are supported by the recent literature. Ely, Inouye et al. (2001b) reported that between 39% to 42% of alert or easily aroused patients who could make eye contact and follow commands were found to be delirious, using the tests for striking delusional and disorganized states. (Experts found 39.5% to be delirious using *DSM-IV* reference standard evaluations, and 42.5% were found to be delirious by those using the CAM-ICU.) These are patients "who are usually assumed to be cognitively intact by ICU personnel" (p. 2709). Imagine how many would be found to be cognitively impaired if we could test for more subtle (i.e., non-striking) impairment. Even on the tests for striking impairment, 10% of patients at discharge fulfilled full delirium criteria, with 20% assessed as partially delirious. Almost half of the patients, at discharge, were rated as having substantive cognitive impairment.

Let us return to the principle of patient autonomy. It carries with it a presumption of competence: we are to assume competence when no explicit evidence to the contrary exists. And when we assume competence, we are to take the person in question as having the capacity to make his or her own choices. Given what we know about the prevalence of quiet delirium in ICU settings, how hard it is to detect subtle mental weakness relevant to competence, and the reasonable desire to mask mental weakness by under-reporting it (in order to be extubated and then released), this presumption seems out of place in the ICU.

That is, it seems to me that the presumption of competence ought not to be accepted tout court, for it reflects a shallow view which *fails to take seriously the complex predicaments in which most critically ill patients find themselves*. My suggestion is that it is better to go on the policy

of doing what is in the patient's best interests, despite the fact that this will be viewed as highly paternalistic by the patient herself and perhaps by much of the community of health care professionals and ethicists. Perhaps this kind of suggestion can be made only in those societies, such as our own, in which paternalism in the medical profession has been significantly eroded. That is, perhaps this kind of suggestion can only be made once the pendulum has swung away from medical paternalism towards patient autonomy. The suggestion is that we cease the swinging of the pendulum and stop it at a reasonable middle position.

Atul Gawande, a surgeon who has written extensively on his profession, is of the same view. He has said:

“Our contemporary medical credo has made us exquisitely attuned to the requirements of patient autonomy. But there are times—and they are more frequent than we readily admit—when a doctor has to steer patients to do what's right for themselves. This is a controversial suggestion. People are rightly suspicious of those claiming to know better than they do what's best for them. But a good physician cannot simply stand aside when patients make bad or self-defeating decisions – decisions that go against their deepest goals” (2002, p. 216)

Gawande's claim has been that “the new orthodoxy about patient autonomy has a hard time acknowledging an awkward truth: patients frequently don't want the freedom that we've given them” (2002, p. 219). I want to add a twist to this claim: patients may clearly want that freedom at the actual decision-making time. But on reflection, patients often see that it is better to be steered or over-ruled. Although some patients will no doubt feel resentful towards medical practitioners who make decisions for them which go against the grain of what they themselves wanted, many, on reflection, will not. Again, the point is that patients find themselves in extraordinarily difficult and complex predicaments. Our principles must be subtle enough to account for those predicaments.

If we do temper the presumption of competence, it is important to see that one motivation comes from the front, as it were: from first-person patient experience. And of course, it is important to not conclude that the patient need not be treated with respect or that physicians need not continue to try to communicate with intubated patients.

Perhaps we ought to recognize that physicians, if you like, need to keep a double set of books<sup>12</sup>: they must, on the one hand, see the patient as an autonomous person who ought to be in control of his or her life and they must, on the other, see the patient as a medical problem in need of the best solution. Another way of putting this is that they must, on the one hand, see the patient as a person, but on the other, as a physical body on which they need to act, often in horrific ways that are in tension with seeing

the patient as an individual with desires, needs, family, and friends. No doubt this is a difficult set of books to keep.<sup>13</sup> But its problematic nature should be reflected in our thoughts about how physicians should treat their patients. Its problematic nature shouldn't be hidden or simplified by a presumption that is too crude an instrument for the subtle phenomenon in question.

Of course, it might well be that the balance of paternalism and autonomy that I am calling for is already nicely in place. I was routinely ignored when I was precariously ill and made it clear that I wanted to be extubated or made some other dangerous request. But my point is that what gets said about patient autonomy should accurately reflect best practice. If the presumption of competence is routinely being outweighed by other factors, we should not conceal that fact.

Another lesson to be learned from reflecting on ICU psychosis is a more practical lesson, rather than an ethical one. Patients, upon discharge, ought to be told that ICU psychosis is something that is common (and that if they are having trouble coping with it, they should get some help). Imagine having been through a significant period of extreme madness and not knowing that this was only to be expected. One wonders whether one has turned some irreversible corner and will remain psychotic, when in fact, the psychosis was locally caused and once the local causes go away, so does the psychosis. In the absence of knowing this, one can only hope that it is the case. At least one study calls for "education about the normality of these reactions" (Jones et al., 2001). I could not agree more. Indeed, I shall argue in the next section that the whole enterprise of educating patients about to be discharged from critical care units needs to be more robust.

### III. GOING BEYOND COMMONSENSE: LESSONS ABOUT TRANSITION

When I was moved from the ICU to the ward, I was still terribly shaky—full of strange pains in the lungs and weaker than it is possible to imagine. I could hardly sit in a chair for few minutes, never mind stand or take a step. (It is fascinating to discover just how many muscles are implicated in keeping one upright and just how hard the lower leg muscles work when one is sitting down, feet resting on the floor.) The ward, of course, was a different world, with nurses so busy it was difficult, if not almost impossible, to get help to do rather necessary things such as go to the toilet (and of course, after weeks of catheterization, one loses one's natural benchmarks for when this might be necessary). The transition from having someone at your bedside 24 hours a day to someone checking you once in the night is unsettling, at the very least, and utterly frightening at the most. It turns out that one is right to be frightened—between 11–31% of patients discharged

from the ICU die in hospital (Smith et al., 1999). Moreno and Agthe (1999, p. 1035) said: “we are losing patients who should not have died if appropriate care had been provided”.

The panic for me was mitigated by the fact that very early on my first morning in the ward, a wonderful nurse from the ICU was at my bedside, just off shift, no doubt dog-tired and in need of getting home. She stayed for a long time and returned before she next went on shift, checking to make sure that I was getting what I needed, answering my countless questions, and providing a much-appreciated link between the maximum protection of the ICU and the minimum protection of the ward. But of course, such care is supererogatory: it is above and beyond the call of duty. It is not systematic and cannot be relied upon. For that nurse will go on holiday and will sometimes be too busy to ensure that patients no longer in her formal orbit of care are being seen to.

Just how far does the duty of an ICU physician or nurse extend? Is it not enough—is it not a fulfillment of duty—for them to spend day and night saving a life? Well no: no one would think that extremely competent but gratuitously cruel physicians and nurses were to be commended. It is just as clear, however, that the duties are not limitless. There is certainly no duty to follow the patient home, stay with him or her for the next five years, and make sure all goes swimmingly. The question arises as to just what is reasonable to expect of ICU physicians and nurses and just what is reasonable to expect from the institution (the hospital) itself. I want to suggest two relatively simple and inexpensive practical measures that would go a very long way to meeting reasonable expectations.

First, there clearly is a duty to try to minimize the trauma of the transition: of the move from the ICU to the ward. The hospital I was in is putting together a Critical Care Transitional Team. If this kind of initiative is to get it right, then, on the view I have put forward at the beginning of this article, it must solicit input from patients who have actually gone through these transitions. It must find out what issues are of pressing concern to patients who move from the ICU to the ward: the lack of human contact they have become used to in the ICU, the reduction in the frequency of checks on their condition, the new intrusive teams coming by to rudely discuss the patient like a slab of meat. No doubt these patients would appeal for a step-down unit.<sup>14</sup>

Second, it also seems clear that there is a duty not to cut the patient completely adrift once he or she leaves the hospital. The general practitioner into whose care the patient is released may be very knowledgeable about what to expect. But there are not so many survivors of these kind of insults that GPs can be expected to be up to speed on the new information which is pouring in about their aftermaths. No doubt these patients would appeal for some information about what they might expect in the days, weeks, months, and years to follow.

In my experience, there is a reluctance to talk about what is to come. Perhaps some physicians are embarrassed by what the patient has gone through and are hesitant to speak about the future. Perhaps it is thought that the best way of maximizing the prospects of a full recovery is to say that the patient will fully recover and let him or her get on with the job. Perhaps the patient simply looks too weak and pathetic to take this kind of discussion. Perhaps there is uncertainty about the prognosis.

But these factors do not in my view make the duty disappear. Certainly in my case, I was enormously grateful to those physicians and nurses who took the time to talk to me. For instance, I was enormously grateful to the student who first saw me in the hospital's rheumatology office, where I had appeared half dead with a referral to see to my week-long painfully screaming joints—the symptom of a massive infection. This student had immediately alerted the rheumatologist who quite literally saved my life by her quick and steely reaction. The student arrived at my bedside in the ICU on the first day I was conscious, asked whether anyone had given me the full story of the last few weeks, and then proceeded to do just that.

But of course, being a trainee rheumatologist, he could not really say what the future held. And no one else spoke much to the future. Far and away the most unpleasant after-effect of my insult was a severe burning sensation, upon the slightest bit of heat or exertion, which started from my feet and roared up my body to my neck. It was very much like I was on fire: indeed, the pain could be doused only by icy water. My GP was stymied. I combed the critical care journals and found nothing about this. The Internet, as is so common, was more than useless, offering outdated and unfiltered information—although now the ARDS support website is quite helpful. I eventually went back to the ICU and asked the head of the Critical Care Department (who had been intensely involved in my care) about the burning. I was told that it was ICU neuropathy and that it would go away in a year. That was good to know, but it would have been better to know earlier. Perhaps what is needed is a critical care hotline that would answer discharged patient's queries.

I also had a distressing pain in the left chest. Having had plenty of experience with muscular pain playing competitive junior tennis and running university track, it seemed to me that this must be scar tissue from the catheter that had run into my heart. My GP said that this hypothesis seemed plausible, but I thought I saw concern in her eyes. And of course, one does not want to self-diagnose under such circumstances. The pain, which seemed to pull right from the heart, was disconcerting given that my heart had been in some trouble. It can still immobilize me, years later. It was only recently that I had confirmation of my belief about the origins of this pain (Herridge et al., 2003). Many ARDS survivors report it. The catheters move around and rip up the surrounding tissue and muscle.

I was in a privileged position in regard to information acquisition. I had access to a medical school library, no special fear of technical academic articles, and since I did not suffer significantly from PTSD, I did not feel that I had to avoid the scene of distress—that is, the ICU. In addition, one of the aftermaths of my illness required me to see the rheumatologist who had stopped me from dropping dead on her office floor. She was not only enormously capable herself but she was also quick to facilitate the seeing of other specialists. Not everyone will be able and willing to avail himself or herself of such expert information.

Much uncertainty and distress could be avoided with some careful provision of information. Although it may have been the case that even in the not-too-distant past not much was known about the after-effects of ARDS and multiple organ failure, there has recently been much significant “outcomes” research. For instance, in “One-Year Outcomes in Survivors of the Acute Respiratory Distress Syndrome,” Margaret Herridge and others looked at 109 patients who survived ARDS and found that they have persistent functional disability one year after discharge, with muscle wasting and weakness being most prominent. The thought is that this systemic muscle and nerve injury is a sequelae of multiple organ failure, a result of prolonged immobilization and the high doses of corticosteroids that are often administered to such patients.<sup>15</sup>

This discovery explained much of what I had struggled with while I was trying to get myself back on the rails in the gym and on the tennis court. It explained the debilitating fatigue after a tournament and it explained the frequent twisting of ankles. More importantly, it gave me something to work on, given that this kind of injury might well be reversible. And if I had had the information earlier, I would have had something to say to those physicians who looked at me as if I was crazy to be trying to play competitive tennis and said, “Don’t you understand the severity of what happened to you?” For it turns out that the best thing one can do after such an insult is to push oneself.

The upshot is that the new research must be made available to patients as it comes out. This is not a frill, a nicety, but, rather, it is a necessity if the physicians, nurses, and the hospital really are going to live up to their duties toward those who have been gravely ill. Physicians and other health care professionals need to do more of this research about the aftermath of grave illness and about how changes in ICU and post-ICU care can help patients achieve the best outcomes. And they need to find a way to make this research accessible to discharged patients.

Matters are of course complex even in this regard. After first presenting this paper, a physician remarked that I was lucky that I had also exercised the neurocognitive part of me, for that exercise will have reversed some of the inevitable damage there. It is asserted that there are alarming rates of long-term neurocognitive impairment that accompany sepsis and ARDS

(Hopkins et al., 1999; Rosene et al., 2002; Jackson et al., 2003; [www.ICUdelirium.com](http://www.ICUdelirium.com)).

I suppose that we might have here a consideration against a full information package. Do we really want to tell discharged patients that they most likely have a neurocognitive deficit? It is one thing to try to get over the physical deficits after such an insult. It is another thing to try to get over cognitive, mental, or emotional troubles. For in order to regain mental stability, one has to in part think oneself out of trouble. Being told of severe neurocognitive damage no doubt would make that project harder to prosecute. For one may well encounter a looping effect—knowledge of the expected difficulties may deepen the existing difficulties. The physicians who cared for me moved with caution around this issue after my release and I cannot say that they were wrong to do so. These questions are very difficult and I shall try to address them in a future project. But one thing is clear: however difficult they may be, it is important to ask the questions and to think hard about the answers. For the long-term well being of those who have been critically ill depends upon it.

#### IV. A FINAL THOUGHT

In closing, let me speak briefly to the philosophical point I have promised about the nature of the self. ICU psychosis is the best kind of madness. As mentioned above, its causes are local and once the patient recovers from the underlying causes, there is no reason to suspect that it will return. The sufferer of ICU psychosis is thus in an enviable position: he or she has had extensive experience of madness and no special fear of descending into it again. He or she can see what is deeply interesting about madness without worrying that examining it will make it come back.

Madness is of course an enormously complex and little-understood phenomenon. Indeed, there are so many kinds that it is no doubt a mistake to call it a single phenomenon. Delusions are sometimes taken to its hallmark, but there is controversy even about how to conceive of delusions. On the standard or “orthodox conception of insanity,” according to Louis Sass, delusions are instances of error or mistaken belief; failures to distinguish adequately between the real and the imaginary (1994, p. 2). On this view, those who suffer delusions take the imaginary to be objective, real, and a motive for action: the “feel” of the imaginary, for the psychotic patient, is identical to the feel of the real.

Sass himself focused on schizophrenia and argued against the standard view of delusions. In his view, the schizophrenic often does not take the delusional experiences to be a motive for action. Rather, the schizophrenic disowns his or her experience, a contradictory phenomenon that corresponds to a not uncommon lived contradiction. You can see the disengagement

with experience, he said, in the work of some alienated post-modern artists, such as the photographer Diane Arbus (Sass, 1994, p. 115).

This rather romantic view of mental illness, if it indeed holds for schizophrenia, surely does not hold across the board. But one thing seems straightforward enough. The experience of madness highlights the fragility of the self. We think of our selves as being individuated by, or constituted by, a set of memories, beliefs, desires, and priorities. I am whom I am because of my history and a set of memories about and attitudes towards that history and because I have a rather stable, if evolving, set of beliefs, desires, emotional dispositions, and life priorities. Imagine the loss of that relatively stable set of mental states and you have a pretty good picture of what it is like to experience madness. What is most deeply interesting about madness is that it is a disintegration of the self—a profound loss of one's self.

What this seems to tell us is that the self is an *achievement*—that it is not always there to be taken for granted. If one has encountered schizophrenia, perhaps one feels the possibility of disengaging with one's own experience. If one has encountered ICU psychosis, perhaps one feels that what constitutes the self can simply and easily disappear. No doubt certain drug-induced states give many people a small taste of what it is like for one's self to be put into jeopardy.

These thoughts directly return us to the question of autonomy. As David Velleman put it, in truly extreme physical circumstances—he spoke of unbearable pain—we cannot claim broad rights of self-determination in a patient's name. In truly extreme physical circumstances a patient “is already in the twilight of his autonomy, where self-determination is more of a shadowy presumption than a clear fact” (1999, pp. 618–619). The patient both is and is not a responsible agent in this twilight. For in such circumstances, one's self is quite literally falling apart, disintegrating, or coming undone.

This discovery of what it is like to lose one's self is fascinating. Indeed, what I learned both about it and about the difficult, taxing, and admirable world of ICU physicians and nurses was almost worth the price of admission.

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## NOTES

1. If this seems opaque, see Misak (2000) and Misak (2004a).
2. I make this point, in an abbreviated way, in Misak (2004b).
3. I am not alone in my perceptions here. Bergbom-Engberg and Haljamae (1989) found that the 'agony/panic' having to do with respirator therapy and suctioning in particular is well remembered years after discharge. See also Turner et al. (1990).
4. See, for instance, Schelling et al. (1998) and the testimonials on the ARDS support website: [www.AARDS.org](http://www.AARDS.org).
5. See Nelson et al. (2000), Ely, Inouye et al. (2001a), Ely, Gautem et al. (2001), and Turnock (1997).
6. See Ely, Shintani et al. (2004) for this thought.
7. "Respiratory distress" here means respiratory distress caused by anxiety: otherwise it would be unremarkable that it was associated with ARDS.
8. Although my experience wasn't the classical cardiac arrest kind, I had the typically described near-death experiences: tunneling and floating above the body, for instance. It seems to me that the thing missed by those who infer the existence of heaven and God from these experiences is that these are but two of a larger number of frequently recurring hallucinations. If only these people had lingered in that state for a more sustained period, they would have seen that these typical near death experiences are just part of a broader package of delusions.
9. See also: <http://www.ICUdelirium.org>.
10. See: <http://www.ICUdelirium.org>.
11. It does: see Ely, Shintani et al. (2004).
12. I owe this metaphor to Donald Ainslie.
13. One referee suggested that what often happens is that the physician sees the patient as a person whose decisions might cause her and her family unnecessary pain and suffering. So the physician places less emphasis on autonomy, for reasons having to do with autonomy, as it were. This strikes me as plausible, but it surely is but one of a number of ways of trying to balance the books.
14. These units have sometimes fallen to cutbacks. It isn't that their worth isn't well recognized in critical care departments.
15. See also De Jonghe et al. (1998). They implicate neuromuscular paralytic agents as well.

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