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This study is dedicated to the memory of Belinda Rossi.

INTRODUCTION

0.1 OVERVIEW

The intention of this study has been to research and represent the experience of delirium in hospitalised patients, using both this written dissertation and musical composition.

It is based on interviews, focus groups, and observation at Wits Donald Gordon Medical Centre (WDGMC) – a private teaching hospital in Johannesburg.¹

Both the composition and this dissertation are based on thematic and narrative analyses of these interviews and focus groups, as well as the observation conducted in the hospital; and both include quotations from the recorded interviews. The composition also includes sounds recorded in the hospital.

The composition – *Delirium Part II* – has been scored for three performers (two on piano and keyboard, one on viola), and was performed for the first time on 2 March 2017 at the University of the Witwatersrand. This performance was recorded and is available at <http://victoriahume.com/delirium> and on CD 2 accompanying this dissertation. An additional studio recording is also available the same website, and on CD1. The score has been included as Appendix 1.

Additional material referred to in this study comes from my own 2012/13 compositional project, *Delirium Part I* (or *Part I*), itself based on interviews with people who had experienced ICU psychosis, their families, and healthcare professionals. The full song cycle is available at <http://victoriahume.bandcamp.com/delirium>, and a blog about the project at <http://victoriajhume.wordpress.com/>.²

This Masters has been co-supervised by Professor Claire Penn, Director of the Health Communication Research Unit (School of Human and Community Development) and Dr Cameron Harris of the Division of Music, Wits School of Arts.

¹ Although primarily a private facility, WDGMC does treat state patients in its transplant programme (see p.38 for more details). The WDGMC Research Office has given permission for the hospital's name to be used in this study.

² *Delirium Part I* was funded through the UK's PRS Foundation for Music Women Make Music scheme. A full description is on p.51, below.

0.2 BACKGROUND

A Royal College of Psychiatrists' leaflet for patients and carers summarises delirium as:

a state of mental confusion that can happen if you become medically unwell. It is also known as an "acute confusional state". Medical problems, surgery and medications can all cause delirium. It often starts suddenly and usually lifts when the condition causing it gets better. It can be frightening – not only for the person who is unwell, but also for those around him or her. (RCP 2012, n.p.)

This study builds on *Delirium Part I* (henceforth *Part I*) – which was performed at a series of venues across the UK in 2013 (and in 2016 at the Wits Institute for Social and Economic Research). My interest in the topic goes back ten years, however, to 2007 and the beginning of a collaborative project called *Transplant*, for which photographer Tim Wainwright and sound artist John Wynne spent 18 months at Harefield Hospital's transplant unit (Wainwright and Wynne 2008). As the then arts manager at Royal Brompton & Harefield NHS Foundation Trust, I worked closely with Tim and John; and sat in on a number of interviews. I was forcibly struck by people's stories of their experiences in the intensive care unit (ICU; sometimes also referred to as ITU or intensive treatment unit) – which were riddled with hallucination and deeply traumatising. Despite having worked in hospitals by that point for eight years, I had never heard of what I later learned was called 'delirium' or 'ICU psychosis'. I wasn't alone in my ignorance: the people we spoke to told us that the trauma of the experience had been amplified by its unexpectedness. One of the security guards at the hospital, however, knew all about it, having had to protect staff from patients' attacks as they emerged from anaesthesia.

I was disturbed by the hallucinatory experiences, which were deeply distressing for patients – "ITU is a place best forgotten for me" (David Botting quoted in Wynne 2013, n.p.) – which often spoke to massive existential unease, and which were initially hard to reconcile with my very secular sense of mortality: I remember in particular the clinical psychologist's inability to rationalise the messages from dead relatives brought to her by a patient.

But I was also fascinated by the *lyrical* quality of the hallucinations. By how odd they sounded in contrast to the everyday, desaturated quality of hospital environments – the boredom and routine. And yet when people spoke about them, it was often without a break in the narrative between the reality we could all agree on and this definitively *other* experience that only they knew. For the people who described them, these *were* real

experiences: “that is what the patient is experiencing, that is their reality. Even though objectively looking in, it isn’t, it actually is” (senior ICU nurse Sara Evans³ in *Part I*).

Moreover, I found a connection between the hallucinations and my own creative practice. The images that populate delirium – pirate ships, chess pieces, guitars, skeletons, bombs, underground caverns, waterways – were often metaphors I had used in my own songwriting. The images had for me an aesthetically appealing quality. Except that these were *lived*. They had bloomed out of the controlled space of creativity to surround the people experiencing them. The longer, more coherent hallucinations seemed, moreover, to be metaphorical stories describing the actual experience of trauma or disease.

Crewing on a Torres Strait pearling lugger [...] I had been captured by pirates and found myself bound, chained and stacked like a piece of cordwood in the hold of a Chinese slaving junk. [...] Something weird had been fixed to my right arm, driven into the flesh, immobilizing me. I realized (in the dream) that it had been surgically implanted there by two fiendish Chinese doctors [...] Their gadget (in the dream) was a broadcasting unit. In reality, [...] it was an “external fixator”, [...] its purpose was to immobilize or fixate my right arm, whose elbow had been smashed into a mosaic of bone fragments. (Hughes 2006, 17)

The art critic Robert Hughes’ 2006 autobiography, *Things I Didn’t Know*, begins with this story of his recovery from a car crash in intensive care. His hallucinations bear a startling resemblance to some of those I had heard described at Harefield – even down to the pirates. Somehow, it seemed, the brain was using cultural archetypes to compose narratives that described an inchoate experience, or perhaps to string together the fragments of reality that were entering perception.

At the root of my continuing interest in delirium are two things: First, the apparently unbidden appearance of stories and metaphor as a response to trauma, and how this might relate to the creative arts; and second, the fact that hallucinations in hospital could be read as a kind of uncensored response to care, from which – if they were to be treated as valid narratives – we could learn a great deal.

It is important to note that the relationship between hallucination and delirium is not absolute. As I explore further in Chapter 4.2, hallucination may be absent from some deliriums, in particular those derived from encephalopathy. But where they do occur, they dominate patient narratives. Their status in clinical research, by contrast, is low. This

³ All names are used with the permission of the interviewees.

contrast is part of a larger disjunction between the severity of the experience and the relatively small amount of research given to it.

0.3 RATIONALE

With this dissertation and composition I aim to add significantly to the study of a subject which remains under-researched in the light of the impact it has not just on patients, but on all those involved in their care (see pp.13-14 below, well as Chapter 5.1).

It is also an attempt to work across the different fields of musical composition and narrative medicine, and to assess what – if anything – music might add to existing narrative approaches to health research in general and delirium in particular.

0.4 STRUCTURE

The cross-disciplinary nature of this study necessitates slight deviations in structure from a conventional dissertation, to allow me to make clear the relationship between ‘conventional’ research methodology, musical composition, and this dissertation itself.

Two chapters look at methodology. The first (Chapter 2) focuses on research design, data collection, and analysis. The second (Chapter 3) focuses on musical composition. I have called these ‘Research Methodology’ and ‘Musical Methodology’ respectively, again for the sake of clarity, but this is intended to imply neither that music is not research, nor that research is not creative.

The narrative structure of the interviews also makes it virtually impossible to separate results and analysis; for this reason I have combined the two in Chapters 4 and 5. Reflecting the two-part structure of the research question, however, Chapter 4 looks at the experience of delirium, while Chapter 5 looks at how music might expand our understanding.

These two chapters are followed by a Conclusion, which also addresses the limitations of this study, and implications for future research.

CHAPTER 1: LITERATURE REVIEW

The following review will cover a range of areas: firstly (1.1), an overview of the experience of delirium in hospital from a largely clinical perspective, looking at both qualitative and quantitative literature. This section also focuses on issues that chime with the findings of this study (for example, restraint and control). Secondly (1.2), a very brief summary of the South African context in which this study is set. Thirdly (1.3), a look at narrative medicine, the discipline within which this study is very broadly situated. Lastly (1.4), a summary of the ever-changing relationship between the arts and health. This section also contains a closer look at possible relationships between music and delirium.

1.1 DELIRIUM IN HOSPITAL

Definition

The first challenge delirium presents to this study is its definition. On the one hand, the term is well-established, and has been around far longer than the bulk of current terminology relating to mental ill-health. Fong, Tulebaev, and Inouye (2009a) explain that ‘delirium’ was “first used as a medical term as early as the first century AD to describe mental disorders occurring during fever or head trauma” (n.p.). ‘Psychosis’, by contrast, is a term that came into being as late as the mid-nineteenth century, ‘schizophrenia’ in the early twentieth (Oxford Dictionaries 2017).

On the other hand, perhaps because of its great age and inevitable mutations, it is a muddy concept. The bulk of the clinical literature uses ‘delirium’ to cover a huge range of experiences. Its manifestation in ICU, for example, is rarely differentiated from its manifestation in the elderly, in cancer patients, or even in liver patients experiencing hepatic encephalopathy (see Chapter 4.2 below). ‘Delirium’ is used interchangeably with terms such as ‘ICU psychosis’, ‘hepatic encephalopathy,’ ‘acute confusional state’ (see for example RCP 2012). This dissertation will explore the ways in which this loose definition (see also Frady 2015) may mask substantial differences between these states, in terms not just of *cause* but *experience* – and also therefore in potential treatment.

To outline its current clinical identity, however, the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*⁴ places delirium within its ‘neurocognitive disorders’ category, and gives its criteria as follows:

- A. A disturbance in attention (i.e., reduced ability to direct, focus, sustain, and shift attention) and awareness (reduced orientation to the environment).
- B. The disturbance develops over a short period of time (usually hours to a few days), represents a change from baseline attention and awareness, and tends to fluctuate in severity during the course of a day.
- C. An additional disturbance in cognition (e.g. memory deficit, disorientation, language, visuospatial ability, or perception).
- D. The disturbances in Criteria A and C are not better explained by another preexisting, established, or evolving neurocognitive disorder and do not occur in the context of a severely reduced level of arousal, such as coma.
- E. There is evidence from the history, physical examination, or laboratory findings that the disturbance is a direct physiological consequence of another medical condition, substance intoxication or withdrawal (i.e. due to a drug of abuse or to a medication), or exposure to a toxin, or is due to multiple etiologies. (APA 2013, 596)

The DSM-5 further subdivides delirium into the following five categories:

- Substance intoxication delirium
- Substance withdrawal delirium
- Medication-induced delirium
- Delirium due to another medical condition
- Delirium due to multiple etiologies (Idem., 597)

Of specific relevance to this study is the fact that the DSM does not separate out hepatic encephalopathy (HE) – which all of healthcare professionals in this study discuss – from the more general “delirium due to another medical condition”. Physicians such as Pinson (2010), however, assert the importance of distinguishing between delirium and HE, delirium being “a mental disorder or [...] symptom”, while HE is “a specific neurologic diagnosis that identifies toxic and metabolic states affecting the brain” (n.p.).

HE is a consequence of liver failure, caused by elevated levels of “neurotoxic substances, including ammonia and manganese” in the brain (MedScape 2015, n.p.). If the toxicity cannot be treated, HE progresses in severity towards coma. The form most often discussed in this study is *episodic* HE, which Rovira, Alonso, and Córdoba (2008) describe thus:

⁴ A publication of the American Psychiatric Association that determines international standardised criteria for assessment and treatment. The DSM is a controversial series, with the DSM-5 arguably coming in for more criticism than any of its predecessors (see for example Greenfeld, 2013).

Episodic HE is characterized by the development of a confusional syndrome, including impaired mental state, neuromuscular abnormalities, asterixis, fetor hepaticus,⁵ and hyperventilation, which develops during a short period of time and fluctuates in severity. (Rovira et al. 2008, n.p.)

In the proposal for this study, I noted that the relationship between delirium and HE might need further consideration given the number of liver failure patients treated at WDGMC; at the time I suggested it would be unlikely that I could distinguish between the two. The interviews, surprisingly, suggest otherwise; and there appears to be a clear line between HE and the other deliriums described in this study (see Chapter 4.2, and Fig.17).

A further issue currently plagues the official definition: while the DSM-IV (APA 2000) describes it as “a disturbance of *consciousness*” (APA 2000, 124; my emphasis), the DSM-5 has altered the criteria quite dramatically, by replacing “consciousness” with “attention”. The European Delirium Association (EDA) and American Delirium Society (ADS) have challenged this alteration:

The risk of misinterpreting these revised criteria is that clinicians may focus inappropriately on inattention and testability, erroneously overlooking the *de facto* disturbance in consciousness (that is, delirium) that comes with altered arousal. (EDA & ADS 2014, n.p.)

Lastly it is worth noting that both Fong et al. (2009a) and the DSM-5 identify three forms of delirium – hypoactive, hyperactive, and mixed – described below.

Patients with hyperactive delirium demonstrate features of restlessness, agitation and hyper vigilance and often experience hallucinations and delusions. By contrast, patients with hypoactive delirium present with lethargy and sedation, respond slowly to questioning, and show little spontaneous movement [...] Patients with mixed delirium demonstrate both hyperactive and hypoactive features. (Fong et al. 2009a, n.p.)

These different forms are not related by either publication to different causes, but there are some grounds for thinking that HE, for example, might relate to hypoactive delirium (see pp.75-76).

⁵ *Asterixis* is a hand tremor; *Fetor hepaticus* a musty breath odour relating to liver failure.

Neurological impacts of delirium

It is clear that substantive changes are taking place in the brain during delirium. *Bradley's Neurology in Clinical Practice* confirms that "EEG changes virtually always accompany delirium" (Mendez and Gershfield 2004, 35). How widespread these changes are across the brain is a little less clear. Van der Kooi, Zaal, Klijn, Koek, Meijer, Leijten, and Slooter (2015) find that an EEG of the frontal and parietal lobes can distinguish patients with and without delirium with a sensitivity of 100% and specificity of 95%.⁶ Yokota, Ogawa, Kurokawa, and Yamamoto (2003) suggest that delirium may result from cerebral hypoperfusion in the frontal, temporal, and occipital lobes of the cerebral cortex, as well as the thalamus of the limbic system and the basal ganglia. Based on Boeree's definition of the cingulate gyrus as an area which maintains attention and focus and allows us to "distinguish real voices from imaginary ones" (2006, n.p.), it seems possible that this area is also affected. *Bradley's* particularly mentions the impact on the anterior cingulate cortex, the right prefrontal cortex, the temporoparietal junction, the thalamus, and the upper brainstem structures; and overall confirms that while "the pathophysiology of delirium is not entirely understood [...] it depends on a widely distributed neurological substrate" (Mendez and Gershfield 2004, 32).

Risk factors and causes

Maldonado's 2008 overview provides a generalised assessment of the history, manifestations and causes of delirium in acute care. His checklist of ten primary clinical risk factors makes it clear just how likely it is that delirium will occur in hospital: "Age; Baseline cognitive functioning; Male gender; Sensory impairment; Use of intravenous lines, bladder catheters, and physical restraints; Severe illness; Exogenous substances;⁷ Sleep deprivation; Over-sedation; Pain, poorly controlled" (2008, 660-661). Less formally, Sara Evans gave the following assessment in *Delirium Part I* based on her experience as a senior ICU nurse:

[T]here are too many factors that can cause it [...] just being really, really ill in itself can cause it; the medications that we use would be some of it; [...] not having visual or hearing; [...] things like a lack of sleep, lack of natural sleep; [...] the sense of time goes [...] if you've been sedated for a couple of days; [...] there are things like low or high blood sugars, sodium levels can affect states of consciousness; there are so many different things that can cause it.

⁶ 'Sensitivity' records the percentage of people correctly identified as experiencing the condition in question; 'specificity', the percentage correctly identified as being free of it.

⁷ Medication, substance abuse, poisons or toxins. Maldonado's list of medications extends to four pages (2008: 664-668).

Prevalence and incidence

Before discussing how common delirium is, it is worth noting that it is widely acknowledged to be under-reported (see for example NICE 2010). Peter confirms a “significant heterogeneity” of studies, with “prevalence and incident rates varying widely across study populations and with differing study design” (2012, 5). There is widespread recognition that *hypoactive* delirium frequently goes unrecognised (e.g. Fleminger 2002); and patient reports in the (UK/US) press (e.g. Scott 2012; Hoffman 2013; Lambert 2014) suggest that *hyperactive* delirium is also routinely under-diagnosed. Accurate figures, in short, are hard to come by.

Of Maldonado’s 15 populations in 2008, advanced cancer (up to 85%) and intensive care (60-80%) represent the highest peak incidence. More recent figures from the US National Cancer Institute (NCI 2014) and Cavallazzi, Saad, and Malik (2012) broadly reflect this. Bhudia (2016) suggests that “It affects 3-53% of those undergoing major surgery, and up to 83% of critically ill patients”. A broad but fairly safe generalisation would be to say that the incidence of delirium increases according to the level of treatment – compounded by the vulnerability of the patient. An older patient in ICU, therefore, may be more likely to experience delirium than a young one. But this is by no means a universal rule, and to a degree delirium overtakes us unpredictably (again, see Bhudia 2016).

Peter discusses the “paucity of data from developing countries settings such as South Africa, where the characteristics of general medical inpatients are unique” (2012, 6).⁸ He suggests that South Africa’s “resource-limited healthcare settings”, as well as the impact of HIV/AIDS, may increase the prevalence of delirium (2014, 11). Against this it may be worth noting that his own assessment finds a prevalence of 20.3% in general medical wards at Groote Schuur, almost matched by the 19.6% the following year in Cork University Hospital, Southern Ireland (Ryan, O’Regan, Ó Caoimh, Clare, O’Connor, Leonard, McFarland, Tighe, O’Sullivan, Trzepacz, Meagher, and Timmons 2013). No literature has thus far been published on the prevalence of delirium in South African *private* healthcare facilities such as WDGMC.

⁸ “The median age of inpatients is lower, there is a dual burden of communicable and non-communicable diseases, and inpatient and 12-month mortality rates are equivalent to those of intensive care units (ICUs) and geriatric cohorts in developed countries” (Peter 2012, 6).

The impact of delirium

In the last 15 years, the literature has shifted considerably in its recognition of the short- and long-term impacts of a delirious experience. In 2002, Fleminger suggested that “A small proportion of patients are troubled by their experiences [...] but for most the psychological outcome is good; they seem to pass off the experience as an unusual dream”. By 2014, however, the EDA had noted a widespread realisation that “the ramifications of delirium on individuals, families and healthcare services are substantive” (MacLulich 2014, 11).

Impacts are wide-ranging: from the cost implications of lengthened stays in hospital (see Bhudia 2016),⁹ to damaged relations between staff, patients, and families (see *Part I*, and Bélanger and Ducharme 2011). Peter notes the association of delirium with “significant short, medium and long-term morbidity and mortality and consequent large healthcare cost” (2012, 13). Delirium’s association with post-traumatic stress disorder (PTSD) has been repeatedly identified (see for example Maldonado 2008; Wade, Howell, Weinman, Hardy, Mythen, Brewin, Borja-Boluda, Matejowsky, and Raine 2012; UCLH 2014). A 2010 Vanderbilt study (in Jaslow 2013) found that cognitive damage is common after delirium (see also Fong, Jones, Shi, Marcantonio, Yap, Rudolph, Yang, Kiely, and Inouye 2009b); and Klouwenberg, Zaal, Spitoni, Ong, van der Kooi, Bonten, Slooter, and Cremer note “severe long term consequences such as cognitive impairment, and [...] long term mortality” (2014, n.p.).

In terms of the key relationships that govern hospital care, Breitbart, Gibson, and Tremblay (2002) suggest that delirium is “a highly distressing experience for spouses/caregivers and nurses” (n.p.). Bruera, Bush, Willey, Paraskevopoulos, Li, Palmer, Cohen, Sivesind, and Elsayem (2009, n.p.) that “family caregivers experience severe distress [which] may impact on [their] psychological wellbeing”, and that “delirium is a frequent cause of conflict between relatives and healthcare professionals”. Bélanger and Ducharme confirm that delirium “undermines the care relationship and leads to a breakdown in communication between nurses and patients” (2011, 304).

In recent years public consciousness of delirium has been raised by media attention (for example, BBC R4 2012; Lambert 2014; Jenkins 2015), as well as the slow emergence of delirium in the arts – from Robert Hughes’ 2006 autobiography to a 2012 Frank Ocean video that clearly depicts a delirious hospital experience (Ocean 2012).

⁹ According to Bhudia, “the cost of post- operative delirium across all major surgeries is \$38-\$152 billion per annum in the USA” (2016, n.p.).

This increased acknowledgement of the potency and prevalence of delirium may not yet have filtered down to the generality of hospital treatment, however. Thus the EDA stated in 2014 that increased awareness “among professionals, policy-makers and the public remains a priority” (MacLulich 2014, 1), and in 2015 reinforced the “need to prompt health policy makers about delirium and its implications” (Morandi 2015, 1).

Focus of the literature on delirium

Although numbers are beginning to rise, there have been remarkably few *qualitative* studies of the experience of delirium. Bélanger and Ducharme (2011) bring together a mere 17 peer-reviewed articles published in the preceding 20 years, and only one single-subject study has been published from a South African setting (Herbst and Drenth 2012). Yet the qualitative seems key to responding to developing debates about what the essential nature of the experience might be (Bhat and Rockwood 2007; EDA and ADS 2014).

What role, for example, do hallucination and delusion play? They are acknowledged *symptoms* of delirium (APA 2013; Maldonado 2008, Fong et al. 2009a; RCP 2012), but qualitative studies (Bélanger & Ducharme 2011; Herbst and Drenth 2012), my own previous work (*Part I*), and press reports (BBC R4 2012; Scott 2012; Hoffman 2013; Lambert 2014), all suggest that hallucination stands out from other elements, as an experience which fundamentally disrupts the sense of self, reality, and relationship between the two. Sarah Wake, a British doctor quoted in the *New York Times*, states that “the fragmented delusional memories [...] prevented my psychological recovery and led to the development of post-traumatic stress disorder” (Hoffman 2013, n.p.). And Nancy Andrews – an artist who has presented extensively on her own experience of delirium – assigns her own PTSD in part to the difficulty of reconciling herself with the false memories given her by hallucination (Andrews 2013). Oliver Sacks has written that hallucinations in general “can mimic perception in every respect, starting with the way they are projected into the external world” (Sacks 2012, ix). It is this mimicry which underpins Wake and Andrews’ PTSD; and yet attention is rarely paid to the detail of this central experience.

Hallucination – in hospital as elsewhere – is frequently perceived as a valueless experience, one to be eliminated or minimised. Its narratives are generally ignored – something which many argue undermines efforts to reintegrate these narratives back into our lives. As Sacks puts it,

Many cultures regard hallucination, like dreams, as a special, privileged state of consciousness [...] But in modern Western culture, hallucinations are more often considered to portend madness or something dire happening to the brain [...] (2012, xi-xii)

Although I would question the notion that it is only “modern Western culture” that pushes hallucinations to its fringes, this study is in some ways an attempt to re-legitimise the narratives of hallucination, to return to them some privilege of insight. The aim is not dissimilar from work being undertaken in the different, but related, field of voice-hearing, where numerous researchers and advocates (see for example the international Hearing Voices movement)¹⁰ are working to take seriously the content of delusion, as much as the fact of it, regarding this as an essential element of treatment and recovery.

Returning to delirium, however, recent clinical literature focuses less on these narratives than on assessment and minimisation. And since assessment has historically been such a problem (see p.12, above), much space has been devoted to the development of tools that might quickly diagnose and document delirium. The most widely acknowledged of these is the Confusion Assessment Method (CAM), and its sister the CAM ICU (see for example Inouye 2014a; Grover and Kate 2012). But as Sara Evans puts it in *Part I*, the CAM is about *confusion*; it “doesn’t actually test hallucinations [...] if you’re hallucinating [...] you might still be able to concentrate but you’re focusing on other things”. It is beyond the reach of this study to critically assess tools for diagnosing delirium; but it is worth noting that there seems to be a breach between the focus of the literature, and that of the people who have experienced delirium.

Violence and health

Most research on violence in relation to health focuses either on what might be termed ‘occupational violence’ – the risk to staff of violence whilst undertaking duties (for example Jackson, Claire, and Manni 2002), or ‘structural violence’ that restricts access to healthcare (for example Farmer, Nizeye, Stulac, and Keshavjee 2006).

What is perhaps less often discussed is the violence *intrinsic to* healthcare. Of course medical history is packed with violence. Museums such as the Hunterian or Old Operating

¹⁰ <http://www.intervoiceonline.org/tag/hearing-voices-movement>

Theatre in London are largely marketed on the grotesque and disturbing, on the *there-but-for-the-grace-of-god* shiver produced by the ancestors of modern surgery.



Figure 1: Publicity photograph for the Old Operating Theatre & Herb Garret
Source: <http://www.thegarret.org.uk/>

But to relegate this violence to the past is mistake. There is no denying that repairing the body remains a violent business – from metal rods in the spine to hefty immunosuppressant drugs for transplant. Some sense of this is present in the burgeoning literature on palliative care – a counteraction to the model of preserving of life at all cost (see for example Gawande 2015), but the ‘good death’ aside, violence is embedded in treatment of all kinds, and usually increases according to the intensity of that treatment.

This manifests itself in relation to delirium in a number of ways: through surgery, through the drugs given to patients, and through restraint (below). But also through the physical environment, and in particular its soundscapes. Delaney, van Haren, and Lopez 2015, for example, alert us to the impact of the clinical environment on sleep and recovery. And from different disciplinary world of sound art, John Wynne’s “ITU: The Din of Recovery” (2013) provides a thorough assessment of the excessive decibel levels common in ICUs and their impact on our emotional and physical health.

The use of restraint

Restraint is used internationally in intensive and general acute care if the patient represents a danger to themselves or others. The UK overwhelmingly favours chemical restraint (Langley, Schmollgruber, and Egan 2011),¹¹ but in South Africa and the US physical restraint remains widespread.

Maldonado (2008) lists physical restraint as a risk factor for delirium. Indeed its use is a fraught, emotive area of care, dominated by the image of a tied-down, vulnerable patient with all its connotations of indignity, violence, control, and punishment – infinitely more disturbing than the sanitised image below might suggest.



Figure 2: Rubber patient restraint strap
Source: Universal Medical Inc.¹²

Two recent South African studies have documented the use of physical restraint in ICUs. Kalula and Petros (2016) find a prevalence of 23% across the acute wards of a Cape Town public hospital, whilst Langley et al. show that almost half (48.4%) the patients admitted to a Gauteng public ICU over two months were restrained during their stay, and for a surprisingly high average of nine days. I have been unable to source data on the prevalence of physical restraint in private ICUs in South Africa, but it is worth noting anecdotally that while one might assume that the resources available to the private sector could ‘soften’ patients’ treatment, one of the nurses interviewed by Langley et al. suggests that “they use restraints more in private ICUs” (2011, 71). And indeed almost all the staff interviewed for this study, and one former patient, describe direct experiences of physical restraint.

¹¹ Incidents are, however, far from unknown, as my experience at Harefield suggests (see p.5).

¹² <http://www.universalmedicalinc.com/rubber-patient-restraint-strap-with-1-buckle.html>

Every interviewee, moreover, refers to chemical restraint – sedation, in other words. Crane (2015, n.p.) reports a shift in attitudes towards ICU sedation – from “thinking we were doing the right thing” to knowing “it’s associated with hurting them and hurting their brain”. There is no question, however, that chemical restraint remains central to the running of ICUs.

Control and health

One final area to note here is the relationship between our sense of control over our own circumstances, and our state of health. The data below returns again and again to issues of control (see Chapter 4.3) but I have been unable to find much reference in clinical literature to this concept. The field of Sports Science has a considerable literature on flow, control, and health, but there is little available with reference to acute or chronic ill-health. If we assume, however, that a lack of control is coterminous with stress, there is a wide literature demonstrating impacts on aspects of recovery. Gouin and Kiecolt-Glaser 2011, for example, focus on the impact of stress on wound-healing; and Müller and Netter (2000) and Müller (2011) both find correlations between feelings of helplessness and perceptions of pain.

1.2 THE SOUTH AFRICAN CONTEXT

Cultural context here, as anywhere, is determined by many complex, intersecting factors. With a population of 9.6 million people,¹³ Johannesburg is South Africa’s largest city. And an archetypal modern conurbation – characterised by what Mbembe and Nuttall call the “fractured, colliding, and splintered orders of urban life” (2008, 5). The small sample size in this study (17 interviewees) and the lack of previous research in this area¹⁴ makes any generalisation about the South African context inadvisable. But it may be worth giving a broad context to the interviews.

¹³ 2011 South African census.

¹⁴ Some research *has* been undertaken into the impact of culture on psychosis (e.g. Makhanya, 2012), a near-relation of delirium; and Herbst and Drenth (2012: 21) do discuss the importance of background history for delirium – but restrict this purely to the subject’s *medical* story.

Health systems

South Africa has a two-tier health system: public and private. Nor are the two tiers close. In 2014, state-funded healthcare supported 80% of the population, but accounted for only 48% of total healthcare spending (South African Data Portal 2017). The South African state system is oversubscribed and underfunded. The link between race and health inequality, moreover, becomes troublingly evident when we consider that:

In 2011, over 81% of black South Africans and over 63% of coloured South Africans mostly used public sector health facilities, whereas 88% of white South Africans favoured private facilities, as did over 64% of Indian South Africans (Davis 2013, n.p.).

It follows of course that the make-up of the patient population at South African hospitals will be determined in large part by which sector the hospital falls into. WDGMC, where this study is largely situated, is unusual: in being a private teaching hospital (part of the University of the Witwatersrand teaching group); and in receiving state patients in its renal, hepatic, and transplantation services. This impacts *to an extent* on the diversity of its patients, but the bulk of people attending WDGMC are part of the private sector, and this study is therefore a skewed reflection of the population of Johannesburg, perhaps one of the most culturally and linguistically diverse places on the planet.

It should be noted, however, that the city's linguistic diversity *is* reflected to an extent, particularly in the contrast between languages used *between* healthcare professionals and those used in communicating with patients. Like all South African healthcare institutions, WDGMC is vulnerable to the additional barriers created by language (see for example van den Berg 2016).

To delve into South Africa's recent political history (beyond common knowledge) in relation to delirium would overcomplicate this limited study. The military does, however, have a particular role to play in delirium (see pp.82-83), and it is worth noting here that despite vigorous campaigns from the 1970s onwards,¹⁵ military conscription was maintained for all white South Africans until the 1990s; and that generations of South Africans have been profoundly affected by their deployment against their fellow citizens during apartheid.

¹⁵ See for example the ECC archive at the South African History Archive (SAHA): <http://www.saha.org.za/ecc25/?folder=ecc25>

1.3 NARRATIVE MEDICINE

This study is situated broadly within the developing field of ‘narrative medicine’ (NM), and is a creative form of narrative research. Narrative research, or narrative enquiry, is a relatively recent (early twentieth century) development of qualitative research. It takes a multitude of forms, but is of course characterised by a dependency on narrative. ‘Narrative’ is by no means restricted to verbal testimony, and could include anything from films to letters; but in the case of this study, interviews and focus groups are the primary sources. What distinguishes this study from the broader world of narrative enquiry is an investigation of the data through music, as well as this text.

There is of course a long history of the telling of stories of medicine, and of physical and psychological disorder, through the arts – from Hieronymous Bosch’s diseased bodies to Puccini’s consumptive heroine. Hallucination and altered states more broadly take up huge space in this (Western) history (Blake, de Quincey, Aldous Huxley, the entire surrealist movement, most of the Romantic poets, and so on). But while they might inform our general sense of how illness sits with the world, the arts are not commonly considered to be research, in the sense in which medicine understands it.

I hope to challenge this assumption and to provide some understanding of delirium through the composition in particular which might elude more conventional research in this area. This is not a unique ambition. Artists like Wainwright and Wynne (2008, 2016) and Nancy Andrews (2015) regularly present their work in clinical as well as public contexts. But it remains rare to bring this approach into the academic sphere and to assess its potential in the context of narrative medicine.

Bringing narrative theory together with medical practice, NM is predicated on the idea of moving past a reductive approach to diagnosis towards a more holistic conceptualisation of health. In *The Wounded Storyteller*, Arthur W. Frank describes NM as “a literary cousin of relationship-centred care”, and defines it as “medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness” (2013, vii). Physician and literary scholar Rita Charon’s foundational 2008 publication – *Narrative Medicine: Honoring the stories of illness* – brings together many of the ideas that inform NM, highlighting the capacity of such stories to “capture the singular, irreplicable or incommensurable” (Charon 2008, 48) in the face of what Peregrine Horden has succinctly called the “technologically triumphalist, dehumanizing” (2000, 21) world of twentieth-century biomedicine, and its treatment of the body as precisely the sum of its parts.

Horden's description comes from *Music as Medicine* – a substantial review of the history of the conjunction of music and medicine. Indeed what Charon describes has much in common with artistic practices in medicine, particularly the arts therapies (see 1.4 below for more on the arts in health). Yet, while Charon's book refers frequently to literature and narrative theory, it makes no mention of existing artistic (including literary)¹⁶ practice in healthcare. She puts the task of "equipping ourselves with narrative competence" firmly at the feet of the doctors to whom her book is addressed. Charon's position has perhaps since shifted – under her direction, the Narrative Medicine programme at Columbia University¹⁷ certainly incorporates artistic practice – but my own experience suggests that the coming together of medicine and the humanities remains plagued with a tendency to overreach – absorbing others' expertise into one's own discipline rather than collaborating with experts in other fields. This approach is typified in Charon's case study of her own treatment of a Mr Ortiz:

Instead of appointing him to the social worker for supportive psychotherapy, I see him myself every two weeks. I asked a colleague of mine [...] to become my supervisor as I undertake this new blend of internal medicine and supportive talking therapy. It feels right for me to commit myself to this work instead of referring Mr Ortiz to a psychotherapist, because his emotional pain is intimately tied to his physical situation. (2008: 186)

In taking over his psychological care "because his emotional pain is intimately tied to his physical situation", Charon implicitly dismisses not only the social worker but the by then well-established profession of health psychologist,¹⁸ specialising in work with the body. Whilst her commitment to her patient is admirable, it undercuts the possibility of multidisciplinary support. The surgeon, writer and public health researcher, Atul Gawande, takes a very different position in his recent Reith lecture, *The Century of the System* (2014), emphasising instead absolute necessity for multidisciplinary teamwork in a situation where "the volume of knowledge and skill has exceeded our individual capabilities" (n.p.).

For all that Charon's book is important and innovative, the hero-physician is alive and well within its pages, struggling on into new realms of knowledge. And inevitably therefore excluding others. This is part of a tension that I would suggest continues to underpin the wider field of medical humanities – between the desire for what Charon calls "an intersubjective relationship of vulnerability and trust" (2009, 208) and the maintenance of

¹⁶ See for example this year's forthcoming Creative Bridges conference, which focuses on Creative Writing for Therapeutic Purposes <https://creativebridgesbristol.com/>.

¹⁷ www.narrativemedicine.org/aim.html

¹⁸ A brief history is given by the Society for Health Psychology, Division 38 of the American Psychological Association since 1978: <https://societyforhealthpsychology.org/about/history/>.

the clinician's elevated position in the hierarchy of care. Nor is this tension restricted to the 'medical' half of medical humanities. The humanities too are exclusionary and – worse – periodically indulge in moralising judgment of the medical professions (see p.32).

"Vulnerability and trust" between disciplines may be just as hard to achieve as it is between patient and physician, and it takes a similar willingness to acknowledge the limitations of one's own reading.

Arthur W. Frank's work, however, remains of specific relevance to this study. He proposes three possible narratives of health: Restitution, Chaos, and Quest (Chapters 4, 5, and 6 of *The Wounded Storyteller*, 2013). These three concepts have come to underpin both the thematic structure of this dissertation (see Chapter 4), and the composition of *Delirium Part II* (see Chapter 5), albeit in slightly modified forms.

1.4 THE ARTS AND HEALTH

Simply by putting these two words together I may be conjuring up a range of expectations relating to fields as diverse as neuroscience and the art therapies. It may therefore be useful briefly to clarify the role the arts play in this study.

As I have explained above, my focus here is on music as a means of exploring the experience of delirium. I am interested in what happens when we use music to gather, organise, present, and disseminate information about a medical topic. This does not mean that music is deployed as an objective means of assessment. Indeed, as I will discuss further in Chapter 5.3, it is the subjectivity of music that may give it value in this context.

The intention is not directly therapeutic (any more than any qualitative study is therapeutic); nor am I focusing on the impact of music on the brain and body, or of music on the delirious state. The two areas I focus on below are rather, first, the relationship between music and delirium – why music might be an apt means to represent delirium; and, second, the ethics of using music to report other people's experiences.

Relating music to delirium

I would state from the outset that there is nothing about music that makes it intrinsically *better* for working with health narratives than any other art form. I use it here because it is the creative tool with which I am most familiar; and hope it will act as a lens through which to understand why *any* creative approach might add something to existing health research practices. Like any form, however, it has its particularities, and the way in which it is used may influence which aspects of the subject are brought to the fore, and how.

Time

Delirium is arguably characterised by the “dissolution of time and space” (Cerejeira and Mukaetova-Ladinska 2011, 3). Bhat and Rockwood, too, suggest that “temporal disorientation is essential” to delirium (2011). Some deliriums are profoundly repetitive: “It was like a video loop, going round and round and round”; some shift our temporal location: “It was way back, way back in the 1800s”; some seem to break out of time altogether, “like a pit of foreverness” (these examples are all from *Part 1*, although delirious time-travelling is also mentioned in Bélanger and Ducharme 2011).

Music, of course, has a particular relationship with time. Different from that of the plastic arts; different even from other performance arts. Lawrence Zbikowski's essay "Musical time, embodied and reflected" explores "the idea that sequences of musical sound have the potential to shape temporal experience in ways that are different from those of language" (2014, 38) – whether through memories recalled or the experience of rhythm in a space.

Music literally plays with time. This play is not represented consistently, however. Bamberger says that music, "shaping time, brings time's transient presence into consciousness – making time palpable, as if hand held" (2014, 1). Others, though, would suggest that, far from making it palpable, music overrides our consciousness of time:

Time does indeed seem to fly when listening to pleasant music. Music is therefore used in waiting rooms to reduce the subjective duration of time spent waiting or in supermarkets to encourage people to stay for longer and buy more. (Droit-Volet, Ramos, Bueno, and Bigand 2013, n.p.)

Then again, (composer) John Berger (2014) describes the way in which

One evening, some 40 years ago, I got lost in time. I was at a performance of Schubert's String Quintet in C major. During the second movement I had the unnerving feeling that time was literally grinding to a halt. The sensation was powerful, visceral, overwhelming. It was a life-changing moment, or, as it felt at the time, a life-changing eon. (n.p.)

So does time disappear or does it become palpable? Does music make time speed past, or stop? Perhaps all these things at once. As Composer Nico Muhly puts it, John Adams's *Common Tones in Simple Time* is as "at once very fast and very slow [...] a 16th-note pulse that carries throughout [...] and yet, from a harmonic standpoint, the piece barely moves at all" (Muhly 2005, n.p.; and Adams 1987). This double-effect, between the (rapid) speed of the surface and the (near-static) harmonic motion, could be said to resemble something like a dust devil – where cyclical movement relates almost antithetically to linear movement. It is a defining characteristic of much minimalist music, but this manipulation of time is only bringing to the surface a capacity latent in all music.

Partridge connects music's play with time to its impact on the limbic system: "Temporal manipulation is central to music's function as an affective technology" (2013, 40). Basing his musings on the Greek differentiation between *chronos* (crudely, clock time) and *kairos* ("a particular quality of time, a moment of significance"), he quotes Richard Till:

When one experiences music and/or dance, one is no longer synchronized to the pulse of the second, the hour, the day [...] one's internal clock is linked to the musical time that is passing, whether bars, beats, or phrases. It thus helps one to become unlocked from chronos, from a normal perception of time, and for one's state of mind or consciousness to change. (Ibid.)

Partridge relates *kairos* to a desire “to restructure ‘normal time’, to expand it into a reflective, affective space” (2013, 40, quoting Paul Willis). Similarly, Brian Eno (in Ross 2008) says that minimalism's sonic space represents “a drift away from narrative” (475). With Partridge, I would expand on this to suggest that *all* music drifts from linearity. And what this drift opens up for this study is the possibility of a different *kind* of narrative – one in a more open relationship with time:

music, especially as it is experienced through performance, is rarely complete in the moment, but is instead a relentless stream within which present, future and past swirl and bob like so much flotsam and jetsam. Yet I would like to suggest that the force of this experience – the sense of being immersed in an ongoing dynamic process – offers another way to think about time ... (Zbikowski 2014, 33)

Memory

As in almost any narrative research, memory plays a central role in this study. Any conversation involves construction through narrative (see Holstein and Gubrium 1997). But after delirium – which replaces real events with false ones, reorganises sequences, and often eliminates whole stretches of time for the people who experience it – memory plays a particularly important role.

Much writing about music refers to its capacity to return us to our past – “knowledge summoned from the strands of memory” (Zbikowski 2014, 34). Whist nostalgia plays a huge role in much popular music production, composers addressing social trauma, too, exploit this capacity to overleap the immediate and reach back to a more stable past, or to mythologise a cultural continuity. In *Performing Pain: Music and Trauma in Eastern Europe*, for example, Maria Cizmic discusses composers' responses to “the disruption of linear time wrought by the Soviet manipulation of history” (2012, 8). She refers to Mazo's interpretation of the “musical interest in memory” in composers such as Alfred Shnittke and Arvo Pärt “as an act of reclamation”, one in which composer and audience can “redefine their values, reconstruct their self-identity” (ibid.). Arnold Schoenberg might provide a different example of reclamation in his *Survivor from Warsaw* (Schoenberg 1947) – which narrows the focus of

the wide-ranging trauma of the Holocaust to one individual. With its brutalised references to the *Sh'ma Yisroel*, and to morning 'reveillés', James Schmidt points out (referring to Wlodarski) that "the orchestra functions as an 'unconscious memory for the narrator', recalling those events that he is unable to remember and, by doing so, allowing him to bring them to speech" (468). *Survivor* opens with the lyric "I cannot remember ev'rything. I must have been unconscious most of the time", and Schmidt emphasises Schoenberg's concern with the workings of memory, suggesting that *Survivor* "offers a glimpse of the torturous process by which the stuff of brute experience is shaped into a coherent memory" (ibid.).

This notion of the orchestra as "unconscious memory" – filling in the spaces we are "unable to remember" – is a significant one for this study. As we have seen on p.14 Sarah Wake speaks of her "fragmented, delusional memories" in delirium (Hoffman 2013, n.p.). Hoffman further suggests that

Other PTSD sufferers — victims of combat, sexual assault or natural disasters — also endure flashbacks, but theirs are grounded in episodes that can often be corroborated. What is unsettling for post-ICU patients is that no one can verify their seemingly real horrors. (Ibid.)

This relates strongly to Arthur Frank's notion of the "Chaos narrative": "an anti-narrative of time without sequence, telling without mediation, and speaking about oneself without fully being able to reflect on oneself" (2013, 98). Similarly, Rita Charon refers to the words of psychologist Jerome Bruner: "it is through narrative that we create and re-create selfhood [...] if we lacked the capacity to make stories about ourselves, there would be no such thing as selfhood" (2008, 68). Frank notes, too, that "the chaotic body has no voice" (2013, 109). Referring back to Robert Hughes' delirium, this voicelessness is painfully palpable: "she found me in a state of dread verging on speechless hysteria, like a prisoner mouthing through the glass of a soundproof enclosure" (2011, 16). Responding to this silence, *Part I* features a song, "Voice Boxed", which focuses on speechlessness in ICU – sometimes a direct result of a tracheostomy, sometimes (like Hughes') a more mysterious psychosomatic phenomenon.¹⁹

Frank does not take this chaos as a permanent state – indeed he specifically notes that stories, and the arts more broadly, may provide an antidote. Of the conclusion of Terry Tempest Williams' cancer narrative *Refuge*, Frank says that "Her narrative wreckage is rebuilt; her map redrawn" (2013, 73). And he refers, too, to Oliver Sacks' *A Leg to Stand On*,

¹⁹ <https://victoriahume.bandcamp.com/track/voice-boxed>

in which Sacks finds a way to “reintegrate” himself (Frank 2013, 109) through listening to Mendelssohn, as well as through the writing of the book itself. In the aftermath of her delirium, artist Nancy Andrews suggests that making drawings was “one of the keys [...] to piecing back together my fragmented sense of self” (Andrews 2012, n.p.). Here, literature, music, visual art are ways to rediscover logical progression, to work through the lesions of chaos. But there is also a slightly different way of looking at the role of the arts, manifest for one in the Surrealist movement of the early twentieth century.

Surrealism

Surrealism prizes the unconscious in a very particular way. Its engagement with the burgeoning field of psychoanalysis, as well as more esoteric phenomena like automatic writing and the séance, speaks to a desire to reach past conscious control toward something more inchoate and fundamental. Breton’s 1924 *Manifesto for Surrealism* tells us that surrealism is “Dictated by thought, in the absence of any control exercised by reason, exempt from any aesthetic or moral concern” (Breton/Anon. 1924/1999, n.p.).

As we shall see (in *Control and Disinhibition* on p.103), “absence of control” and “moral concern” is characteristic of some deliriums. In relation to this, it may (in ways similar to many ‘altered states’) appear carnivalesque or theatrical. Transformations of various kinds characterise delirium: behavioural change in the delirious person, and shifting identities in their hallucinations. It has a *punning* quality, straight out of psychoanalytic traditions, and familiar to the surrealists, whereby meaning is multiplied, and unfixed. To take examples from *Part I*, a nurse is a nurse, but also a pig, jumping over the ward clock; a patient is served up as a kebab; a doctor moves down an underground waterway dispensing medicine in a paper bag (for a full list of hallucinations reported in this study, see Appendix 7).

Satie, the composer perhaps most clearly identified with surrealism, was immersed in cabaret, and much of his work is founded on “musical borrowing”, parody, and the shifts in the meaning that accompany it (Davis 2007, 62-90). Davis goes into some detail (92) about the puns Satie employs in “Sur un Vaisseau” from the 1913 keyboard suite “Descriptions automatiques” (Satie 1913), which revolves around fragments of popular song. Satie’s musical contemporaries were – if not directly surrealist – certainly engaged in the same play with the past, and with popular culture. Thus for example the heady irony of Ravel’s *Valse* (Ravel 1920) – a “tour of destruction of the Austro-Hungarian Empire as embodied in one of

its foremost cultural forms, the waltz” (Graham 2016, 128) – permanently changes the significance of the waltz. If the Great War removed the props from a certain kind of civilisation and culture, composers responded by blasting open venerated objects, revealing their instability, opening up their meanings to something more plural and disturbing.

If surrealism (like Andrews’ drawing, like Sacks’ writing) finds a thread through the chaos of imagination, it is not through a defiantly straightforward narrative, but through jokes, mirrors, elisions, and diversions that reflect the disorder. Daniel Albright describes it as “a phenomenon of semantic dislocation and fissure” (1999: 289). This is not to say that surrealism is ideologically evasive; indeed its jokes are its weapons, as Breton suggests when he says “Beloved imagination, what I most like in you is your unsparing quality” (Breton/Anon, 1924/1999, n.p.). Albright, however, notes a contrast between the “dislocation and fissure” of Surrealism and its cousin, Dadaism: “a phenomenon of semantic destruction” (ibid.). It could be argued that, at least in clinical understandings, we have traditionally regarded delirium as a phenomenon of semantic destruction – an experience which negates meaning. But it might yet be reclaimed as the former – an experience that carries a great deal of meaning, dislocated. Psychotic delirium, in this study at least, is not nonsense, but dislocated sense: in part a collection of fragments from popular culture (skeletons, spaceships, heroes and villains, religious figures),²⁰ carrying new meanings. And what Breton might have called its “unsparing quality” is what allows us to learn about the real experience of care.

Communication, accessibility, and advocacy

Given that this is a masters in Music and Health Communication, accessibility is, of course, key. It would seem an obvious point that research should be comprehensible and communicate ideas. But academic writing is not always intended to reach beyond its own discipline. And music, too, can be an insular business. The American composer Milton Babbitt, for example, represents a particular extreme of self-reference and isolationism, one often associated with the Serialism to which he was devoted. Indeed Babbitt’s muse, Bethany Beardsley, said in a 1961 interview for *Newsweek* that:

²⁰ Examples of all of these can be found in *Part I*.

I don't think in terms of the public... Music is for the musicians. If the public wants to come along and study it, fine. I don't go and try to tell a scientist his business because I don't know anything about it. Music is just the same way. Music is not entertainment. (Quoted in Duffie 1995, n.p.)

If the position taken by Beardsley and Babbitt continues to haunt perceptions of contemporary classical music as reified and elitist, the prevailing tide of ('high') musical thinking was changing even as this interview took place, with the emerging figures of John Cage and (only a few years later) Steve Reich, both of whom would substantively shift the audience for 'classical' music, as well as the development of popular music as a site of serious study (see for example Tagg 2015 or Ross 2008), along with a growing (western) recognition that the history of the arts is not confined to northern Europe and the US.

Nonetheless anything 'easy listening' remains suspicious, perhaps due to the aggressively populist music at the other end of the spectrum from Babbitt, designed by committee to sit within a marketing framework, associated with lifestyles and brands:

these days the biggest hits are collaborative team efforts. [...] the lead producer will work with the team to bring it all together into something that meets the artist's and the label's visions. [...] The mixing engineer and the mastering engineers bring their expertise as to how to make something sound more modern or more retro based on the technical trends (frequency analysis, song dynamics, depth, etc.). (Plantz 2015, n.p.)

Accessibility can be democratic, but it has within it an Orwellian potential, an opiate edge. A serving up of musical expectations, an inevitable reliance on emotional tropes to convey a point quickly. But (to suggest just two genres) folk and blues and are also concerned with accessibility, immediacy, and memorability, and have far less to do with aspiration and commercialism. Moreover their accessibility gives the audience credit for its intelligence and judgement, and unlike the cynically-wrought marketing enterprise described above, makes humorous, frequently defiant play of musical expectations. The Euro-American folk tradition contains a huge number of jaunty 'murder ballads'²¹ – like, for example, "Lily of the West" (Anon, Irish trad.); and 'the blues' speaks for itself. Take Bessie Smith's "Electric Chair" (Smith 1927), a riot of major chords supporting lyrics such as "I had my knife and went insane [...] send me to the electric chair". It is nothing if not accessible, but nor is it easy listening.

²¹ See https://en.wikipedia.org/wiki/Murder_ballad.

Songs like these have contemporary equivalents in songwriters like P.J. Harvey (see for example Harvey 2011), as well as composer-musicians reinterpreting old folk tunes somewhere at the boundary between contemporary classical music and song (such as Nico Muhly and Sam Amidon's amazing fragmented collaboration on the murder ballad "Two Sisters" – Muhly 2008). This is the kind of accessibility to which this study aspires.

Related to accessibility is the question of advocacy. As I have indicated, the motivation for this research includes the lack of qualitative work on the subject despite its prevalence and impact (see p.12). If research is generally designed to form part of a patchwork of ideas building over time into a corpus of knowledge, the presentation of this research in music is partly designed to push it out from the patchwork and declare itself important. Ideologically speaking, this is not unproblematic. Take for example the "multibillion pound juggernaut" of the breast cancer "industry" (Smith 2012), and more generally the growth of "cause-related marketing" (Fernandez 1998, n.p.). Advocacy of all kinds can create arbitrary hierarchies of disease and suffering. Finding ways of raising your head above the parapet does not mean your cause is more important than any other, after all.

Using music to represent others' experience

I have been writing music for about 20 years – a practice that evolved from writing poetry, and then songs. In retrospect both seem to have been about communicating something I found could not be communicated adequately through conventional means – even if I was only communicating it back to myself. Music, songs and poems have been a way to order chaos, to unknit complex emotions, to give narrative to whatever feels overwhelming in one way or another.

Songwriting and music, however, (for me) do something a little different from poetry, in giving the words a coherent emotional context. A particular mood emerges dominant from every song. This mood becomes a way to understand what seems inchoate and overpowering. This is not about simplifying emotion, but using it as a guide – a thread to follow from inside a ball of wool.

A similar process is underway with this project, for me as a composer, for the participants as 'storytellers', and for us all and others as the audience; for listening, too, can be about finding this thread, a way of directing chaotic emotion through a formal space – and to an extent releasing or transforming it. Amongst many other forms of music, anthemic pop does

this very successfully. Alyx Vesey (2014) describe this as “the promise of bodily and spiritual connection, however briefly” given to us when we’re immersed in music. Transformation, loss of self, communion with others: these are all possible in music. Hesmondhaugh reminds us, however, that for every stranger who comes together through shared musical experience, “there are those who feel excluded from such collective pleasures” (2013, 104).

To challenge this exclusivity, a degree of ambivalence could be said to be important in music: there must be enough non-specificity to allow the listener to place themselves in it. One of the risks inherent in writing music about an apparently narrow topic like delirium is that, rather than exposing what is universal, the music reinforces a them-and-us situation. This is far from unknown in art-making about health. In fact the arts are dogged by an ignoble history of gore and differentiation in relation to both physical and mental health. Depressing examples can be found in the history and pre-history of psychoanalysis – in particular Jean-Martin Charcot’s photographs of his new discovery, hysteria²² – the very concept of which has been devastatingly debunked by Elaine Showalter (1998), amongst others. Since then this has mutated no less troublingly in two directions: firstly, into a kind of ‘pity porn’, in which the unwell person becomes a holy plot device for teaching life lessons (Johnson (2012, 13) cites *Children of a Lesser God* and *My Left Foot*, but examples – especially on film – are almost too numerous to mention); and secondly, ramping up stigma based on prejudicial and incomplete understandings (epitomised most recently by the appearance of dissociative-identity disorder in M. Night Shyamalan’s *Split*).²³ To an extent these tendencies are on the wane on the face of decades of successful advocacy but they remain forceful in popular culture. Against such a background, ethics looms large.

There are differences and similarities, moreover, with qualitative research. In both cases the researcher interprets the data and presents their own conclusions. In both cases the data are the building blocks of someone else’s career: conferences, performances, royalties, publications.²⁴ The general audience to which this study aspires is arguably different from the somewhat closed world of research, which perhaps increases the danger of exploitation. But the primary difference between this and other types of qualitative research is (of course) to do with sound.

²² An uncredited but very thorough exploration of ‘Charcot’s Photographic Iconography of Hysteria’ can be found at <http://www.slideshare.net/suhawes/charcots-photographic-iconography-of-hysteria>.

²³ <http://www.imdb.com/title/tt4972582/>

²⁴ In this case the music will deliberately not be sold but made available online for free, but there may be fees associated with its performance in the future.

Firstly, there are the implications of ‘musicifying’ a story. In *Performing Pain*, Cizmic sums up both the opportunity and the risk: “Can music create a point of entry into an empathetic response to another’s pain or do the dangers of aestheticizing suffering lurk nearby?” (2012, 3). And secondly, there is the question of using participants’ voices. The sound of a voice is inarguably more recognisable and intimate than a written quote (“the ‘grain’ is the body in the voice” – Barthes 1977, 188). Interviewees are in this sense *exposed* by the music. This means that the relationship between researcher and participant *must* be different from the conventional research model, in which – typically – the participant loses contact with the study entirely, rarely seeing the results of their contribution. (This is of course not universally the case, and broad movements within various fields seek to shift the balance of power and maintain engagement – see Karnieli-Miller, Strier, and Pessach 2009.)

During another recent process of making music about others’ experiences of ill-health (for *The Isle is Full of Noises*; see pp.54-55), I was given a strong warning by an advisor on the project about the dangers of ‘experience-mining’ – in other words, using information from a particular grouping of people to further my own ends. But how does one focus on an experience that is not universal without putting those who experience it into a box?

There are practical steps that can be taken; and it is also of course a question of approach. In this instance the obvious practical measure is to ensure that the people interviewed are given an opportunity to hear and comment on the work before its performance or publication. This is not unproblematic. I should state at the outset that this is not a collaborative project – by far the bulk of the creative work happens alone, and as such the composition can only respond in a fairly limited way to comments and suggestions. But this does at least afford a chance for people to withdraw consent to use their voice, to suggest different emotional directions for work, and to ask for edits.²⁵

In terms of approach, there are two important things to avoid. Firstly, generalising judgement: it is all too easy, when regarding medical suffering, for the humanities to blame obvious villains: clinical hierarchies, communication problems, pharmaco-industrial conspiracy, cultural mismatch. Patients become victims, and the system becomes an impenetrable monolith to rail against. As we will see in Chapter 4, however, there is little victim-like about the patients and families interviewed for this study (P3, for one, “was in

²⁵ This happened in two instances in *Part I*. In the first case, an interviewee felt an early sketch to be misrepresentative in tone, at which point I changed musical direction; in the second, an interviewee decided they would prefer their voice removed. This was done, but after seeing the piece live, the same person asked for it to be reinstated – which it was.

total control” – see p.98). Nor do the clinicians represent unforgiving certainties. HCPs, families, and patients alike generously express vulnerability, doubt, and hesitant determination in equal measure. Secondly, entering into a pact (as the audience or artist/researcher) with the healthcare professional. In presenting qualitative information about a condition, it is possible to give *the whole experience* to the patient, and leave everyone else – families, physicians, researcher, audience – outside, observing it; perhaps sympathetically, but objectively. Both clinicians and patients are experiencing illness, however. Not equally, of course, but they are part of the same indivisible mesh of activity, helplessness, and will. Both express opinion and emotion, frustration and capacity, ignorance and knowledge. To acknowledge this in the creation of works of art brings us closer to Charon’s intersubjectivity, whereby knowledge is in recognition as much as it is in distance.

1.5 THE AIMS OF THIS STUDY

I am undertaking this study because of a personal fascination with delirium – which derives from its *other*-ness in relation to clinical, quantitative, physiological ideas of what medicine does, and yet it is at the heart of intensive medicine. Delirium is the madwoman in the attic of medicine. And as such teaches us about the systems of power which have put her there.

To understand this otherness, however, I contend that we need something more than the same quantitative methods that have allowed it to flourish. This study uses music to get under the skin of medicine – it is complementary to conventional research methods, but also opposes some of them in intent; as Chapter 3.4 and 5.3 will demonstrate, my own subjectivity as a researcher is essential to exploring an experience which is *by definition* subjective – and to reinstating the importance of the arts as creators of knowledge, not just therapeutic interventions, or illustrative partners, in the field of health.

Delirium is understood poorly. We need narrative research to uncover what is really going on, and in particular to value the subjective experience of hallucination and what it tells us about care from a position of crisis, but also about health and mortality more broadly. The use of music will I hope not only illuminate the experience, but also render it accessible in a particular way. I aim to perform *Delirium Part II* in additional public settings, educational events and conferences after the performance at Wits on 2 March (see p.124), building on the work already begun by *Part I*.²⁶

The music is to an extent a work in progress. *Part 1* altered after each performance, thanks to the collective responses of the original interviewees, the musicians performing it, and the audience hearing it. *Delirium Part II* has already begun to change through the research phases described below on p.36, a process I hope will continue based on future performance.

²⁶ See <https://victoriajhume.wordpress.com/some-thoughts-about-the-project-after-its-first-year/>

CHAPTER 2: RESEARCH METHODOLOGY

As I explain in the Introduction above, I have separated the two methodologies into Chapters 2 (narrative research) and 3 (music). It is worth re-stating that this is not to imply that research is not creative, or that music is not research. But without separating them it is difficult to track how they work together. To an extent it is also appropriate to separate them since, at least initially, the process of this study was sequential: research design and data gathering preceded both data analysis and composition (as I explain further in Chapter 3, the composition process was a form of data analysis in itself). This chapter will look at research design and data collection (2.1), as well as briefly investigating methods of data analysis (2.2).

2.1 RESEARCH DESIGN AND DATA COLLECTION

Permissions and ethics

Permission for the study was given by the CEO of WDGMC, Dr Sue Tager. Additional permission for observation in the ICU was given by Dr Gunter Schleicher. The Human Research Ethics Committee (Medical) at the University of the Witwatersrand approved the study in three stages, as per the organisational chart below (see Appendix 2: HREC approval certificates). The study was undertaken with the support of the Research Office at WDGMC and its director Dr June Fabian, as well as WDGMC's clinical psychologist, Dr Tina Sideris.

Site of study

The most important characteristic of WDGMC in terms of this study is that it is a privately-run teaching hospital. Its patients depend on Medical Aid to receive care. It is unusual, inasmuch as a small number of state patients are seen at WDGMC for dialysis and transplant care, but its resources are greater than the Gauteng state hospitals. Working in private care obviously imposes real and significant limitations on this study, and it is important to point out that the choice of WDGMC as a site was pragmatically rather than ideologically driven. Firstly, given the unusual nature of the study and my own lack of familiarity with its healthcare systems (I moved to South Africa from the United Kingdom shortly before beginning this study), the support of the research office (with whom I was already working

on a different musical project) was critical. Secondly, the research processes were simplified by WDGMC’s affiliation to Wits. And lastly, the challenges of tracing patients three months after a delirious episode (already considerable in private care) would likely have derailed this time-limited study in state care, where loss to follow-up (LTFU) is a substantial problem (see for example Mberi, Kuonza, Dube, Nattey, Manda, and Summers 2015). It should be noted, however, that as a tertiary centre specialising in transplant, WDGMC has an unusual patient population. Many patients have end-stage kidney and liver failure, and as such the incidence of encephalopathy (see Chapter 4.2) is atypically high for acute care. The significant presence of HE in this study is therefore a direct result of the choice of site.

Sources of data

The study is based on three primary sources of data:

- Interviews, with former inpatients, carers, and healthcare professionals at WDGMC
- Observation and audio recording (of ambient sound) in the hospital
- Focus groups or second interviews with the same people

Data collection was carried out in four phases, as below.

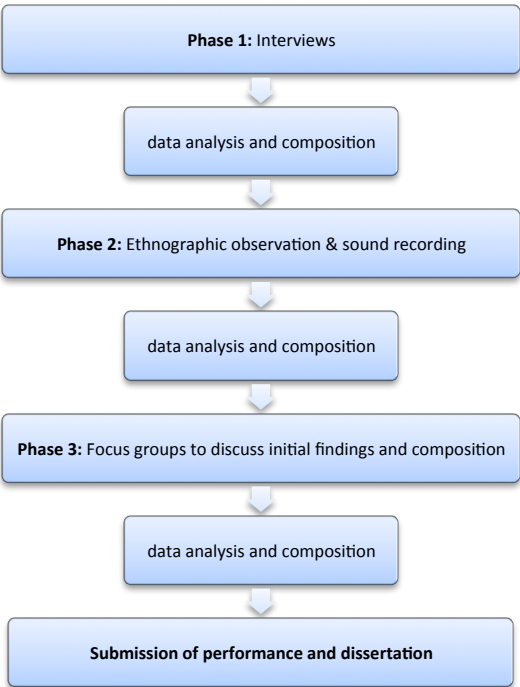


Table 1: Research phases

Selection and recruitment

For the purposes of this study, delirium was defined as experiences of hallucination, confusion, or atypical behaviour (see pp.8-10). Participants were sought from the following three groups:

- people who had received treatment at WDGMC and experienced periods of confusion and disorientation;
- primary carers who were aware of these experiences;
- medical and allied staff (henceforth referred to as healthcare professionals, or HCPs) who were aware of such experiences.

As per the DMS-5, patients with dementia or any other pre-existing neuro-cognitive disorder (APA 2013, 596) were excluded.

To recruit a participant during or immediately after an episode of delirium would be inappropriate in terms of both informed consent and the potential for further psychological disruption. The bulk of patients experiencing delirium in a hospital context are also extremely physically unwell. In the absence of formal guidelines, my previous experiences of interviewing people at different distances from their experience of delirium (ranging from three months to 16 years) suggested that leaving three months after a delirious episode would be a sensible minimum – a limitation agreed upon by my supervisors and by Dr Sideris. Given the associations between delirium and PTSD, however, further safeguards were put in place in the form of an offer of counselling from Dr Sideris at the expense of the study should any participant be adversely affected by the process.

I was able to approach healthcare professionals (HCPs) at WDGMC directly; patients and carers were initially contacted by a healthcare professional with a brief overview of the study. With Dr Sideris's support, I presented the project to the liver team in October 2015, returning to individuals within the team later to seek interviews and patient referrals.

Challenges in recruitment

Table 2, below, details the makeup of the study participants. I had initially hoped for a larger number of patients in relation to HCPs, but several factors militated against this. As we have seen, delirium can be a profoundly frightening experience. Those who experience it may fear for their sanity, and may experience things that cannot be externally verified (see p.26 above), or things about which they feel embarrassed or even ashamed (see pp.92-93 below). Clearly not everyone will find it easy to discuss these experiences, particularly not for a study that seeks to record them in a number of ways. Recruiting participants for *Part I* relied

heavily on the support of the Reading ICU Support Group – 11 of the 13 interviewees were involved in this group and, crucially, had already begun to talk about their delirious episodes at meetings – meaning that some of their fears about discussing these experiences had already been addressed. No such support group exists in South Africa.

Moreover, since I could not approach former patients directly, I relied on HCPs both to suggest potential participants and to make initial contact. An initial group of ten was identified by an HCP. Of these, six either could not be contacted or were not interested in taking part. Three who had initially expressed interest did not respond to messages (I would speculate that there is a difference between being asked by a clinician you know and trust and being telephoned by an unknown researcher), and the remaining person participated in the study. I then approached several other HCPs to widen the possible pool of referrals. It became quickly apparent, however, that leaving three months after an episode of delirium created two referral difficulties. Whilst almost every HCP could tell me who was delirious *at that moment*, it was not particularly easy for HCPs to think back three months to who had been delirious *then* (nor is delirium always noted in medical charts); and in a resource-pressured space it was problematically time-consuming for an HCP without personal investment in the study to make initial contact. Furthermore, some of the suggested participants were subject to *repeated* bouts of delirium (albeit of varying severity) – making it hard to find a three-month ‘safe space’ in which to interview them. This applied particularly in the case of hepatic encephalopathy in chronic liver disease (as opposed to deliriums in acute care of various kinds), with the result that I was unable to interview anyone who had experienced HE. (I make some suggestions in Chapter 6.1: Limitations for how this process could be improved in future studies.)

Research phases

Phase 1: Interviews

Initially aiming for between five and 15 participants, I ultimately interviewed 17 people, across 11 interviews. All interviews were audio recorded using a zoom recorder and smart-phone (interviews have since been deleted from both devices and are held securely on a laptop as per the approved ethics application).

The 17 interviewees consisted of

- Four who had experienced delirium (two interviewed individually, two with their primary carers) – referred to henceforth as P1-4.
- Three primary carers (interviewed with the patients above) – referred to as C1-3.
- Ten HCPs (three of these interviewed in a group) – referred to as S1-10.

Table 2, below, orders the interviews chronologically (all took place between 29 October 2015 and 18 June 2016).

Interview number	Staff/Patient/Carer	Male/female (respectively)	Clinical discipline	Length of interview (hr:min)
1	P1, C1	M, F	NA	01:05
2	P2, C2, C3	F, M, F	NA	01:46
3	S1, S2	F, F	Transplant coordinators	01:13
4	S3	F	Senior nurse	00:34
5	S4	M	Senior nurse	00:21
6	S5	F	Consultant physician	01:08
7	S6	F	Clinical psychologist	26:15 and 01:03
8	S7, S8, S9	F, F, F	Transplant coordinators	01:07
9	P3	M	NA	00:50
10	P4	M	NA	00:31
11	S10	F	Consultant physician	00:38

Table 2: Interviews conducted

Three of the people who had experienced delirium were patients of WDGMC. The fourth agreed independently to take part, and has since written to confirm they are happy to be included in this study. Five interviewees were male, 12 female. All interviewees were comfortable conversing in English, and no interpretation or translation was needed. Interviews ranged in length from 21 minutes to an hour and 46 minutes, and took place in a number of different settings, according to interviewees' convenience, but always in a private space to ensure confidentiality.

HCPs came from a wide variety of medical and allied disciplines; and all spoke about experiences both at WDGMC and at other hospitals in which they had previously worked, in the same or different roles. The transplant coordinators all had long experience of ICU nursing, for example, to which they referred frequently.

Consent, interview structure, and interview technique

The project was explained to all participants prior to interview. Written consent was taken at the start of each interview, using information sheets approved by Wits's Health Research Ethics Committee (Medical), which were left with participants. Separate consents were sought for the interview itself, for audio recording, and for the use of recordings in the musical composition. All participants were given an opportunity to listen to and check the musical work prior to the performance on 2 March, and to check the key findings of this dissertation (see Phase 3, overleaf).

The initial interviews began with a 'narrative', or open question to allow as much space as possible for broadening our existing understanding of the experience. This also relates to Charon's concept of "bearing witness" (see p.64). In the case of former patients and carers, the opening question was "Tell me about your time in hospital". For HCPs, it was "Have you experienced patients under your care being confused or hallucinating while they are in hospital? Tell me about that". To ensure some measure of comparability, however, a series of semi-structured prompts were used (see Appendix 4: Interview sheets) to assess how common the experience was, what might be causing it, how it is diagnosed, long- and short-term effects; and to provide an entry point for answers to the second part of my research question: how music might expand our insight into delirium.

Phase 2: Observation and ambient sound recording

Quinn Patton suggests that "there are limitations to what can be learned from what people say. To understand fully the complexities of many situations, direct participation in and observation of the phenomenon of interest may be the best research method" (2002, 21). Whilst direct participation in delirium was neither possible nor desirable, observing one of the spaces most likely to house it (ICU) was. This also offered an opportunity to record ambient sounds in the space – a component missing from *Part I*, which might allow for an extension of the compositional techniques.

The observation was a limited part of this study, conducted over short periods of time. Adhering closely to Jones and Somekh's model of "Unstructured observation" (2012, 133), it involved maps and notes, and followed "decisions [...] usually made in advance about the kind of things to be recorded, either on the basis of analysis of data already collected [...] or derived from the focus of the research" (ibid.). It was very much an etic approach, with no

attempt to become absorbed into the culture of the ICU, but while my alien-ness in the space and consequent discomfort on occasion may have provided a particular sense of the physical, social, and linguistic divisions in the ICU, this was by no means problematic for the study (see p.118 on decontextualisation).

Three sessions of observation were undertaken in the ICU of WDGMC. These took place on Friday 27 May (14:33-15:18); Monday 13 June (10:32-11:08); and Saturday 18 June (10:15-11:10). I took notes on the physical nature of the space, my own impressions of the atmosphere and events, and the impact of my presence, aiming for as much “depth and detail” (Quinn Patton 2002, 23) as possible, as well as for some acknowledgement of my own prejudices and history. These notes are included as Appendix 5. Recordings of ambient sound were taken at the same times with a smart-phone and a Zoom recorder.

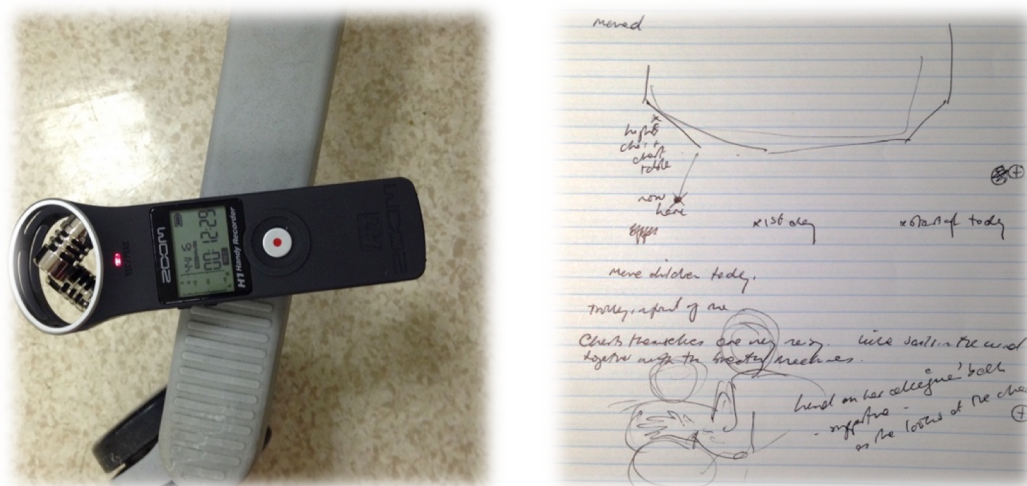


Figure 3: Zoom recorder on an unused drip stand

Figure 4: Some of my observation notes

Phase 3: Focus groups, second interviews and general follow-ups

After the initial data had been analysed, and music composed, I contacted interviewees again to ask them for a second interview, or to attend a focus group at WDGMC.

All interviewees were sent a short summary of key findings (Appendix 3), and a recorded draft of the composition (available at <https://soundcloud.com/victoriahume/delirium-full-draft-for-sharing/s-VXqNN>). Two small focus groups of three HCPs each were held at WDGMC, as well as a one-to-one interview with one HCP. These conversations were focused on the draft composition and key findings.

Again, the process was explained and written consent taken at the start of each conversation, using information sheets approved by Wits HREC, which were left with participants. Again, separate consents were sought for the conversation itself, recording, and the use of recordings in the musical composition.

It was not possible to meet all the interviewees again prior to the formal end of this study in the six weeks set aside for this purpose. One expressed no interest in meeting again but was entirely happy for his testimony to be used; the remainder were keen to meet, but did not have time (see Chapter 6.1: Limitations). With those who could not meet, I discussed the work briefly by email or telephone, to ensure they were happy for their voice to appear publicly in performance. All interviewees confirmed this prior to the 2 March performance, and further conversations are planned with three of the four after the completion of this dissertation.

One of the interviewees had sadly died shortly after her initial interview. Additional consent to include her voice and words in this study was confirmed by her immediate family and colleagues.

Focus group 1: S2, S6, S10 (Dr Harris also attended as supervisor)
Focus group 2: S3, S7, S8
Second interview: S9
Checks for consent and/or brief comments: S1, S4, S5, P1-4, C1-3

2.2 DATA ANALYSIS

Audio-recordings of interviews and focus groups were transcribed, and the observation notes typed up, both processes central to the analysis in allowing for a close 're-reading' of each text, and also initiating the composition (see Chapter 4 below).

Data analysis was undertaken using an "exploratory", data-driven approach – as opposed to "confirmatory" or "hypothesis-driven" (Guest, McQueen, and Namey 2012, 7-8; also Schreier 2014, 176). Although I have investigated delirium in hospital before, I made every attempt to assess these texts first in relation to each other and their circumstance, before allowing comparison to previous work. It was sometimes impossible to ignore this entirely, particularly in the case of striking similarities in hallucination (see Appendix 7), but the themes discussed below derive first and foremost from interviews undertaken for this study.

Both thematic and narrative analyses were employed. Shaw (2011, n.p.) summarises the difference as “what is being said” (thematic) – themes consistent *across* the texts – versus “*how* it has been said” (narrative) – treating each text as a whole.

For the former, the data was coded using qualitative content analysis (see Schreier 2014). A pilot analysis of the first interview suggested an initial ‘coding frame’ (see for example Schreier 2014, 174), which was adapted during the remainder of analysis into 20 headings. A more quantitative approach was used to assess the types of delirium named by interviewees, the various characteristics associated with these types, and the risk factors mentioned by interviewees (leading to spreadsheets which form the bases of Chapter 4.2, Defining Delirium, and Table 3: Causes/Risk factors, on p.67 below). The terminology used by HCPs to refer to delirium has been assessed in some detail in discussing its definition (Chapter 4.2), and the words used to describe the emotional tenor of delirium have proved important in distinguishing HE from psychotic deliriums (again see 4.2 below) and understanding the severity of its impact.

Once all the interviews had been transcribed and the process of composition begun, the main thematic analysis reduced the initial coding frame to five key findings (see Appendix 3, and Schreier 2014, 174 for a summary of the steps of qualitative content analysis). The data from all 20 headings was categorised amongst the following: Defining Delirium; Violence, Loss, and Humanity (imagined as a thematic group); and Risk Factors. The final period of analysis, after both the follow-up discussions with participants in Phase 3, and the first performance and responses, confirmed the validity of the three central themes, Violence, Loss and Humanity, and suggested that definition and risk factors might be the subjects which would benefit from further, and different research (see Chapter 6: Conclusion, as well as Appendix 8 for a full list of headings).

Narrative analysis provided a means of moving beyond the ‘categorising’ approach of thematic analysis described above, and offering a more “holistic” approach to the texts (see Maxwell and Chmeil 2014, 27). Willing (2014, 147) suggests that there are two main approaches to narrative analysis: that which “seeks to advance the researcher’s understanding of the relationship between the stories that are told and the storytellers’ subjective experience” and that which has “a more discourse analytic flavour”, focused more on narrative *strategies*. The analysis undertaken for this study is far closer to the former strand, driven by what Willing calls “a phenomenological curiosity” (ibid.). In a summary of the tensions between different approaches to narrative research, Smith and Sparkes suggest

that Arthur W. Frank (see pp.20-22) exemplifies and expounds a particular sub-type of narrative analysis, one which acknowledges that “when people tell stories, they use analytic techniques to interpret their worlds”, meaning that the stories told by interviewees “are, thus, themselves analytical” (Smith and Sparkes 2006, 185). For Smith and Sparkes, Frank is “a storyteller who performs narrative analysis and thinks with stories” (ibid.). This is the closest I can thus far come to a definition of both my own *process* of narrative analysis, and the final *form* it takes in the music of *Part II*. As with Smith and Sparkes’ assessment of Frank’s approach, “the goal and responsibility is to evoke and bear witness to a situation [...] enticing people to think and feel *with* the story being told as opposed to thinking *about* it” (idem., 185).

Indeed the narrative analysis takes its form most obviously in the musical composition, which gives space to participants’ stories as they are told (see p.62), and which rests as much on the *delivery* as the words themselves. The “grain” of the voice and all it contains (Barthes 1997, 118) are paramount in the audio clips, and have dictated the course of the compositional process.

CHAPTER 3: MUSICAL METHODOLOGY

This chapter describes the process of composing *Delirium Part II*. 3.1 looks at the structure, staging, and sounds used, 3.2 at semantics and themes in the finished piece, and 3.3 at the process of and influences in the composition.

For ease of reference, *Delirium Part II* (2017) can be found here:

<http://victoriahume.com/delirium> (2017) as well as on the enclosed CD – both as a single live recording of the whole piece from the 2 March performance, and as separate studio recordings of each smaller section. Where I indicate music below, I use titles and timecodes referring to the studio recordings.

It should be noted that whilst the performance is in quadrophonic sound (see below), the recordings are in stereo, which inevitably alters the spatial aspects of the music.

3.1 STRUCTURE AND PERFORMANCE

The full piece lasts for just over 40 minutes and is structured as follows:

I Prologue

II Violence & unreality

- i. Cycle of violence
- ii. Expressed
- iii. Internalised (On patrol)
- iv. Sleepless
- v. Theatre
- vi. Struggle
- vii. Imposed (Restraint)

III Interlude

- i. Naked
- ii. Pleasantly confused

IV Loss & humanity

- iii. HE
- iv. Psychosis
- v. Taken to Tampa
- vi. ICU (Restitution)
- vii. Brokenness
- viii. Gloria and the Water

The overall structure consists of two movements: “Violence & unreality” and “Loss & humanity”, with a *Prologue* and *Interlude*. The intention is in part to refer to (if not actually map) Frank’s three narratives: Quest, Chaos, and Restitution.

The *Prologue* consists of an excerpt taken from the same random section in time in each of the Phase 1 interviews. Each of the following movements then consists of a series of separate but interlocking smaller sections. These were not initially meant to be clearly distinguishable to the audience, but rather to act as guides for the performers. The focus groups in Phase 3 suggest, however, that dividing *Part II* into these smaller pieces online may make the piece more accessible (see Chapter 5.3, Initial responses).

Instrumentation and staging

The piece is performed by three musicians: two swap between piano and keyboard, and trigger audio files on a laptop; a third plays viola. There is also a short section with live vocals. The sound is mixed in four channels and sent to four speakers, which surround the audience (see Fig. 5 overleaf). For the first performance on 2 March, I played piano and keyboard, sang, and triggered audio files, with Dr Chris Letcher, also on piano and keyboard, and Waldo Alexander on viola.

Although it is not necessarily part of composition, performing one’s own work is entirely normal for a singer-songwriter; and it also follows in the tradition of composers like Reich and Glass in the late 60s and 70s, who built and toured with their own ensembles, partly because of the struggle to find performance opportunities for their then experimental music (see for example Ross 2008). Many contemporary classical composers have built on this trend: to name a very few, South African Kevin Volans, the US’s Nico Muhly (a protégé of Glass, and a member of the wider “Bang on a Can” group of composer-performers) and from the UK, Thomas Adès and, even more recently, Anna Meredith and Johnny Greenwood.

Vesey writes about performance that:

Pleasure resides in the voice’s interaction with instrumentation, composition, and production aesthetics. It’s not just about the singer, but the singer’s voice as one interactive element in a larger compositional or performative space. (Vesey 2014, n.p.)

Although she is speaking from the perspective of pop and song, performance in this project, too, is part of finding equilibrium between research participant, music, and composer. The

relationship between the performers and interviewees is particularly important. My experience suggests that the intimacy of writing and then performing alongside other people's words can lead to emotionally charged relationships with research participants, even if they are short-lived.²⁷ In *Delirium Part II* the instrumentation is frequently allied with the patterns and tonality of voices, and the musicians must wait for verbal cues from the interviews to know when to play. In some cases they must also play responsively to the voice clips and each other (for example in "Brokenness", which is played freely, changing slightly each time it is performed). Each musician is subject to the interviewees' words, which does something quite important to the power dynamic, and being part of this as a composer (rather than standing to one side observing) is, for me, central to the process.

This desire to affect an involved balance between musician and research participant is also reflected in staging. At one point I considered hiding the musicians to make the experience more strange and immersive, but in fact it is vital that we are visible. Part of breaching the territorial divisions between medicine and humanities (p.22) is to expose the workings of the piece: watching us swap instruments, for example, or trigger sounds. This opens up the process rather than protecting any implicitly mysterious or special skills.²⁸ Equally, however, the musicians should be unobtrusive (ideally without an elevated stage), and the sound should be mixed to surround the audience, in such a way as to balance the live instruments with the voices of the participants and the recorded ambient sounds.

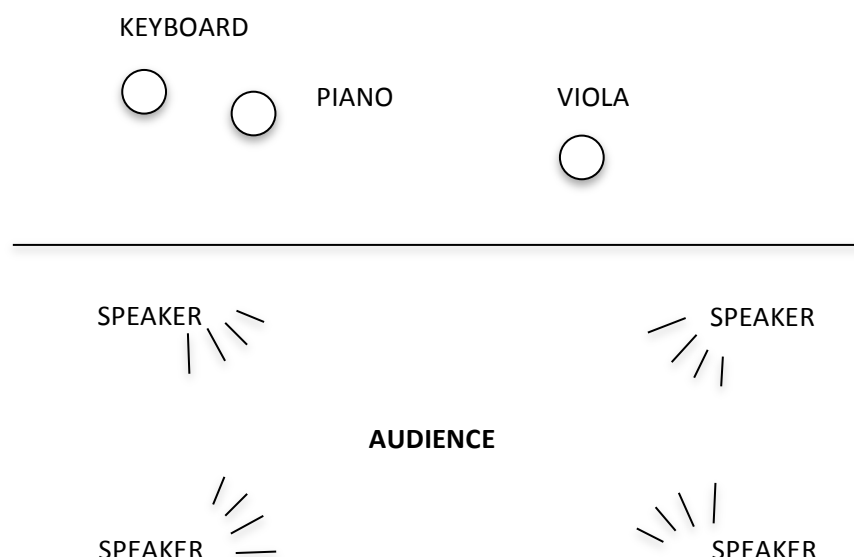


Figure 5: Staging for Part II

²⁷ I am still in touch with, and co-present with people involved in *Part I* and *The Isle* (see pp.54-55).

²⁸ One of my inspirations here is the Paper Cinema, where both animators and musicians are visible at the same time as the film they are projecting. See for example: <https://vimeo.com/68071023>.

Sounds

Along with the live instruments (piano, viola, voice), the keyboard uses various sampled instruments: a glockenspiel and several synthesisers, some of which I have designed to sound similar to the sounds recorded in the ICU (see “ICU”), and one of which is made of my own voice, with the attack removed and a fade added to take away the immediacy of the vocal and blend it with other instruments, rather than pushing it to the front.

In addition, sampled sounds from both interviews and recordings in the hospital are played from the laptop. The interview samples work in two ways in the piece. Firstly, as straightforward documentation of experience: “Naked”, for example, is simply an interviewee telling an anecdote. Interviewees’ voices are often left untreated (except by EQ to clarify them), to let them sit in the music almost as they might in a documentary. But in other places they are used to create particular sonic effects. The *Prologue* for example is intended to give an impression of qualitative research: of multiple narratives, from which certain phrases and words emerge from certain speakers, before sinking again into the general sea of information. Voices are also moved around in space (around the speakers, and further back or forward with reverb) to mimic or create disorientation, and suggest sedation or hypervigilance (see Chapter 4 below).

Some of the ambient hospital sounds also undergo manipulation. All of the rhythms in the piece are generated from ambient sound clips. In some cases background noises from interviews make up these rhythms, as in “Imposed (Restraint)” [from 01:49]. In others, I have used noises from the ICU – for example the percussive slaps in “Struggle” [from 00:23]. In my notes from the day of this recording, I register this sound as a “v. odd slapping/clapping noise next door” (see Appendix 5). I later discover that this is the sound of a physio clearing mucus from a patient’s lungs, a procedure appropriately enough known as “chest percussion”.

Audio clips are also used to create atmosphere. The footsteps and background speech at the opening of “Struggle”, for example, are intended to underpin the paranoia expressed in the interview clip. Again these footsteps are something I noted initially in the observation, when I register a senior nurse wearing “Smart low heels. Noisier than others’ shoes”.

Non-hospital samples have also been added as additional instrumentation. In some cases these have been chosen simply for their sonic qualities (chair springs and a music stand in “HE”, for example – sounds which are played both forwards and backwards [as in 01:36-

01:45]). And in other cases they relate more directly to the text. The same recording of a food blender, for example, is treated with different EQ and reverb to represent both the “blender” metaphor used by P1 to describe the mixture of reality and “dreamworld” in which he finds himself (“Psychosis” [05:10-06:00]) and a recurring image of flight – including the officers in the air force, and the flight to Tampa (in “Taken to Tampa” [00:50-01:00]).

3.2 SEMANTICS AND THEMES

Individual sections of *Part II* work according to differing semantic rules. “Cycle of violence”, for example, is built around three chords:

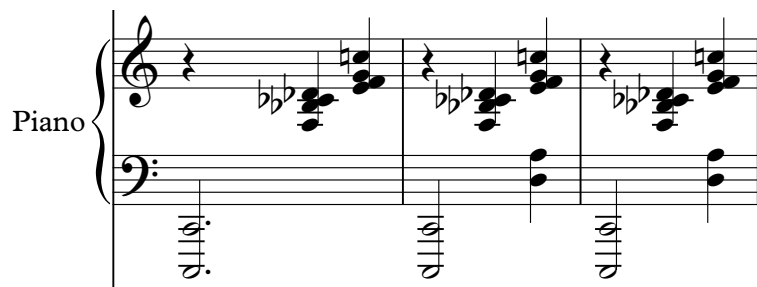


Figure 6: Bars 27-29 of “Cycle of violence”

This very simple structure is intended to represent the cycle of violence discussed from p.80 below. The C octave represents violence imposed; the Bbm-9, violence internalised; the diatonic cluster with a D in the bass, violence expressed. These are purely subjective chord choices, based on nothing more than my personal response to the way they sound in relation to the concepts – I make no suggestion that a Bbm-9 somehow *means* internalised violence in any fixed way, but for me they provide a useful way of structuring a discussion within the music. Thus the audio quotes are positioned with the chords. For example, where P4 says, “I was being tied up”, a C accompanies him on the viola [05:05-05:11]; when he says, “I was getting out of hand”, the D chord is added [at 05:10]. Where C1 talks about restraint, we hear low Cs on the piano again [05:22-05:30]. The Bbm-9 then carries over into to the later “Internalised/On patrol” as an ostinato, maintaining its ‘meaning’, with the C-natural of ‘imposed’ violence added in:

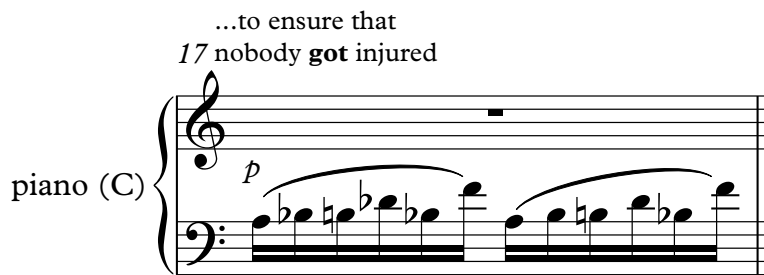


Figure 7: Bbm-9 Ostinato in "Internalised/On patrol"

Other relationships between music and text are scattered across the piece. *Part II* shifts, for example, between pronounced, exact rhythms ("Imposed" or "internalised") and more spacious sections without a rhythmic anchor ("Brokenness"). This is a response to the two opposing senses of time in the ICU, discussed on pp.89-90 below. Two pieces, moreover, are mapped closely onto guidance derived from the interviews. Firstly, "Psychosis":

It started off slow and it builds up and it builds up and it builds up and it builds up and it builds up; and then there's this tremendous explosion-crescendo, that's overwhelming; and then I guess ... it can subside, [...] starting out slowly, softly, a little bit different, and then [...] you have all these extraneous beats and it's somewhat arrhythmic, and it builds up, and it's more arrhythmia, and it builds up in a crescendo of rhythm and arrhythmia [...] almost to the point of noise. (P1)

P1 and C1 go on to describe heavy sedation, and then "peace afterwards". P1 also says that "it's almost like you toss [...] all these different bits of information [into a] blender and it's all getting mixed up and none of it makes sense but you're in the blender"; and that "there were brief moments of reality coming into my perspective". I translated this collection of descriptions – "the crescendo of rhythm and arrhythmia", the blender, and the moments of reality, the final peace – first into a drawing, and then into "Psychosis".

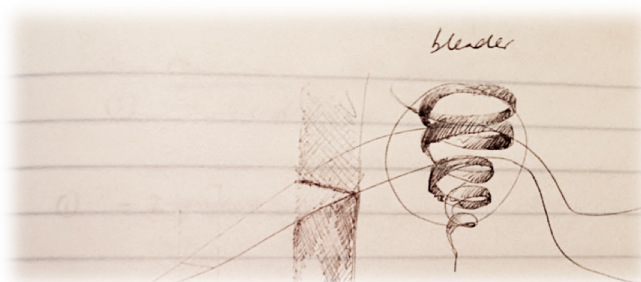


Figure 8: Sketch for "Psychosis"

A second map is given by S5 to describe HE:

Their delirium is episodic; it's not like a constant thing. They will become normal for a certain period of time. And then out of the blue they become so delirious. [...] So we have got *episodes* of delirium, it's not a constant thing. [...] Without treatment it does get worse. [...] You'll see that they – episodes now become more frequent. It starts gradually and then it builds up. (S4)

This too began as a drawing (Fig. 10 below), and eventually mutated into a longer ostinato (Fig. 11, overleaf), disrupted with patches of sound:²⁹

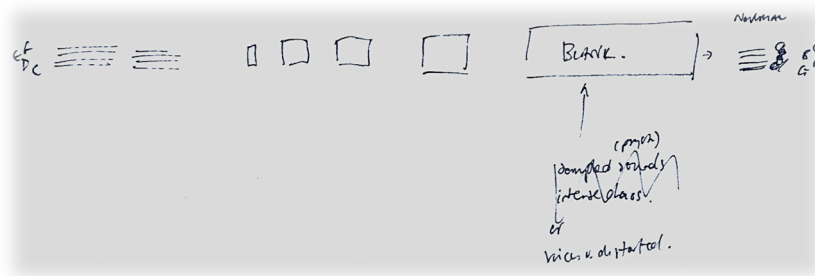


Figure 9: Sketch for “HE”

²⁹ Early in the process of this study I showed some sketches to S6, who confirmed that they registered somewhat with her experience: “I imagine sort of ploddy ploddy music with the encephalopathic patients, and quite high-pitched quite persecutory music with the psychotics. That’s what it feels like”. This too helped refine the music.

$\text{♩} = 75$

...unfortunately they're not.

p very freely

Piano

6

Pno.

9

Pno.

12

Pno.

Figure 10: Bars 1-15 of “HE” – including the first occurrence of the ostinato

Cycles and water

Two final concepts that hold *Part II* together are cycles, and water. As I have explained above, the first movement begins with a “Cycle of violence”. “HE”, too, is made up of a cycling narrative. Further small ostinatos – again often disrupted – appear in “Struggle”, “Theatre”, “Imposed”, “Pleasantly confused”, and finally “Gloria and the Water”.

The concept of the cycle relates back to the issue of time and memory, discussed in the literature review on pp.23-27 and below in Chapter 4. It is a form that sits at odds with the idea of linear progression, and offers the opportunity of writing and re-writing a story.

Water is of course involved with cycles, tides, birth and death, and has mythically transformative properties – the “sea change” of *The Tempest*, the spiritual rebirth of baptism. There are watery associations too with crescendos, life force, and collapse, which chime with the ‘shape’ of the psychotic episode described above.³⁰ Arthur Frank says of Chaos narratives that they are “sucked into the undertow of illness and the disasters that attend it” (2013, 115). Delirium can also be seen as a kind of submergence, a loss of contact with the surface, and a series of increasingly distorted images seen from beneath it. There is powerlessness in this submergence – a destruction of direction. Thus in “Sleepless” and “HE” the voices move in and out of heavy reverb – referencing submergence and movement away from a discernable place.

In the second part of “Gloria and the Water”, however, water has merciful, reconstitutive properties [01:23-04:14]. This last section is a microcosm of the whole of *Delirium Part II* (and moves from Chaos to Restitution). In this is a deliberate implication that submergence into psychotic delirium may itself have healing properties – that these alternate narratives may be a thread through chaos in much the same way as the creative arts (see p.30). Frank speaks of illness as “a call for stories” (2013, 53-73). It may not be too much of an imaginative leap to see delirium as one answer to this call.³¹

³⁰ Interviews for *Part I* suggested that sea journeys were a recurrent theme in delirious narratives. Sara Evans says “we certainly see some more commonly than we see others – like for instance the being-at-sea one [...] I’m assuming because people are on those moving beds very often, the biowave mattresses, and if you’re a bit thirsty or you’ve not had your mouth cleaned for a little while, so...”.

³¹ The Hearing the Voice movement, too, suggests that aural hallucination may be a healing means of reporting traumatic experiences.

3.3 CONTEXT: PREVIOUS AND CONCURRENT COMPOSITIONS

This section takes the form of a brief auto-ethnography. I will refer primarily to four previous musical projects, which can be accessed as follows:

1. *The Isle Is Full of Noises* (2016): <http://hearingvoicesdu.org/the-isle-is-full-of-noises/>
2. "How to organise delirium" (2015): <https://soundcloud.com/victoriahume/how-to-organize-delirium/s-3JZ49>
3. *Delirium Part I* (2013): <https://victoriahume.bandcamp.com/album/delirium>
4. "Mirror" (2012): <https://soundcloud.com/victoriahume/02-mirror>

I mention above (p.6, p.30) that my musical background is largely in songwriting. My formal musical education ended at the age of 17, and my development as a composer has until this point been through performance and recording (as well as commissioning work from other musicians during a long tenure as a hospital arts manager in the UK).

Delirium Part I represented a departure from the relatively conventional albums I had been producing up to that point.³² As I explain in the Introduction (p.5), I recognised something in the lyricism of delirium that led me to design a songwriting project. This was based on a series of 13 interviews, two with senior ICU nursing staff, and the remainder with people who had experienced delirium in hospital. As I transcribed the interviews at home I found myself caught by particular words or phrases and composing along with them. I had not expected to use actual clips from the audio (and had never done so before, although I had experimented with 'found sound' on previous albums),³³ but in the end this seemed the most natural thing to do – and the final piece blends these clips with my own singing; the lyrics often riffing off interviewees' own statements. Thus in *Part I*'s "Introduction and Dream Song" [04:27-05:14], the audio clips and my lyrics (italicised) interweave as follows:

...I can't go back into a dream, but this I can. If I had a dream last night, say, I would try and think "what was that about?" and I could not remember. But this sticks.

This sticks in me, like ink in the veins

My mind a beam that patterns and flames

They are like dreams, but the power – the power of them...

They are like dreams

...and the impact that they make on me

But sharp, like knives...

...was very very strong.

³² Most of this work can be found via victoriahume.com

³³ See for example "That was hard" from 2009's *Limbs and Digits* album, available at <https://victoriahume.bandcamp.com/track/that-was-hard>.

Delirium Part I opened up an entirely new world of composition for me – giving me access to new compositional techniques, reaching new audiences, bringing together the parallel lives I had lived as an arts manager and a songwriter, and hinting at the potential for composition and performance as research methodology.

More recently, *The Isle Is Full of Noises* (henceforth *The Isle*) has built on what *Part I* had begun. *The Isle* was commissioned by Hearing the Voice at Durham University for their 2016-17 exhibition *Hearing Voices: Suffering, Inspiration and the Everyday*, and is an 18-minute animation with music and sound, based on a workshop with five people who hear voices. Like *Part I* it includes audio clips from the workshop, and some song; but the songs have become shorter and more fragmentary, and *The Isle* includes far more environmental and found sound. The shift away from song has continued with *Delirium Part II*, which includes only a fragment of a song towards the end (“Taken to Tampa”). While I have continued to use my voice in *Part II*, it appears largely in the form of sampled notes in the instrumental texture (described on p.48 above).

As well as *The Isle*, during the masters I worked on several other compositional projects, including three short films relating to health,³⁴ and a two-minute piece written for celebrations of Pierre Boulez’s 90th birthday in Johannesburg: “How to organise delirium”. This last proved a useful bridge between *Delirium Part I* and *Part II*.

Researching Boulez, I discovered a relationship with delirium through the dramatist and writer Antonin Artaud. Artaud, and in particular his “Théâtre de cruauté”, exerted significant influence on Boulez, who felt that he had “showed us [...] how to organize delirium” (Infanti, n.d., n.p.). Developing the interview method I had used in *Part I*, I combined clips from *Part I* with a 1946 recording of Artaud’s “Aliénation et Magie Noire” (alienation and black magic), a diatribe against the electro-shock and insulin shock therapy to which he had been subjected as a psychiatric patient:

et la médecine moderne, complice en cela
de la plus sinistre et crapuleuse magie, passe
ces morts à l'électrochoc ou à
l'insulinothérapie.

and modern medicine, complicit in
this in the most sinister and
villainous magic, passes its dead into
electroshock or insulin therapy.

³⁴ See <https://victoriahume.com/2015/12/08/other-musical-projects/>.

The sung words in “How to organize delirium” are those of René Char, whose 1934 poem “Le marteau sans maître” (The hammer without a master) is the basis for Boulez’s work of the same name (1955). Char’s poem is situated firmly in the surrealist tradition; again finding a helpful resonance with delirium, I reused [from 01:13] its third part, “Bel édifice et les pressentiments”, in a very different style from that of Boulez – one closer to Satie:

J'écoute marcher dans mes jambes	I hear marching in my legs
La mer morte vagues par dessus tête	The dead sea waves overhead
Enfant la jetée promenade sauvage	Child the wild seaside pier
Homme l'illusion imitée	Man the imitated illusion
Des yeux purs dans les bois	Pure eyes in the woods
Cherchent en pleurant la tête habitable.	Are searching in tears for a habitable head.

Char talks about mirrors and doubles (the imitated illusion) – as well as a kind of anxious twitching of the legs reminiscent of the tactile irritability S3 describes below (on p.71) in delirious patients. Mostly, however, the phrase “Cherchent en pleurant la tête habitable” seemed to sum up the distress of psychosis.

Technically, the piece opened a number of doors for *Part II*. Limitations of time and personnel meant that I was forced to use my own voice as a multi-tracked recording, which has developed into the use of my voice as a synth in *Part II*. The piece was also the first time I used the Reichian technique (see p.62) of hinging the melody and rhythm precisely on spoken word (“How to organise delirium” [00:30-00:33]):

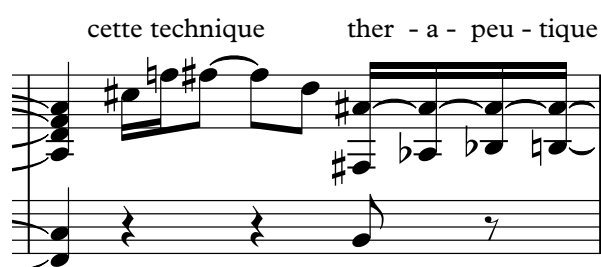


Figure 11: Bar 7 of “How to organise delirium”

In *Part II*, I pursue this technique in “Taken to Tampa”:

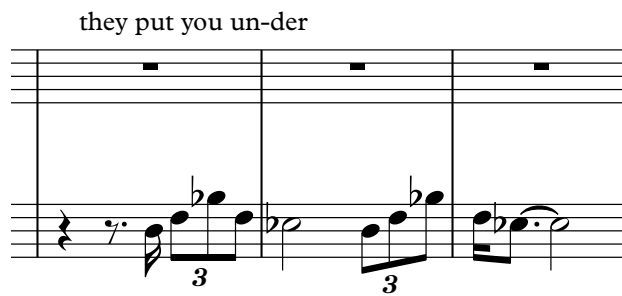


Figure 12: Bars 6-9 of “Taken to Tampa” [00:09-00:11]

In the context of the cabaret, surrealist style of “How to organise delirium”, however, the mimicry has a very particular, de-realising impact on the text. The relationship between spoken word and audio in *Part II* has a different, more integrative quality. In other places it is also more subtle than in “How to organise”. “HE”, for example, is written around a G minor chord based on a (approximately) Bb–G descent in S4’s voice when he says “out of the blue” [01:05], and undermined by the G major chord of the telephone which interrupts us in S4’s office during the interview, and which is used in interrupting ‘episodes’ in the piece [e.g. 00:26-00:30], via an octaver and various other effects.

Part I and *The Isle* both developed the idea of working architecturally across a larger space. In the latter, I used a storyboard to structure the work, which proved a useful tool in *Part II* as well. And there are also elements of both that I have discarded in this new piece. *Part I* for example has a very straightforward “Introduction”.³⁵ The first four minutes are spoken word only – as the interviewees introduce the concept of delirium. Although this has a useful function in live performances, it is also unmusical (coming as it does before we have started to hear ‘musically’) and off-putting to a first time listener hoping for music. The *Prologue* to *Part II* serves a different function (see p.48, above) and draws attention immediately to the sonic qualities of the interviews.

The principal difference between this piece and the bulk of my other work, however, is in my voice, or the lack of it. Although I was initially confident that this too would become a song-based project, in the final few weeks the lyrical sections seemed unnecessary to the story and have fallen away. This has had a substantial impact on the sound palette, which is, in most of my music, dominated by my voice. Responses to *Part I* and *The Isle* suggest that

³⁵ <https://victoriahume.bandcamp.com/track/introduction-dream-song>

song/lyrics have been important to perceptions of the piece: at a WiSER performance, for example,³⁶ it was suggested they helped “translate” the experience. It will be interesting to compare responses to this new work as we continue to perform it.

One of the elements I have deliberately maintained between *Part I*, *The Isle*, and *Part II*, however, is humour. This has featured fairly rarely in my other musical work, but has become essential to working in narrative medicine. As I discuss further on p.95, humour is a critical means of reasserting control in health. It is used frequently by interviewees describing both delirium and (in the case of *The Isle*) voice-hearing, sometimes as a way to acknowledge that, with the listener, the person who has experienced altered states realises that “it might sound mad. It sounds mad, to me” (*The Isle*), and sometimes as a way of coping with the discomforting gravity of the situation. Mordent humour is a known coping mechanism for HCPs (see for example Ghaffari, Dehghan-Nayeri, and Shali 2015); and indeed in Phase 3, S6 at one point laughs during a particularly harrowing story and explains that “I’m laughing because it’s a comfort”. Within the music, humour asserts the agency of the participants, and reflects the way in which they choose to tell their own stories.

3.4 PROCESS

I began with the same basic approach to audio-recorded narratives used in *Part I* and *The Isle*: as I transcribe interviews or group discussions I highlight areas that strike me in the text, or start writing music around them immediately, breaking off from transcription before the idea deserts me. I found initially that these were *not* the same sections as those I was highlighting for more conventional thematic and narrative analyses (see Chapter 4 below). As the project has progressed, however, the two have largely – and surprisingly – coalesced. The moments that initially struck me *musically* have ended up defining the overarching themes of both the music and the dissertation: violence, loss, and humanity.

One of the first phrases I wrote, for example, was “Taken to Tampa” [00:34-00:40]. It is an obvious musical response to the sound of P1’s voice as he describes a hallucination of being flown across a bay in Florida. For a long time I felt this might be (to use a less-than-academic expression) too *cute* for this project. But the combination of flight, the fear that his wife might not find him, and the American songbook-ness of the expression “taken to Tampa” seem to work in the wider context of the piece. It is a fairly straightforward, immediate

³⁶ See Discography (p.127) for details.

piece of song breaking through more opaque impressions of a condition, and relating strongly to the theme of 'humanity'.

Not all my immediate impressions have made it into the final piece, however. One of the advantages of this cross-disciplinary project was to be forced to step back from *both* methodologies and processes. Thus while I was initially fascinated by the idea of 'inappropriate' behaviour and what this meant in terms of the moral universe of the hospital, and started writing somewhat moralistic pieces about restraint and etiquette, the process of analysis has forced me to re-evaluate this idea, and to set the restraint of patients in the context of their own expressions of violence (see "Cycle of violence", "Expressed", and "Imposed (Restraint)", as well as Chapter 4.3 for more on the cycle of violence).

Moreover the method described above makes for a chaotic and time-consuming process of moving back and forth between audio, transcription, and composition. Here I have made some progress as a composer: I had felt initially that these first impressions of an interview were the one chance I would have to write something worthwhile – and that these intuitive points of contact could only be made the first time around. I have instead found that although some of these first ideas remain vital to the composition, the process of written analysis for this dissertation has been equally important for developing both the structure, and therefore much of the content of the piece.

3.4 MUSICAL INFLUENCE

I can draw a clear line back from this piece via *The Isle* and *Part I* to earlier music that relates to kinds of ‘madness’. “Mirror”, from an album released in 2012, looks at just the kind of dissociation and fragmentation that fills delirium. Its chord structures, as in much of my music, owe much to the French composers of the early twentieth century, Debussy and Ravel in particular:



Figure 13: Bars 9-16 of “Mirror”

Bars 17-20 of "Theatre" (*Part II*) show the influence of the same composers:

The musical score is divided into two systems, each covering two bars (17-18 and 19-20). The instruments are piano, glock, and grungy organ.

- Bar 17:**
 - piano:** Treble clef, whole note chord (F#4, C#5). Bass clef, whole note chord (F#2, C#3).
 - glock:** Treble clef, eighth-note triplet pattern (F#4, G#4, A#4) repeated four times.
 - grungy organ:** Treble clef, whole note chord (F#4, C#5). Bass clef, whole note chord (F#2, C#3).
- Bar 18:**
 - piano:** Treble clef, whole note chord (F#4, C#5). Bass clef, whole note chord (F#2, C#3).
 - viola:** Treble clef, whole note chord (F#4, C#5). Bass clef, whole note chord (F#2, C#3).
 - glock:** Treble clef, eighth-note triplet pattern (F#4, G#4, A#4) repeated four times.
 - grungy organ:** Treble clef, whole note chord (F#4, C#5). Bass clef, whole note chord (F#2, C#3).
- Bar 19:**
 - piano:** Treble clef, eighth-note triplet pattern (F#4, G#4, A#4) repeated four times. Bass clef, eighth-note triplet pattern (F#2, G#2, A#2) repeated four times.
 - viola:** Treble clef, whole note chord (F#4, C#5). Bass clef, whole note chord (F#2, C#3).
 - glock:** Treble clef, eighth-note triplet pattern (F#4, G#4, A#4) repeated four times.
 - grungy organ:** Treble clef, whole note chord (F#4, C#5). Bass clef, whole note chord (F#2, C#3).
- Bar 20:**
 - piano:** Treble clef, whole note chord (F#4, C#5). Bass clef, whole note chord (F#2, C#3).
 - viola:** Treble clef, whole note chord (F#4, C#5). Bass clef, whole note chord (F#2, C#3).
 - glock:** Treble clef, eighth-note triplet pattern (F#4, G#4, A#4) repeated four times.
 - grungy organ:** Treble clef, whole note chord (F#4, C#5). Bass clef, whole note chord (F#2, C#3).

Figure 14: Bars 17-20 of "Theatre"

What drew me to these composers in the first place may be the same impulse that draws me to delirium as a topic, namely a kind of opening up of the imagination, and a liminality – in the composers’ case abandoning the safety-net of functional tonality (what Debussy called the “empty phantoms” of tonic and dominant, quoted in Ross 2008, 41) for more modal spaces. Along with many of his contemporaries working in radically different styles, Debussy’s move into modality pushed him to what Ross calls the “threshold of so-called atonality” (Ross 2007, 41). This freer use of tone suggests for me the dance in delirium between reality/structure and surreality/chaos; perhaps best exemplified in *Part II* by “Psychosis”, “HE”, or “Theatre”.

Another obvious reference point is Steve Reich. The quotation from “Taken to Tampa” on p.57 above (Fig. 12) bears strong resemblance to Reich’s combination of interview and music in *WTC 9/11* (2010) and *Different Trains* (1988). I make use of voices in quite different ways to Reich; where his are almost always fragmentary, pre-recorded, or ‘found’, the voices in *Part II* (as well as *Part I* and *The Isle*) derive from my own conversations with interviewees, which are given extended space in the piece, creating a different balance between composer and participant.

There are also aspects of Reich’s work that I initially found discomforting – feeling sometimes as if “the dangers of aestheticizing suffering” (Cizmic 2012, 3; see also p.32 above) had been realised in the sheer ‘prettiness’ of some of his music – but I have found myself going back and back to *WTC 9/11* in particular, and note that (for me) its accessibility is part of what ultimately makes it successful. The question of pleasure remains complicated, however. To me, *WTC 9/11* is undeniably pleasurable. It is also scary and horrifying at times, but without the uncompromising nihilism I find in, say, Penderecki’s *Threnody for the Victims of Hiroshima* (1960). But despite Cizmic’s warning, I would contend that the union of understanding Vesey discusses (see p.46) – depends on this pleasure. This is not pleasure as synonymous with entertainment, but as something more abstract, which might create an empathic space.

Related to the question of accessibility is that of melody. Although I have moved away from song in terms of the use of voice, *Part II* nevertheless has song-like qualities, and much of it depends on melody (see for example “Theatre”, from 01:30). Western music arguably made the break from tone and tune as early as 1908 in Schoenberg’s Second String Quartet (see for example Ross 2008, 50). So is melody – indeed all the approximately surrealist influence I discuss above – now innately conservative? Here I would refer back to the discussion of

surrealism in the Literature Review, above (pp.27-28). Albright (1999, 289) explores Poulenc's broadly surrealist disruption of steady meaning, suggesting that its simpler tonal world was "a principle of orientation" (ibid.) from which it could semantically disorient the listener. Albright suggests that

When we look at musical compositions that might be called surreal – works by Poulenc, Martinu, Ravel, and so forth from the 1920s – and compare them with Schoenberg's early twelve-tone compositions, also from the 1920s, we notice that the surrealist works seem strikingly conservative in certain ways. (Ibid.)

He points out, however, that the radicalism of this group of composers was merely of a different quality to Schoenberg's: "Poulenc attacked musical conventions as fiercely as Schoenberg, not on the level of harmonic syntax, but on the level of semantics" (ibid.). There is also a point to be made about the potential conservatism, more than a century after the Second String Quartet, of atonality, or more broadly, of the need to reach for an 'uncomfortable' harmonic world. Perhaps most importantly, in the context of delirium, there may be an ethical question in whether one chooses to exacerbate existing discomfort (P1's response to the music, given on p.118, suggests the reality of this concern).

CHAPTER 4: RESULTS & ANALYSIS

Exploring the experience of delirium in hospital

As I explain in the Introduction (0.4), the Results and Analysis have been divided into two chapters to respond to both parts of the research: “Exploring the experience of delirium in hospital”, and “how music might expand our insight into this phenomenon”.

This chapter will begin with some contextual information about the participants and general information about delirium (4.1). This is followed by a discussion of the definition of delirium (4.2) and of the three overarching themes emerging from the data (4.3).

A note on narratives

Although this study depends upon three sources of data (interviews; observation; follow-up interviews/focus groups), the first interviews provide the basis for everything else. It may therefore be useful briefly to outline some of the ways in which the interview data are influenced by the nature of the study.

Charon devotes a full chapter of *Narrative Medicine* to the concept of “bearing witness” (2008, 177-200). She opens the chapter by describing a kind of ideal narrative consultation with a patient. Her opening question is “Please tell me what you think I should know about your situation”. Thereafter, she steps back:

I do my best to not say a word, to not write in his medical chart but to absorb all that he emits about himself [...] I listen not only for the content of his narrative but also for its form – its temporal course, its images, its associated subplots, its silences, where he chooses to begin in telling of himself, how he sequences symptoms with other life events. (2008, 177)

Here Charon summarises the techniques of both interview and analysis to which this study initially aspired. For the most part, however, the narrative opener I discuss above (p.40) was not enough to uncover the detail of the experience, and prompts became vital. To encourage a flow of information, I found myself moving away from Charon’s model and towards a conversation.

I would speculate that the slippery nature of delirium itself has a part to play in this. An established, well-researched and publicly-visible concept such as cancer, HIV, heart disease,

might be more amenable to open questions. Delirium by contrast is subject to a fair bit of “what do you mean by...?” and “what exactly is it you’re interested in?” But the use of narrative questions is also impacted by circumstance, mood and so on, and the desire “to not say a word, to not write” falls prey not just to my own instinctive need to fill space, but to a list of other factors relating to hierarchy and environment.

Charon’s ideal circumstance seems to relate best to the model of a one-to-one-therapeutic session. I would suggest that this depends upon the particular hierarchal positioning of interviewer and interviewee – one that allows the physical, temporal, and psychological space ‘owned’ by the doctor-interviewer to be *offered* to the patient-interviewee. As a non-clinical interviewer, sometimes meeting people in their homes, sometimes in their offices or even hospital bed, I am in a different position – unable to create this cocoon. Moreover under the surface of this encounter is a persistent hierarchal problem. Charon’s patient says that “No-one ever let me do this before” (2008, 177). Whilst the space Charon creates is both innovative and impressive in terms of clinical consultation, it is important to note the supplicatory positioning implicit in the patient’s use of the word “let”. This is – almost inevitably – not a conversation between equals but a space *allowed* by a person in a position of power. By contrast, Holstein and Gubrium, acknowledging that the interviewer cannot absent themselves from the process, offer a model of active interviewing (1997, 113-127) that more democratically assesses the positioning of interviewee and interviewer.

Meaning is not merely elicited by apt questioning, nor simply transported through respondent replies; it is actively and communicatively assembled in the interview encounter. Respondents are not so much repositories of knowledge [...] as they are constructors of knowledge in collaboration with interviewers. Participation in an interview involves meaning-making work. (Idem., 114)

This study acknowledges with Holstein and Gubrium that the interview is a “social encounter in which knowledge is constructed” (ibid.).

It is worth noting also that the people who had experienced delirium presented themselves as highly unreliable narrators, often suggesting that their families have filled in gaps in the narrative, reordered events, or provided the ‘fact’ to their ‘fiction’: “I remember *all of it*, but the reality has been told to me” (P3, interviewee’s emphasis). HCPs, moreover, suggest that there may also be layers of denial (S1) or even wishful thinking (S7) in the narratives: “maybe they try and make it a better reality or something, or a better way of explaining it” (S7). Finally, the length of time between the delirious episode and the interview may have a

further impact on the narrative (the issue of memory is discussed further on p.92). For those who experience it directly, delirium may be an intrinsically fragmentary experience, patchworked together with others after the fact, and then reconstructed in interview.

4.1 CONTEXTUAL INFORMATION

Length of stay

P1 spent two to three weeks in ICU. It is unclear how long altogether he was in hospital, but he went back to work 'after about four months'. His delirium began on his tenth day in hospital. P2 spent 62 days in ICU and about five months altogether in hospital. P3 spent six days in surgical ICU and began experiencing delirium on his ninth day – his total time in hospital is not clear. P4 spent 33 days between theatre and ICU, including four operations; again his total time in hospital is not specified. He had returned to hospital for further treatment at the time of the interview. (Where HCPs describe other people's delirious experiences this data is absent.)

Risk factors

The chart below includes risk factors mentioned in three or more interviews. It is not intended as an accurate reflection of the causes of delirium, but is instead meant to give a sense of the scope of factors uppermost in interviewees' minds – as well as interviewees' general bias towards some over others. Interviewees' omission of phenomena does not mean they are not risk factors, simply that they did not arise in this conversation.

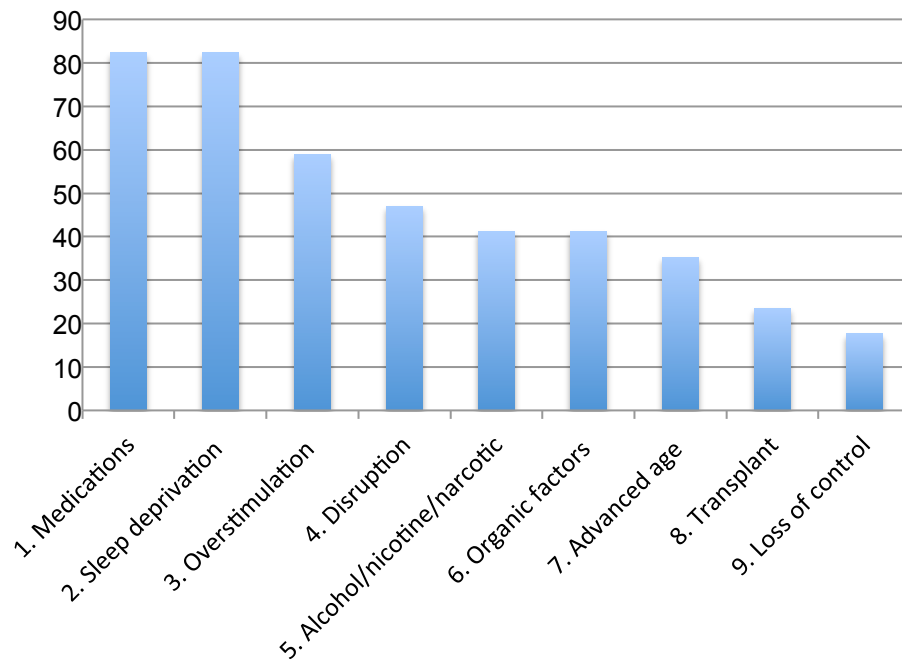


Table 3: Causes/risk factors mentioned, by % interviewees

1. Medications are mentioned by everyone except P4. They are specified in some cases as Prograf³⁷ (S1, S2, S5), steroids (S2, S5), analgesics and opiates (S10) such as pethidine³⁸ (P2, S7) and morphine (P2, S6, S7), and carbapenem antibiotics (S6, S10, S5³⁹). S8 and S10 also mention anaesthesia. P3 talks about *changes* in medication, S3 about coming *off* medications, and many interviewees discuss *combinations* of drugs. S8 explains that delirium is “very common in ICU [...] directly after any big operation [...] Because of the anaesthetics”. It is primarily drugs used in post-operative recovery that are highlighted. P1, however, says that “I don’t see any relationship, because the medications had been stabilised at that point”.

2. Sleep deprivation is mentioned by everyone except P4 and S4. But the testimonies suggest that this itself is caused by a combination of overstimulation and disruption, brought about by entry into the hospital environment, so it becomes difficult to parse this from the following two risk factors.

³⁷ Prograf is a brand name for tacrolimus, an immunosuppressant drug.

³⁸ Like morphine, a painkilling opiod. It is strongly associated with delirium, and highly addictive.

³⁹ S5 identifies carbapenems, such as meropenem and ertapenem: particularly powerful antibiotics used to treat multi-drug-resistant (MDR) bacteria (see <https://en.wikipedia.org/wiki/Carbapenem>). See for example Duquaine, Kitchell, Tate, Tannen, and Wickremasinghe (2011) for a small study of the “profound changes in mental status” relating to ertapenem use in the elderly.

3. Overstimulation is mentioned by everyone barring P4, and S4 and S5. P1 describes “an overwhelming burden of stimulation” (see also p.81, on the violence of the treatment environment); others speak about excessive light, noise, and touch (SATs probes stuck to the skin, nurses “always touching the drips and moving the lines, and pulling the sheets” – S1); and “constant interruption” (S3). S7-9 talk at some length about noise: “ICU’s *very very* noisy [...] If it’s not the monitors and everything, it’s the staff; [...] I only realised it when I was a patient lying there myself, how noisy we *can* be. And how you don’t sleep properly, you don’t rest properly. I only slept when I went back to the ward” (S8). Delaney et al. (2015) confirm that “Both subjective and objective studies have reported noise as a primary source of sleep disturbance, with staff being the primary source of the generated noise” (n.p.). In my observations in ICU, I note the HCPs’ consciousness of keeping the noise down during the formal “quiet time”, but also that

the soundscape would drive you mad – because although it’s varied within itself, it’s also unchanging, and constantly *blurring*, with the odd word coming into focus. Exacerbated for me by the accents, different languages code-switching. Same for patients? (see Appendix 5: Observation notes)

4. This relates, too, to broader **disruption** to routine and environment – something mentioned by every staff member. This can include both the disruption of being admitted to hospital, and disruptions within that time – moving from theatre, to ICU, to the wards (S7). S10 says that “just being in hospital is a risk factor. Because your normal routine is disrupted”. Most HCPs also discuss disrupted staff patterns, and S10 relates this to a wider “fragmentation of healthcare”:

the anaesthetist and the surgeon will see them day one post-op, then they’ll get moved out and go to high care where a different clinician will look after them and then they’ll go to the ward. And in that chain of events you might have three different people looking after them.

This impacts on the management of delirium: “the minute they leave ICU it’s not the ICU clinician’s problem any more, so even if they were delirious it becomes something someone else manages”. It is worth bearing in mind, though, that while HCPs often suggest a *lack* of routine, P2 talks about her boredom and loneliness and says “everything works on a – like a routine, and – they should have mixed it up a little bit”.

5. Alcohol/nicotine/narcotic withdrawal is mentioned by all HCPs, and associated specifically with *delirium tremens*. **6. Other organic** (i.e. physiological/disease) **factors** are

mentioned by S1, S2, S4, S5, and S6 in relation to encephalopathies (see 4.2 below, Defining delirium). **7.** Six of the ten HCPs associate delirium with **advanced age**: “most of the ones I’ve experienced are the elderly, in the setting of them having an acute infection, for example” (S10). **8.** Four HCPs specifically mention **transplant**, and the psychological stressors around it, in association with delirium. More broadly, the extent of the person’s illness/trauma/operation is mentioned by both S7 and S10. S1 mentions specifically that “it also comes in with the fear of death”. **9.** Lastly, three interviewees (S8, S10, P1) mention a **loss of control** concomitant with the hospital environment as a contributing factor.

It is also worth noting that **isolation** is mentioned by five interviewees, but only S2 and S8 specifically associate it with delirium. S2 calls it “cabin fever” or “the fishbowl effect” (P2 also uses the “fishbowl” metaphor), while S8 says that isolation exacerbates paranoia (see p.92 for more on paranoia): “the person that’s in isolation room for a long time, they will basically go into that people are busy conspiracying [*sic*] against them”. P2 makes no direct correlation between isolation and delirium, but it is clear that the isolation is not a positive experience – and that she “lived for” visitors and a break in the routine.

Additional risk factors mentioned by one or two interviewees are:

- Sepsis (S3, S5)
- Length of stay in ICU (S3, S8)
- Lack of daylight (S8/9)
- Hepatitis C (S1/2)
- Pain (P1/C1)
- Fear of death (S1)
- Paranoia itself (S6)

Prevalence/incidence

Only HCPs were asked how common they felt delirium was; again, these are expressions of opinion rather than quantitative assessments. All HCPs suggest, directly (S4, S5, S6, S8, S10) or indirectly, that it is common; and all refer to ICU as a primary site. For S8, “ICU is [...] where it all happens”. S3 says “it’s very normal” for ICU; “on your overnight cases, not many. But on your longer-term patients, yes”. S7 says she has been aware of post-op delirium⁴⁰ in particular “many times” and suggests “90% of the patients” in ICU. S8 confirms that “it’s very common” but suggests more like 20% (this would be unusually low according to the clinical literature – e.g. Maldonado 2008, Bhudia 2016).

⁴⁰ Most patients would be in ICU post-operatively.

S10 specifies that it is rare in outpatients, and that “certain people are higher risk than others”, but these high-risk groups cover a lot of ground: “the elderly”, people taking “classes of antibiotics [...] classically associated with altered mental states and seizures”, people with liver failure (or any encephalopathy), post-op transplant patients, and “trauma patients [...] with multiple injuries”, and again people in ICU. S2 mentions older patients, alcoholics, and people with hepatitis C.

S4 and S5 confirm that “for liver failure patients it is very common”. S5, S1 and S2 differentiate pre-and post-op deliriums in liver failure patients (see 4.2 below on Defining Delirium). S4 and S10 indicate that delirium also occurs (rarely) in renal failure. All HCPs (barring S4 and 5) also refer in Phase 1 or 3 to delirium tremens in people detoxing from alcohol or (less commonly) narcotics, including tobacco. Importantly, however, S1, S2, S5 and S10 also say that “you just can’t predict” (S1) who will become delirious.

In summary the interviews suggest that (for these HCPs), delirium

- is common, and familiar to HCPs in a variety of clinical and allied disciplines;
- occurs in ICU as a primary site;
- occurs frequently in three other groups: liver patients,⁴¹ elderly patients, and detoxing alcoholics;
- can also be found unpredictably across normal care.

Diagnosis

None of the staff use the diagnostic tools mentioned in the literature review (p.15). S3 notes that the CAM (Confusion Assessment Method) ICU scores aren't part of the ICU documentation; in their group interview, S7, S8 and S9 confirm that they have never used CAM scores despite long nursing careers. S5, whilst she downplays delirium in the following quote, nevertheless says that “I think we should be scoring people [...] because it’s a very subtle thing, but I think with the busyness of the environment [...] you attend to the big needs and you leave the small things”.⁴² S3 and S6 both note that new documentation processes for patients’ psychological wellbeing are about to be brought in to their ICU.

Beyond specific mechanisms, however, several HCPs discuss how they know a patient is becoming delirious. S10 says that “there are diagnostic tools, but [...] it’s more like recognising a pattern, I think”. S7-9 explain that answers to standard questions about “time,

⁴¹ For a brief commentary on the prominence of liver failure patients in this study, see p.36.

⁴² Here S4 is referring to the normal care ward environment, not ICU.

place, and person” (part of their training as HCPs) will often indicate delirium.⁴³ And others refer to physical manifestations as early signs of delirium. S3 and S4 both speak about patients becoming irritated by objects attached to the body:

That’s where now we know that *there* now the problem is starting. So it manifests with small little things, you know, they will start pulling out their drips. (S4)

Often they will focus on small, almost insignificant things. [...] And that’s also a way to tell that they’re starting to teeter a little bit. They’ll be almost constantly bothered about the BP cuff, or the SATS probe, or [...] something tactile, very often. (S3)



Figures 15 and 16: SATS probe; BP (blood pressure) cuff

Sources: medtronic.com; quinn.anya on Flickr

S3 also refers to patients’ eyes:

Then you get the really quiet ones who’ve got that wild look about them. And you know they’re almost just teetering on the edge [...] they almost get that wide-eyed spooky look about them; and you can say “oh, here we go!” (S3)

S4 talks about “a change in behaviour. All of a sudden they will do strange things”. This might be “dressing inappropriately”, displays of ‘aggression’ (see 4.3 below), or unusual behaviour: “Sometimes they go in the shower or in the bath and stay there, not doing anything” (S4).

Beyond the initial diagnosis of delirium,⁴⁴ S1 mentions that CT scans are sometimes used to differentiate between types of delirium: “we’ve seen so much confusion in the elderly or the

⁴³ In the focus group they expand on this to say that with greater experience nurses learn to vary these questions to avoid patients learning answers by rote.

⁴⁴ It is unclear from the data whether delirium is always formally diagnosed. A comment on Lambert’s 2014 article on delirium, however, suggests that in ICU it is “[s]o common in fact that it doesn’t go into the notes and is dismissed as ‘one of those things’” (n.p.).

long-term alcoholics that we're now starting to question 'is it dementia? Normal dementia? Or is it from the encephalopathic status, or the damaged liver?'" S3 also mentions that doctors *anticipate* delirium in ICU: patient notes on arrival will often include "their high potential for ICU delirium":

if they are quite highly strung out, stressed individuals [...] Dr— will then often earmark them ahead of time, and he'll say "when this one comes in we need to start something straight away". Maybe it's depending on their home medications, or [...] if they are heavy drinkers, or if they're heavy smokers even, we do start them on stuff, to prevent them getting a bit wild.

As we have seen above, however (p.70), some HCPs in this study suggest that delirium is unpredictable, and Bhudia confirms that pre-admission assessment is by no means a failsafe means of assessing its likelihood:

a patient who was fairly young, through the standard pre-operative assessment, would not have been identified as a patient at risk of Delirium. However by day 3 post operation the patient was quite delirious and ended up in ICU and high dependency for extra 2 days. (Bhudia 2016, n.p.)

In summary, for the HCPs interviewed for this study, the signs of delirium are fairly clear: behaviour change, obsessive attention to small details – particularly relating to foreign objects touching the skin – and the wild-eyed look of someone experiencing psychic discomfort. For S10 it is a whole "pattern".

S10's is the final interview, so I take the opportunity to ask specifically about the absence of diagnostic tools. S10 explains that their absence is a common issue in medicine, and that "the scales that get uniformly adopted [are those] used by everyone". If only one staff group uses them (doctors, nurses, allied health professionals etc.), they are useless in a multi-disciplinary environment. It seems unlikely therefore that we can infer anything about the weight given to delirium in the clinical environment from the absence of diagnostic tools.

Interestingly, S4 also sees delirium as a diagnostic tool in itself – a way of identifying the need to correct liver function. Strange behaviour will lead the staff to test ammonia levels as a way of positively identifying HE, and then to attempt to correct the chemical balance. In ICU, similarly, delirium may draw attention to problems with medications. (I discuss delirium as a way of understanding medicine and care more broadly in Chapter 6.2).

4.2 DEFINING DELIRIUM

A total of 12 clinical terms were used by interviewees under the general rubric of 'delirium': Confusion, Prograf toxicity, delirium tremens (DTs), psychosis, steroid psychosis, ICU psychosis, hypoglycaemic delirium, renal encephalopathy, hepatic encephalopathy, PRES (posterior reversible encephalopathy syndrome), uraemia, and acute brain failure.

With the exception of P1 and C1, both of whom have long experience of work with health professionals, and who use the term "ICU psychosis", former patients and carers tended not to use umbrella terms for the whole experience, instead focusing on the delusory component of delirium. All four use variations on the term 'hallucination'; and P4 and P1 use variations on 'dream'. When I bring this up in a Phase 3 focus group discussion, S6 responds that the lack of overarching terminology "speaks to something about the experience" (S6). To me this implies that the experience cannot be boxed away in the way it can be for observers, and suggests also that hallucination has some primacy.

The remainder of this section will refer to terminology used by the HCPs. The chart overleaf and explanations beneath are an attempt to summarise the relationships between the different terms as they are used by the HCPs. I have separated two areas that emerge from the data as having distinct properties: psychosis and encephalopathy. Similar to Pinson's distinction between delirium: "a mental disorder or [...] symptom" and HE: "neurologic diagnosis that identifies toxic and metabolic states affecting the brain" (2010, n.p.; see p.9), I have broadened this, however, to psychosis and wider encephalopathy. This distinction was agreed upon by all seven active participants in Phase 3.

DELIRIUM / ACUTE BRAIN FAILURE / CONFUSION

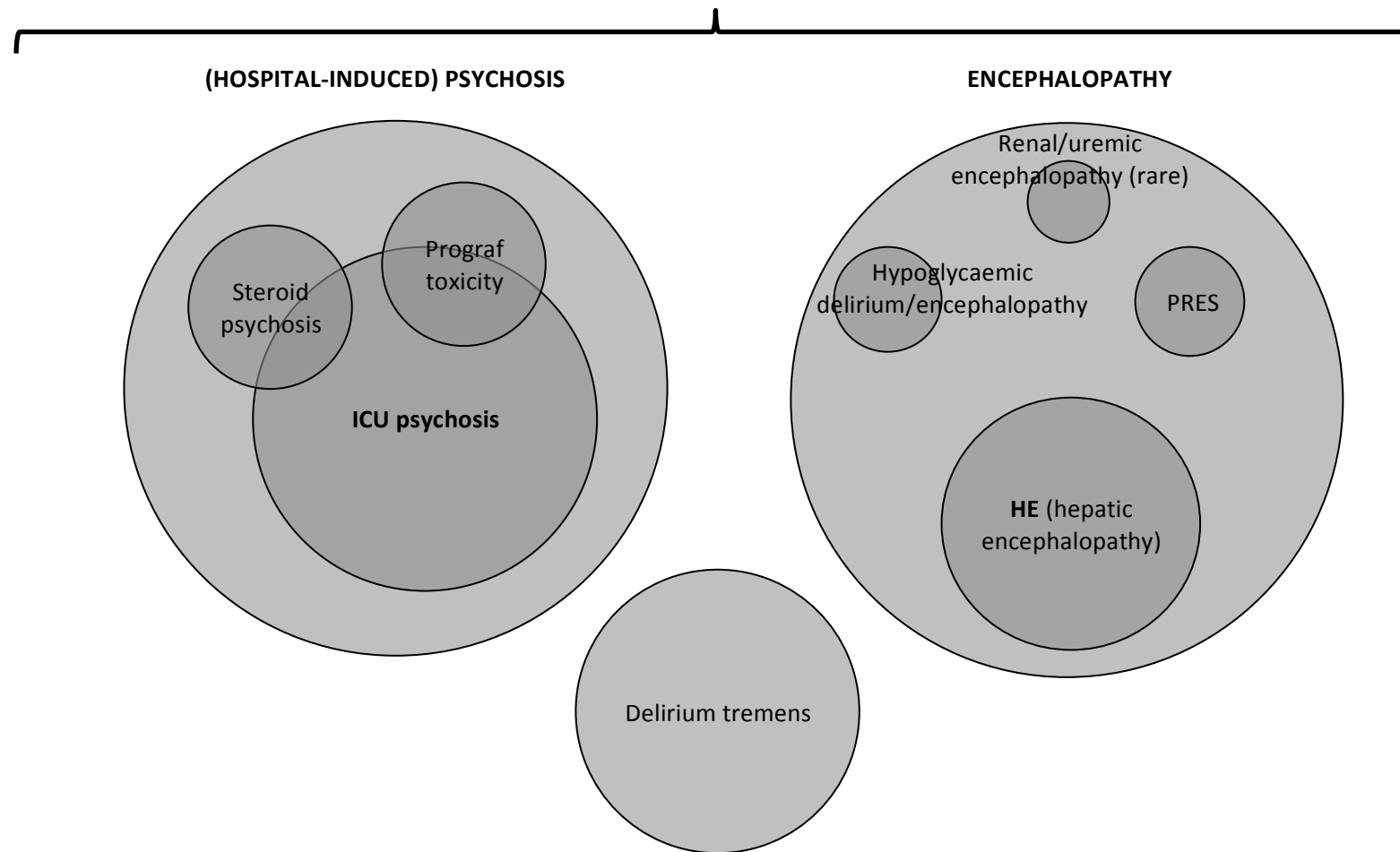


Figure 17: Relationships between different types of delirium – as described in interviews

Delirium / confusion / acute brain failure

These terms could be regarded as synonymous for the HCPs in this study. 'Acute brain failure' is mentioned only once, as a relatively new term that S6 thinks may become a useful way of understanding delirium. 'Confusion', however, merits some explanation. S2 (in Phase 3) says that "the catch-all term of confusion is [how] any patient who is not quite themselves would get termed – they don't call them *delirious* patients. The patient is confused". S10 (Phase 3) explains that "you're not orientated to time, place or person; that's the medical definition. So if you don't know what day it is, you don't know where you are. Then we would say someone's confused". As S6 puts it "it's one of those words that is different in a medical setting to in ordinary language" (Phase 3). For these HCPs, the term 'confusion' does not *necessarily* imply, as it might outside healthcare, lack of attention or focus, or the fogginess associated specifically with HE (see below).

Encephalopathy

As we have seen (pp.9-10), encephalopathy derives from chemical imbalances due to the patient's condition *before* treatment, impacting on the brain. Renal encephalopathy (also uremic encephalopathy or uraemia) is described as rare, thanks to dialysis – "we never leave them to that state" (S10). The bulk of conversation relating to encephalopathy refers to hepatic encephalopathy (HE).

Both S4 and S5 suggest that HE responds well to treatment of the organic cause, "when the ammonia gets better" (S5):

they just sit and they're sluggish and they stop eating, and then they're very weak and then they don't move and then they stop talking [...] it almost mimics a mild stroke. And once you correct the encephalopathy and decrease all the [...] things that precipitate it, then the next day suddenly they're walking around and they're fine. (S5)

S10, however, points out in Phase 3 that "you often can't [treat] an encephalopathy [...] you can't just take off the ammonia, you only treat that with a liver transplant". Nor is there an absolute relationship between ammonia levels and the severity of the encephalopathy: "you can have an ammonia of 100 and you can still be talking to me, and answering my questions [...and others] can have an ammonia just slightly elevated [...] and can be completely out of

it" (S5). HE is characterised by *intermittent episodes* (S4/5) of increasing sluggishness (S6 characterises this as a "foggy brain, a confused brain"), an enervation leading (untreated) towards coma. This may be accompanied by uncharacteristic aggression or "inappropriate" behaviour: anything from nudity to defecating in public spaces in the hospital (S5). Spatial awareness is also diminished – so for example "patients lying oddly in the bed – sort of across the bed" (S6).

Hospital-induced psychosis

Of the areas above, hospital-induced psychosis is the area to which I devote the most attention. This is partly because it is the only one of the different deliriums reported by the former patients in this study, and partly because my historical interest in delirium is coalescing into a particular interest in this form – as something which is induced not (only) by disease or addiction, but by care itself. Hospital-induced psychosis results from a combination of trauma with treatment and its circumstances: medication, physical environment, noise, disturbance of sleep and routine. ICU psychosis could be said to be a specific type of hospital-induced psychosis,⁴⁵ and both steroid psychosis and Prograf toxicity are drug-induced forms that may appear in ICU or in lower care wards.

Hospital-induced psychosis is broadly characterised by paranoia, persecutory hallucinations, and an almost hyper-alertness to these experiences. S3 talks about "a lot of paranoid behaviour – thinking you're out to kill them, you're out to hurt them, calling out for help from their family members, that kind of thing". S6 says that this delirium is defined by "perceptual disturbance and paranoia" as well as hallucinations, and adds that "getting out of touch with the reality" may be the "key element" distinguishing it from other deliriums.

S4 is unusual in finding psychosis to be a component of *HE*: "with psychotic obviously some of them they become aggressive; some of them become a risk to them[selves] and to other patients as well". In all the other testimonies that mention it, HE lacks the intense, almost manic quality of psychosis. S5 says that pre- and post-op delirium are "completely different" in terms of "alertness" (see my comments about 'confusion', above), noting that she has

⁴⁵ The term ICU psychosis is more commonly used (see p.67 and Appendix 4 for the risk factors which explain this, as well as Maldonado's list on p.11, above). A similar-looking psychosis may, however, extend into the 'normal' ward environment – as it does for P2 and P3, hence my use of the term 'hospital-induced psychosis' (Crane 2015, n.p.).

observed patients talking about “a whole lot of things, or the *fleet* of ideas”.⁴⁶ C1 similarly talks about her husband being “very stimulated” in his delirium. Even “quieter” patients are described by S3 as having “wild eyes”.

Psychosis is also described as having a greater impact on the patient:

I’ve not had any patients talking about [encephalopathy] being terrifying. I’ve had patients talk about it being disturbing and distressing and not nice, and wanting to be better, and hope it doesn’t carry on. But I’ve not had a patient talk about being terrified in the same way as, for example, my most recent patient saying “it’s been horrendous” [...] whether it’s demons or the room is losing its proportions, or – those are horrifying, psychotic experiences. And the encephalopathic patients will be distressed about being disoriented, but they’re not as traumatised by it. (S6)

S2 (in Phase 3) puts it thus: “the psychosis is often what the patients tend to [...] need help dealing with, as opposed to the encephalopathy. Because it seems to *scar*”.

Delirium tremens (DTs)

DTs are mentioned by all HCPs, and the focus groups confirm that it is characterised by acute distress and formication (a sensation of insects crawling on the skin).⁴⁷ S9 suggests that it is “a lot worse” than the other deliriums, although this is not backed up by other interviews. Because of its extremely specific relationship with drug/alcohol addiction, its unique characteristics, and its absence in the former patients’ interviews, I have not devoted specific attention to it in this study.

Colliding deliriums

Separation in the above chart does not indicate that one person cannot have more than one type of delirium. It is meant to suggest rather that there is no *intrinsic* overlap between the two; where they exist, overlaps are circumstantial. In Phase 3, S10 makes it clear that “one

⁴⁶ This may also relate to P2, who says that her friends “loved to talk to me, cause I would just talk rubbish; like, absolute rubbish. And I thought I was making complete sense”.

⁴⁷ The term is derived from the Latin *formica*, meaning ‘ant’. HCPs in this study associate formication exclusively with DTs (confirming this in the focus groups), but elsewhere it is associated with schizophrenia and psychosis (see Scheinfeld 2016), and is a known side effect of numerous prescription and recreational drugs (Litt 2009).

person can have all of those [encephalopathy, DTs, and post-op psychosis] in a period of their hospitalisation”.

Moreover, S2 explains that

in my patient profile [...] there's a very fine line between drug-induced psychosis and a patient who's encephalopathic, sometimes you don't know where that line is. They go from being encephalopathic pre-liver transplant [to] waking them up in ICU and they've already had their first dose of Prograf, for example. You don't know what is residual from the liver, versus the new process of giving them the drugs. (Phase 3)

S1 explains how difficult it can be to pick 'delirium' out from general extreme ill-health, in describing what she calls the “most profound experience I've had” of delirium, with a young transplant recipient, who refused a second transplant, and eventually died:

I don't know how much of it was delirium, and how much of it was a deterioration in her – hierarchy of needs, that she dropped right down to like, just eating, drinking, sexual needs [...] Was it really delirium, or was it just a degradation of needs? (S1)

Despite their distinct properties, moreover, the encephalopathic and psychotic experiences do have much in common: a loss of sense of orientation to time, place, and person is a feature of both (see *Theme 2: Loss*, p.87). And both are episodic. Participants noted in Phase 3 that the draft music effectively communicated the ups and downs of all deliriums, which are “not a fixed, total state, you shift in and out. There are moments of lucidity [...] and] points of worse and softer and harsher” (S6, Phase 3).

Why is definition an issue?

If S6 says that “to unravel this almost feels a little bit impossible”, why should we try? C1's testimony suggests one reason:

he's trying to calm me down, like he's saying that, you know “it's *probably* ICU psychosis”, and I said “but I don't work on *probably* – we need to find out exactly what's going on”, because at the *time*, you know, you don't know if it's evolving into something else. (C1's emphasis)

When experienced HCPs are suggesting that 90% of ICU patients are experiencing a phenomenon, and no-one is sure what is going on, where the causes lie, how to prepare for it, or how to respond to it, this should alert us to vast inconsistencies in treatment, and added stress for everyone dealing with it. More often than not patients are being *treated* less than they are being *managed*. As S10 puts it, “I don't think we medicate them to relieve *their* distress, I think we medicate them to make them manageable” (S10's emphasis). Managing requires no sense of the experience for the patient, only the experience for those *around* the patient; and these, as we will see on pp.108-109, can be very different things.

Definition is an issue because at present, to an extent, we don't know what to do with delirium. Sedation is one treatment. S8 confirms that sedation is “just easier for the nurses; cause it can get *very* exhausting to have a patient that you have to calm down all the time”. The HCPs interviewed for this study are generally ambivalent about sedation (echoing Crane's 2015 reports of changing attitudes – see p.18), and S10 and S3 concur that “the kneejerk reflex to just sedate someone, which we used to do *before*, we do less of nowadays” (S10). At least some of the risk factors described above (pp.66-69) suggest that the need for sedation could be reduced through preventive measures, however. S6, for example, says that while lack of sleep and sensory overload may be “considered just a factor of the environment”,

I imagine there are ways of reducing some of that, in the way that ICUs are designed, some of those cubicles are awful [...] there are about six beds where there's no outside. Or they face the reception, and [...] there's no outside. And I think it is sensory overload [...] it's not knowing what the nursing staff are talking about, it's not knowing what the doctors are talking about, it's – it's kind of this stuff going on *around* you. Often it's very simple things that can help the patient: explanation of what I'm doing; reminding you what day it is; reminding you where you are; tone of voice...

A better understanding of the nuance of different deliriums might encourage simple changes in practice. In response to the Key Findings (Appendix 3), however, S10 points out that the niceties of definition may be less important than attitude: “it's like we have to re-programme our responses, more than sub-categorise delirium, for me” (Phase 3).

4.1.3 THEMES: VIOLENCE, LOSS, AND HUMANITY

As I have suggested, three overarching themes emerge from the data. Although not themselves narratives (other than within this text), they can to be mapped back onto the spirit of Arthur Frank's three narratives of health: Quest, Chaos, and Restitution respectively (2013). Within the three, a number of 'sub-themes' will be discussed below, relating to (for example) loss of control, or the violence of care itself. Delirium is complex and highly individual, and these themes are in no way intended to provide a comprehensive sense of the experience, but they may be a useful set of lenses through which to understand the potential impact of the experience, as well as our potential to alleviate some of its worst extremes. Violence, loss, and humanity have emerged from the dual process of musical and textual composition. All three were agreed and expanded upon by participants in Phase 3.

Theme 1: Violence

Violence manifested itself very clearly in a number of ways in the interviews.

- Violence on/in the patient (illness, trauma, medications – and restraint);
- Violence in the delirium;
- Violence expressed by the patient.

Based on the data below I would suggest this causal relationship:

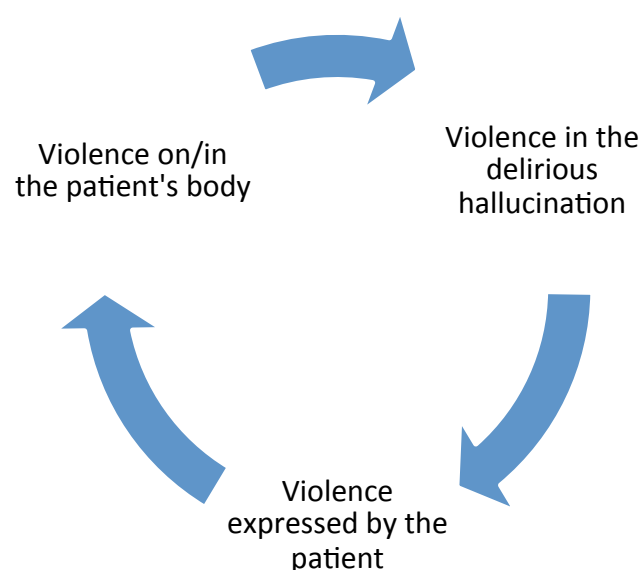


Figure 18: Cycle of violence

This cycle appears, for example, as P1 and C1 discuss a psychotic episode that begins ten days into P1's care. P1's story begins in a pained, confused state on his admission to hospital (violence on/in his own body). His hallucination then mirrors his sense of being trapped/controlled by the hospital experience (violence in the delirium). He then tries to pull out the lines that are keeping him alive (violence expressed). Lastly, the nurse steps in and threatens him with restraint (the second instance of violence on his body):

P1: I wanted to be out of there [...] I think I was becoming very physically agitated, and trying to remove all the lines from my arms. I remember the people who were the nurses, but they were part of the hallucination [...] They were officers in the air force [...] And part of the hallucination was that they were trying to control me and keep me in that subjugated, uh, enforced type of state, but I always wanted to break away, I wanted to get out of there.

C1: [...] I would have to call for the nurse, and they had one large male nurse that would come in and [...] say, "Do you want me to have to restrain you?" And he would look at him and say "No". And then he would calm down.

Violence in/towards the patient

The starting point of this cycle would seem to be violence in/on the patient, which itself breaks down into three areas: the violence of ill health or trauma; the violence of treatment itself; and the violence of responses used to curb delirium (restraint of various kinds). Restraint will be discussed further below (pp.85-87), since it is the point where the cycle is pushed onwards, driven by the patients' sense of persecution, their "desperation" (S9, P1) to escape. S8 says that "we put you in a war zone almost". It is worth noting that the violence of treatment is not confined to surgery or medication,⁴⁸ but is also constituted in the physical environment. Thus P1 describes

an overwhelming bombardment of stimulation [...] you're getting overwhelmed, bombarded from the bed pumping up and down, from the noises – there's constantly noises [...] – and to being awoken every few hours: "What's your name? When's your birthday? Let's check your sodium", or "Let's check for your blood pressure", you know? "Let's check this" [...] and yeah, the pain [...] it's almost like the psychosis is an escape [...] your brain being able to deal with the harshness of what you're undergoing.

⁴⁸ One frightening example is reported by S5: "one guy one day woke up and he says he can't see, he's blind. You know? But he wasn't blind – he just said 'I can't see, I can't see, I've gone blind'. But you know, cortical blindness is a sign of Prograf toxicity. [...] And then the next day he was suddenly fine".

Violence in the delirium

Hallucinations described in this study include kidnappings, military “subjugation”, and poisoning by drips (see Appendix 7 for a full list). P3 is “smuggled” out of the hospital to be displayed at a shopping centre. Indeed there is often an element of the undercover: attempts to kill, maim, or display are frequently made in secret, and they tend to be extremely personal. As MW puts it in *Delirium Part 1*, “there may be innocent bystanders and whatever, but the collateral damage doesn’t matter – it’s the fact that they’re going after *you* rather than anyone else” (his emphasis). S8 describes a patient in his 70s who, after three months in ICU, “thought he was in the army base”:

And he was shouting on [*sic*] the top of his voice that everybody must duck because there’s a war going on. And [...] for him it was such a reality, and when the nurse came to him to calm him down, he basically attacked him, to tell him, you know, “you must lay down, because they’re now gonna shoot the bombs”.

Here again we can see the movement round the cycle, from internalised violence to its expression at the expense of HCPs.

P4 describes scenes reminiscent of his own army life as a conscript in the SADF (South African Defence Force; see p.19) “I remember – be careful don’t drag the ox; or [...] don’t drag the sheep to the mud. Cause we’re gonna eat it. [...] that’s the type of thing that came from the army [...]; we would go and shoot at buck; and that’s supper” (P4).

P4 and S8’s example above are both atypical amongst descriptions of violence I have thus far come across, either in my own research or other qualitative studies such as Bélanger & Durcharme (2011). Where violence is normally a threat to the *hallucinator*, for both these people, it is a threat to *others* (“he was shouting on [*sic*] the top of his voice that everybody must duck”), which in P4’s case he is employed to forestall. “I would go out on patrol with the guys to ensure that nobody got injured and nobody was shot” (P4). This makes no difference to the way it manifests in the ‘real’ world; P4 too pulls out his lines, and is physically restrained (“the family say I was being tied up here [...] because I was getting out of hand, pulling...”), but “the reason I was being tied up was – in my mind of minds – I was protecting people”. It may seem a nice distinction, but in P4’s case the protection of *others* rather than himself may relate to the emotional impact of his delirium. He specifically says that this was “not at all” an upsetting experience and that “it was what it was” – despite the

fact that “they were gonna kill me. There was no question about it”. He does not report associating his hallucination with any kind of heightened emotion.

In Phase 3, S6 points out that his time in the SADF may be significant here, and there may be connections here with previous trauma.⁴⁹ Indeed, P4 refers to his hallucination as “an affliction from the past” and returns again and again to the SADF in his interview:

I mean nobody has looked at the implications of the South African soldier while he was doing his training. Nobody has. We were the bad guys who killed the bad guys. But I mean you’ve gotta understand that basically what happened is when we turned 16, you had to apply for your ID card. So you were issued with an ID card at the age of 16. That ID card entitled you to go to the army. There was no question about – are we going to the army? We were going to the army.

Even when I ask about the relative importance of the delirium in his hospital experience, he responds in the context of the *hallucination*: “Well because the average [...] white South African male spent an average of two to three years in the defence force, our sort of age group, it’s nothing. It’s expected”.

While military scenarios are extremely common in delirious hallucinations, P4’s experience of a militarised setting may be quite different from (for example) P1, who as a US citizen has not been subject to conscription. P4 treats the threat in the hallucination as “nothing”, as “expected”. Where for P1 (and indeed many interviewees in *Part 1*) the emotions attendant to being “in some kind of military war operation” are quite different. P1 uses words like “forced” and “subjugation”, and expresses his desperation “to get out of there”. P4, by contrast, expresses total acceptance of the situation. P4 is also the only person who describes the nurses as benign, protective – perhaps (although this is entirely speculative) suggesting a different relationship with uniformed institutions:

I’m sure that the senior nurses took pity on me. They were like the mummies. Looking after us. So they were like the senior inspectors that were looking after us, the minister of defence, that type of thing [...] for example, the head of the Northern Cape board...

⁴⁹ P4’s story appears (with his permission) in the music, and is therefore discussed in the focus group.

Violence expressed by the patient

‘Aggression’ from patients is mentioned by every HCP interviewed, in relation both to HE and hospital-induced psychosis. This is perhaps most frequently directed at the inanimate objects that constrain us in hospital (drips, tracheostomies etc.), which people try constantly to remove. In extreme examples, despite the risk to their vocal cords, people are described as using their tongue to push out an ET (endotracheal) tube “even if they’re restrained, they’ll push that tube out. They feel they can’t breathe” (S7).

But violence is also turned outwards, towards staff and other patients. S8 relates this story from her time as a student nurse:

He was completely out of it and very very aggressive and [...] he wanted [me] to give him some Etamin⁵⁰ and I was shift leader that night and he actually hit me, with his fist in my face [...] he literally, he broke [...] away from the nurses and he came and he hit me, with his fists in my face.⁵¹

The study is filled with further examples: S10 has been bitten by patients; S1/2 and 6 all refer to an incident in which a teenaged patient “jumped on” S6 during a consultation (“she could have choked me to death”), although S6 interprets this as “playful” (see p.104 below); S5 describes one encephalopathic patient who “almost punched Prof — in his face”; and another who “hit the patient next to him”; S2 says that “even petite little grannies can do significant harm. You know they can come out of their coma like a raging bull” (Phase 3); and P3 describes his own threatening behaviour towards HCPs (see p.97).

To people unused to hospitals these outbreaks of violence might be surprising, but although the more extreme examples do make it into hospital legend (two incidents are reported in separate interviews), they are clearly commonplace enough to be considered a part of the general business of the institution.

Most interviewees make it clear that violent behaviour is uncharacteristic (“later he came and he apologised, and he felt very bad. But he didn’t know what he was doing at all” – S8) and several HCPs and carers discuss people’s embarrassment when their behaviour is reported back to them (for more on disinhibition see p.103). Despite this recognition that

⁵⁰ A coronary circulation-stimulating drug.

⁵¹ He had been “admitted with confusion”, and was an alcoholic, although S8 does not associate this behaviour with delirium tremens or encephalopathy.

patients are not their “normal charming selves” (S5), however, HCPs still regard these outbreaks as ‘aggression’. Bélanger and Ducharme suggest that in treating delirium, nurses “must seek out the meaning that patients ascribe to this experience to understand the situation” (2011, abstract). Given that, as we have seen, people do not perceive themselves as *initiating* violence, but attempting to *escape*, or to *defend* against a variety of threats, the word ‘aggression’ may be misrepresentative, and may play into justifications for restraint.

Violence toward the patient: Restraint

Most HCPs express, directly or indirectly, an antipathy to restraint of all kinds. The two-thirds who discuss physical restraint express fairly specifically what S2 calls “an *intense* discomfort with your human rights, and your dignity”. Yet this study suggests that is still relatively commonplace. Although one HCP says that chemical restraint is generally favoured over physical, S1 and 2 agree that they have seen “much more physical restraint”:

they’ll get confused and agitated, [and] as opposed to chemically sedating, they will physically restrain the patient, which *increases* the level of agitation [...]; we go around untying patients. (S2)

S7 says that “I always feel guilty if have to restrain my patient, and I always make sure that there’s a good reason”. And indeed there *is* often good reason to contain behaviour:

some of them become a risk to them and to other patients as well [...] they become more physical. [...] Pulling out drips, if they were on oxygen, take out the oxygen. If they were immobile before, they will now want to get out of bed independently; the physical strength is not there, you know, and then that poses a risk of them falling. (S5)

Chemical restraint may represent a more “benign” approach than physical:

obviously to see physical restraint is quite disturbing and alienating [...] so chemical restraint just seems like a much gentler approach, for the patient – and the family. It just feels [...] almost barbaric, [...] to tie people down, strap them [...] I think there can be a relief in having a light sedative that calms you down [...] I’ve seen people respond to that with relief. Because I think it’s torment often when you’re going through that. So I do think [chemical is] a more *benign* way. (S10)

As I have noted above, however (p.73), HCPs in this study regard chemical restraint, too, with some caution. Although both C1 and P3 describe sedation as an absolute necessity in bringing down the psychosis (p.87), in *Part 1*, an ICU nurse says:

even though they look asleep to us, [...] you can't sedate the soul, you can't sedate your mind; you can sedate physically but all that is still being very active, [...] and there have been patients that have actually heard maybe discussions in the next bed, or heard wailing, and heard... and so they must sense that there is this feature of death around them...

Given the discomfort with both kinds of restraint, S7 suggests that the first call will more likely be a change in staffing: "Sometimes you'll have to get a nurse just to sit there in the room with them, and watch them" (S7). S1, too, discusses using staff to manage delirium rather than restraint, but suggests that this change – and perhaps more importantly the consciousness of the patient's perspective that underpins it – is not yet embedded in hospital culture:

if somebody's *confused*, you need to be in the room 24 hours, you need to be *engaging* with the patient; if the patient's pulling out the nasogastric tube, are you saying to the patient, "are you aware there's a tube in your nose? D'you know you can't take that out?" But [the nurses] don't, they'll smack the hand, tie the hand up...

In relation to doctors in particular, S10 points to the limitations on staff time: "no-one's gonna interrupt their ward-round to sit down for 15 minutes and talk to someone about why they think there's a bunch of people negotiating their murder". But S10 also suggests it is about more than simply resources:

[It's] the safety of the patients, it's the safety of the staff, if they're aggressive and violent; so you kind of tend to focus on [...] the chaos that's happening *around* them instead of, well maybe this person's just deeply traumatised, which is how I would look at it now, but I never used to think about it. (S10)

Without the benefit of long experience, or perhaps specific training, we respond to apparently irrational behaviour (pulling out drips) in fairly primal ways: not just safeguarding patients but projecting the environment more broadly from the chaos bubbling under the surface. To understand the urge to restrain, it also helps to understand the soundscape of ICU. During a period of observation I was able to hear a man wailing for a period of 45

minutes. The urge to relieve his pain was immense, and sedatives would certainly appear to offer that relief.

P3 presents an interesting case in relation to restraint. Although clearly agitated, he is initially neither physically nor chemically restrained,⁵² and begins moving furniture around his hospital room, which has become his hallucinatory workshop: “I had three drains on one hand; lazyboy in that same hand. [...] and I was in – in and out [of delirium] [...]. I could have pulled those drains out like this [snaps fingers] – you see? But praise the Lord I didn’t”. He does rupture his sternum, however, an injury that has never completely healed; and to apply some *chemical* restraint (sedation) after this incident, the staff and his family are required to undertake an elaborate game *inside* his delirium:

I said to my wife “now, did you bring the car?” But she’d already been prepared now. By the doctors and the whoever. So she said “*jah* – come climb in the car, come sit here by me”. She was on the bed. My Ford bakkie⁵³ was the bed. And she said “come sit here next to me”. So I came and sat next to her, and she went and lay down on the pillow and she says “lie next to me”. And as I lay down [...] my daughter ran [snaps fingers] like mad, to the nurses’ station. Because the injection that the doctor wanted to give me [...] was there, waiting for this moment [... And] my wife said they came in, stuck it in, pushed it, and that’s the *last* I remember.

After three days without sleep, he then sleeps for 24 hours. A similar pattern break is described by C1: “they had given you something to sleep but it really [...] didn’t break the [hallucinatory] cycle until they put you under, and you rested for that little bit of time”. Here, it is chemical restraint that breaks the cycle of violence.

Theme 2: Loss

They lose orientation on time, environment and place and stuff like that so those are the ways that we see them, so it’s mainly changing behaviour, disorientation; and they become psychotic. (S4)

Delirium is not simply about visual hallucination, it is multisensory, and immersive. In P3’s delusions, “I could smell, I could taste, I could see, I could feel”. S8 describes an older patient

⁵² I said to [the doctor] “you cannot give me that injection”, so he decided “this man is a bit bigger than me” [...] “OK we’ll leave that”.

⁵³ Afrikaans slang for a small truck.

disappearing into her own world: “she’s knitting, drinking tea, talking to her granddaughter, she’s having a ball there. But absolutely nothing in front of her”. Given the widespread neurological impacts discussed above on p.11, it is unsurprising that delirium would affect more than just sight or sound; it also means that people experiencing it are immersed into a new world, and lose contact with the ‘real’ one around them.

The process of loss begins, but does not end, with this split. In a Gifford lecture at Glasgow University on “Illusion, Delusions, and the Brain”, neuroscientist V.S. Ramachandran (2013) lists four of the “dozens” of attributes that define our sense of the self. First, “unity – you feel like you’re one person acting in the world”. Second, “continuity in time [...] having an autobiography, being able to look into the future and look into the past”. Third, “a sense of agency”. And fourth, “self awareness [...] a sense of personhood”. All of these are challenged by delirium – as well as a sense of location in space.

Loss of place

When HCPs describe patients’ loss of orientation to place, they are generally referring to a diminished understanding of reality. People are either unsure where they are, lose visio-spatial awareness (“lying oddly in the bed” – S10), or lose orientation entirely, leading to “inappropriate” behaviours such as (to give one extreme example) passing stools in the passageway of the ward (S5).

These descriptions generally pertain to encephalopathy. Three of the four patients describing hospital-induced psychosis suggest, however, that rather than *diminishing* our sense of place, delirium can put us somewhere else entirely. S6 confirms that while encephalopathic patients “will kind of know that they lost consciousness and orientation, but not know”, patients with psychosis will be “fully aware and conscious, but [...] confused and disorientated”. This appears to result in P3 finding himself variously in Dischem;⁵⁴ on display in a shopping centre; in his bakkie; and in his workshop. P1 is “cloned, put into the computer, and taken down various different levels of dream computer state”. P4 is “on patrol” in the rural northern cape. In *Part 1*, which again focused on hospital-induced psychosis, six of the ten former patients also describe being somewhere else: transported by plane, or four-by-four, or spaceship; in an underground waterway; on a pile of rubbish in the

⁵⁴ A South African chain-store pharmacy.

woods – the list goes on.

Loss of Time

1. Out of time

It was weeks. I was in the delirium for weeks [...] that's why I always ask you 'how long, how many days, how many days?' because in my delirium state, I was gone for weeks. (P1)

As we have seen on p.23, Bhat and Rockwood state that “temporal disorientation is essential [to delirium], not just because it is common [...] but because ‘time ordered-ness’ is integral to conscious experience” (2011, n.p.). In this study, S1 and 2 confirm that some of their patients have “whole, *huge* issues of time” (S1, interviewee's emphasis). Time seems to shift in numerous different ways, both inside delirium and as a consequence of it.

For P1, quoted in the box above, time has clearly *stretched* to a significant degree; he was in ICU for only a few days, but experienced it as weeks. And his time is also *disordered*:

I was having hallucinations about the operation. But I had already had the operation, and I was having hallucinations about being moved into an ambulance, but I had already been moved in an ambulance [...] Time was just totally out of whack (P1).

He goes on to describe the experience of reality thus:

you're just bringing information in and it's almost like you toss this information, all these different bits of information [into a] blender and it's all getting mixed up and none of it makes sense but you're in the blender, and it's all getting mixed up.

Reality here is not observable, linear and composed, but immersive, fragmental, and scattered. For P2, this disordering comes *after* the delirium, and impacts her confidence in her memory more widely:

[...] the order is the biggest thing. I'm sure things happened this way, and when I speak to mom and dad they're like 'no, no,' they happened before or after. [...] and then there are things that I *think* happened, and I'm positive that they were real, and then I think well, maybe they're not? (P2)

As we have seen on p.82, P4 relates his delusions directly to his past. Moreover he has no sense of how much time passed in the hallucinatory world. He says both that the hallucination was ‘flashes’, and that it was an entirely self-contained world, separate from the ‘real’ time of the hospital. Although his family tell him he flashed back into reality periodically, he has no memory of this, or of communicating with them.

S9 echoes P4 by saying that “they’re reliving their past”, but this is not always the case. Two interviewees in *Part 1* travel back in time, but it is definitively not *their* past – both find themselves surrounded by Victorian costume, and one in particular says that he has no idea where his surroundings have come from, and in real life has never been to the places he hallucinates. P1 is clear that his hallucinations are contemporary (although they have a sci-fi, futuristic quality), as are most of P3’s, P3’s most powerful vision, however, seems to occupy a kind of non-time:

I saw, and I can still vividly see it – that I was walking through a field of – it looked like corn, or lavender, or something. I didn’t know what it was, and then I came to the end of that field. And at the end of that field, only when I got to the end of the field, it opened a *total blanket of flowers*, and in that there was a sign [...] and I – I saw there, that it was on the sign, just standing there, “tell G— I love her”. And all I could at that moment think of is that Jesus has put that there for me to tell G—. ⁵⁵

Taking *Part I* and this study together, I would suggest that the highly symbolic or heavily image-based hallucinations, those with the fewest reference points with reality, such as P3’s above, may be moving *out of time* entirely. Often these are static, closer to tableaux, rather than a complete, quasi-real world through which the delirious person moves. Other examples from *Part I* include being “being on the edge of a cliff, looking down into the abyss”; a lift shaft in which MW has been for “hundreds of years”;⁵⁶ and “a vision of some matchsticks or candles – all different colours, all alight. [...] and then this person under a sheet of ice – a male figure, with this crown of thorns on his head”. All of these suggest a proximity to death, a kind of ending of time – and concomitantly of narrative: a flowering of pure image, “outside the loop of time”. I would suggest in fact that this is an unbidden creativity at the very precipice of personhood.

⁵⁵ G— is the name of P3’s wife.

⁵⁶ “it was grey, cobwebby, and dusty. [...] I could see a lift door, but I knew the lift was broken, and I’d been down there hundreds of years and I knew I was staying there – that was it, it was over” (MW).

I am left alone to find an answer. The figures mean nothing now. Meaning has gone. The clock ticks. The two hands are convoys marching through a desert. The black bars on the clock face are green oases. The long hand has marched ahead to find water. The other painfully stumbles among stones in the desert. It will die in the desert. The kitchen door slams. Wild dogs bark far away. Look, the loop of the figure is beginning to fill with time; it holds the world in it. I begin to draw a figure and the world is looped in it, and I myself am outside the loop; which I now join – so – and seal up, and make entire. The world is entire, and I am outside of it, crying “Oh save me, from being blown forever outside the loop of time!” (Woolf 1931/2007, 646)

2. Fixed in time

For I have known them all already, known them all:
Have known the evenings, mornings, afternoons,
I have measured out my life with coffee spoons... (Eliot 1920, n.p.)

On the other side of the coin, clock time plays a very particular role in ICU, perhaps in more conscious patients:

you are just bored. You live from breakfast [to] lunch and dinner, but I just ate out of the tube the whole time, so [...] And then I knew it was coming, you know, the injections and – everything works on a routine [...] they should have mixed it up a little bit. So I didn't know what was coming next. (P2)

The boredom, and the dependency on drugs, means that time is marked out very clearly for some people. As S9 puts it, “they’re counting the minutes”, and “they know when it’s four hours” (the allotted time between doses of pethidine). This time-consciousness is matched by HCPs themselves, a habit ingrained over years of nursing: “I know exactly when it’s 15 minutes later, half an hour later, an hour later – ‘cause your observations of the patients, it’s [at] 15 minutes, half an hour, an hour”.

Time, it seems, is either a trap, just like the other (physical, sonic, visual) impositions of intensive care, or it loses its anchor in the self – drifting, stretching, collapsing; sometimes disappearing entirely.

Memory

What do people remember of the experience? S6 says that “psychotic patients remember almost everything or a lot”. S3 similarly says that one former ICU patient who “experienced a whole ICU psychosis episode and was on multiple meds [...] remembers almost every single thing that happened” (in his hallucination). Certainly the rich detail given by many interviewees in both *Part 1* and this study backs this up. P4, for example, can remember which song was playing in the shops in his hallucination. It seems, moreover, that these memories endure. Ten years after the experience, P3 says that “that to me is – very scary [...] something out of this world; I’ll always remember it – *always always always*. And I can actually still, if I close my eyes, and I focus on what I – I went through, I can actually pick up all those various things” (P3’s emphasis).⁵⁷ In relation to these longer-term impacts, S6 notes that she is “seeing more and more” hallucination-related PTSD, post-ICU,⁵⁸ while P2 notes the long-term impact the experience has had on her general faculty for recall, which “is a lot worse”, as well as the re-traumatising impact of returning to the hospital: “it brought you back to that state of mind that you were in at the time. [...] That sense of trauma that you were there; it’s revisiting the scene”. S3 also describes the difficulty the long-term ICU patient mentioned above had visiting the hospital:

He didn’t want to come in the doors of the ICU. [...] I said “why don’t you come and say hello to everyone?” and he said “no, I’m not ready to go back in there yet”.

P3 and P4 both distinguish their detailed memories from ‘reality’, however: “I remember all of it, but the reality has been told to me” (P4). Each of those who had experienced delirium expressed a dependency on their family for the ‘real’ narrative, filling in gaps, re-ordering events, and so on. This is confirmed by S4:

Most of the times [sic] they are not aware. Unless if a family member tells them that this is what happened [...] And they feel very embarrassed about it [...] They could recall events before the episode [...] and then from there they don’t know exactly happened. (S4)

⁵⁷ S1 and S2 also discuss a longer-term paranoia that seems to have taken root in a patient post-transplant: “she had *many* episodes – when you looked at her she had these big wild eyes, of not knowing where she was, why she was here. And she did things where she would drive to the airport and lock herself in the boot of the car”.

⁵⁸ S6 notes that this may be because she is “more alert to it” thanks to an increasing literature on the relationship between ICU and PTSD (e.g. Maldonado 2008; Wade et al. 2012; UCLH 2014).

It seems likely that encephalopathy would impact memory in a different way from psychosis, given their respective chemical processes. S1 says that ‘the liver patients, depending on their degree of encephalopathy, sometimes [...] don’t even *remember* the process of their workup [to transplant], never mind the process of their transplant’ (S1). Yet in both encephalopathic and psychotic delirium the real events are elusive. The difference is that few encephalopathic patients appear to hallucinate. And it is often the hallucination that people who have experienced psychosis primarily remember. In fact it is this *clash* of realities (hallucinatory and externally observable) that may be at the root of some of the longer-term impacts of delirium (see p.14). As ever, however, this is not always the case, and S1 describes one patient who cannot remember the hallucination, but remembers the feeling that inspired it: “she remembered having episodes where she was overwhelmed with the feeling that she was going to die. But she couldn’t remember the confusion⁵⁹ that went with that feeling”.

Our knowledge of how memory works in delirium is also compromised by a possible reluctance to discuss some details of the experience; fear and embarrassment may play a part here (see pp.37-38, and also *Control and Disinhibition*, p.103). S1 says that she senses some patients “guarding their hallucinations”; and in Phase 3, S7-9 and S10 all suggests that amnesia maybe a defence mechanism: “not traumatising yourself with the memory” (S10).⁶⁰ S10 further suggests that HCPs’ knowledge of the experience in general may be compromised by the etiquette of patient-clinician relations:

I think it’s harder to talk about than a side effect of a medication. Or “my wound isn’t healing”, or “my stitches need to come out” [...] I would never go to someone and go “you know when I was in hospital and I thought you were all gonna kill me and rip my head off, well, actually, I’m still having dreams about that now”. (S10)

S10 makes it clear that this depends on the relationship between patient and clinician, and also suggests that it might be a more likely conversation with a receptionist, nurse, physiotherapist – implicitly professions where both the hierarchy is less pronounced and the patient is more likely to spend more time in casual conversation.

One last example to note in relation to memory is the exacerbating impact of alcohol:

⁵⁹ The term ‘confusion’ is used here to refer to the patient’s hallucination of a fragmented body, described on p.107. See also p.76 on the use of the term ‘confusion’ to denote delirious experience.

⁶⁰ For a brief discussion of these dissociative states, see Ramachandran 2009.

He was an alcoholic [...] And he had *big* episodes missing. He can't remember *this* episode, but he remembers being a bit aggressive *there*. [...] I remember him telling me "there's chunks of my life missing; first of all there's chunks when I was an alcoholic, and then [...] there was chunks when I was so sick that I *couldn't* drink [...] but I can't tell you what happened in those 18 months". (S1, interviewee's emphasis)

The impact of long-term alcohol abuse on memory is well-documented (e.g. White 2004); for a patient experiencing multiple deliriums (see p.69) this may be a significant factor.

Control

[T]he loss of control; I think it's a huge, huge, huge thing in the ICU. [...] even if] you were one day in the ICU, still you can't walk, you can't really eat for yourself – I think all these things contribute to [...] your status. (S7)

Delirium could of course be defined as a loss of control of mental faculties. One fundamental issue this raises is patients' capacity to make choices about their own treatment:

[W]hen we get a patient who presents with an acute liver failure, there's always something that bounces in my head about: 'they're encephalopathic; they don't actually know who they are or what they are. [...] and therefore they can't make that choice'. So family members make the choice for them. And we actually don't know if it's a choice they *wanted* to make.

Although this is of course a serious issue, the question of control I want to discuss here is larger and more amorphous – and relates to the wider situation of hospitalisation.

I am nobody; I have nothing to do with explosions.
I have given my name and my day-clothes up to the nurses
And my history to the anesthetist and my body to surgeons.

They have propped my head between the pillow and the sheet-cuff
Like an eye between two white lids that will not shut.
Stupid pupil, it has to take everything in. (Plath 1960, n.p.)

In "Tulips", Sylvia Plath examines the passivity required in hospital spaces, the waiting, the exposure, the timelessness, the silent absorption of our personalities. The stories of three of the four people interviewed who experienced delirium, however, defy this norm, and are threaded through with different means of expressing or exerting control over circumstance.

P2 says that “I don’t like to not be in control [...] even if I’m not in control, it must be *my* decision”. In this, she meets with considerable success – to the point where her mother says explicitly “You had control” – a sentiment rarely expressed after periods of time in hospital, certainly during periods of such extreme illness.⁶¹ Indeed the risk involved reminds us *why* it is so unusual. P2 treads a dangerous line between asserting the kind of control that will ensure her psychic survival and defying her doctor’s instructions: “She said to me a few times that I was gonna die if I didn’t listen to what she was saying and [...] some of the stuff I did and I hated, and other stuff I was just, like, no – I’m not doing that”. As the gatekeepers of her decision-making, her parents share the pressure of this risk: “you’d just got up from the couch, and you took down the drip [...]. That was awesome, and I thought ‘oh God, now – if I let her do it, and she dies,’ you know” (C2). It is clear from our conversation, however, that the control she takes is felt by all three to be directly linked to P2’s recovery and general wellbeing. As I note on p.18, I have not yet found literature that directly relates a sense of control to recovery, but links have been made between helplessness and perceptions of pain (Müller and Netter 2000; and Müller 2011), as well as between stress and recovery (e.g. Gouin and Kiecolt-Glaser 2011). Humour, too, plays a significant role, becoming P2’s primary means of communication, a way to break the isolation and boredom and connect with the distant figure of the medical professional: “if anything makes me uncomfortable then I’ll go the humour route [...] – even if it’s so inappropriate”. Her parents admiringly confirm that “she was outrageous”. The shock she generates through being humorously inappropriate is an expression of agency, a way of asserting herself as a distinct person, one who has the power to make people laugh. More broadly, as I describe above on p.54, in both *Part 1* and the current study, interviewees often laugh when describing their hallucinations – another expression of agency. The use of this humour in the musical composition (for example in “Naked” or “Pleasantly confused”) is, as I explain above (p.58), intended to acknowledge this agency.

For as long as I can remember I have had dreams about losing power over my life. These nightmares of dependency [...] must have been reawoken by the systems of intensive care, which dissolve the patient’s will in a sort of therapeutic absolutism. (Hughes 2011, 16)

Our fear of “systems which dissolve the patient’s will” is profound and frequently leads to counter-productive behaviours. This is strongly evident in teenage patients as they transition

⁶¹ I base this generalisation partly on interviews conducted for *Part 1* and Wainwright and Wynne 2016, and partly on many years’ experience of work in hospitals.

to new levels of independence, and frequently refuse treatment (see Machado, Succi, and Turato 2010 on the challenge this presents to clinicians). An extreme example is found in the young patient S1 describes above on p.78, who “*chose* not to be re-transplanted. [...] and it was very disturbing because she *made that choice*. I mean the surgeons were begging her to have a second transplant” (S1’s emphasis). P2, though, conducts a tricky balancing act that appears to allow her to maintain a sense of agency through the hospital experience, connecting her back to her previous self. Where she seems to stumble is *after* hospital, experiencing a massive loss of confidence. Her relative control in the contained space of hospital gives way to a more diffuse loss of control afterwards: “hospital for me was easier than *now*. [...] I feel like it was on me, and I decided what I was gonna do. Now there’s other people involved, and so it’s not just about me” (P2).

P3’s loss of control clearly happens in hospital. But he also finds a means of reasserting himself, *through his hallucinations*. After being (in his delusion) “smuggled out the back door” by the doctors, for example, he responds by (actually) telephoning his wife at 6am, asking her to “bring the whole family here *now*”:

her, my daughter, my grandson, my son, my daughter-in-law, my granddaughter, all rushed through, thought “this is the end”. [...] And I said “Listen. This is what’s happened; they displayed me, I’m not happy with it, and I want to sue the hosp[ital], the doctors”. And I said to my son, “You, you will see that none of them come into [...] the boardroom [...] with anything other than their underpants on. Because I don’t want them to have any recording apparatus on them, or anything else”.⁶²

As we have seen on p.87, P3 also reconfigures his hospital room (usually a very *passive* space) as his workshop (a very *active* space). As he moves the furniture to achieve this, he ruptures his sternum. As with P2, physical risk and psychic survival are weighed against each other. P3 describes his activity as a manifestation of his nature – assertive, practical, self-reliant, physical: “When you’re like me, [...] I don’t stand back for nothing. *Nothing*”. But he also admits that his assertiveness tips over into something more problematic:

we were walking down the passage [...] And I remember saying to the Sister, because she was holding me and holding, I said to her, “look, do me a favour, don’t pull me, don’t try and make me do something I don’t want to do. Let *me* do it. Otherwise, *you* are the one that’s gonna come short”.

⁶² P3 enjoys this anecdote, and describes his grandchildren laughing uproariously and having to leave the room.

The phrase “don’t try and make me do something I don’t want to do” is precisely comparable with P2’s “you can make it a suggestion, [but ...] don’t tell me that I have to do it”. But where they differ is both in how this attitude manifests itself, and in their physicality. C2 says of P2 that “she looked like 12 years old, so I think they all felt sorry for her, the doctors”. P3 on the other hand, is “not a small person”, with the consequence that after his exchange with the nursing Sister in the corridor, “she thought ‘well that’s it, if he hits me I’m dead’ [...]”; she said to my wife, she was *terrified*” (P3’s emphasis).

P3 also describes the following hallucination:

In that period, I was told – so, told, but not realistically [...] that my doctor was diabetic, which he isn’t. And he was manufacturing his own insulin [...] I could remember that he came in and he said “[P3], would you [...] like to go and help with the insulin?” And I said “yes I will”, and I can still clearly remember having to go to the end of the ward to go in and come around into the laboratory, and starting helping manufacture insulin. And then he had a [...] low, or a high, whatever it is for – for the insulin, and we had to [...] administer the insulin because he passed out.

In fact it is P3 who is diabetic, but seems to have swapped role with his physician, first collaborating with him, and then treating him. This is the obverse of the usual *done-to* hospital relationship, as it is described by S10:

You’re kind of suspended, with very little control over what’s going to happen. At *all sorts* of different levels. From what diagnosis is going to be made to what treatment is going to be made, to what investigations are going to be required, when those investigations will happen – even down to when you’re going to see your doctor, you have absolutely no idea. (S10)

Where P2 seems to maintain her sense of self by asserting *conscious* control over her treatment (humour, defiance), in P3’s case this balancing act is undertaken *inside* his delirious state: bringing in his family to deal with the hospital, building a workshop in his room, threatening his nurses, treating his doctor. Both P2 and P3 demonstrate a strongly maintained sense of the type of person they are: “I don’t like...” “I don’t stand back...” etc. Their different assertions of control perhaps contribute to this maintenance.

P4 is, as we have seen above, may be unusual: “I never felt threatened. [...] I was in total control [...] I didn’t have a fear”. He is neither active, like P2, nor fighting against passivity, like P3, but instead both accepts his position – “I had a job to do and that was that” – and

transforms it into that of protecting others. This is unusually outward-looking, and also gives him back some control: he is not the attacked, but the defender.

P2 talks about a number of different doctors involved in her care at various stages in her life. She differentiates strongly between her current physician, a father-figure who clearly follows a collaborative (Charon-esque) model of care – “he always made me feel like I was included, like it was my choice” – and a former physician, who was “very old school [...] very unapproachable” (P2); “he hardly looked at us [...] he hardly spoke to you” (C2).

Unsurprisingly the former experience was “more traumatic” (P2). It also featured “horrible” hallucinations (the devil in the place of her mother, crocodiles), while under the care of her new team she reports in the main “happy hallucinations” – of fairies, and of beneficent, protective figures like her own dog, and Isabel Jones.⁶³ This could of course be attributable to any number of circumstantial and treatment factors – but I would speculate that her relationship with her physician could be one of these.

It is worth noting more generally that not all delirious experiences are negative. S3 notes that for some patients the experience appears to be benign – “we call them pleasantly confused” – and S7-9 also talk about “pleasant” hallucinations (interestingly, all four of these interviewees associate this type of hallucination with older women). S5 discusses euphoria: “the opposite side of things, suddenly you’re so happy [...] We’ve had one man, he’s like so excited to see us in the morning post the transplant”. But this is not necessarily allied with control. S5 notes that “the same patient who was euphoric on day two, on steroids, and ‘I’m feeling great’, [...] a week later was seeing things, and persecutory delusions on Prograf”. P3, as we have seen on p.84, experiences a transcendent vision, but his response could be read as one of awe more than pleasure – he is at once terrified and exalted by his helplessness, using phrases like “very scary”, “out of this world” and “absolutely beautiful”.

A lack of control extends, too, to families and HCPs. I note in my observation that “Wife arrives to see man behind me [...] husband is about to be taken to x-ray. Relatives must adapt to whatever greets them when they get here” (see Appendix 5: Notes from observations). On the same day, I am “Struck by constant-ness of work. *Responsiveness*. Do you make a plan or do you just respond all day?” In Phase 3, S2 confirms that “ICU staff are

⁶³ The fairies seem associated with an improbably upbeat experience of lung-draining: “I said ‘ooh look at the fairies dancing in the wall’, and I was like ‘what are you getting out?’ and he was like ‘it’s a bit of blood and a bit of liquid and stuff’; I was like ‘is it a *lot*?’ [...] I felt like [...] is there like a competition that I’ll win if a lot of liquid comes out? [laughs]”.

generally stressed. They live on this hyper-accelerated [...] adrenaline response: What's gonna happen today? How's it gonna happen?" When S10 says that "we medicate them to make them manageable" (see p.79), it is worth bearing in mind that this management is about the patients' own safety: "most nurses like to be in control. To know the patient is safe – 'cause that is ultimately what we do" (S7).

Control and paranoia

If P2 demonstrates a connection between agency and recovery, P1 describes the opposite:

I think being ill, and I think being in pain [...] at that point you know something's going on, you know you're in a hospital; but you don't really *know*. And you know a little bit about what's going on. But [...] you're confused, and some paranoia sets in. (P1)

The immediate consequence of P1's loss of agency, compounded by an absence of facts about his own circumstance, is paranoia. S6 suggests that "confusion, paranoia, and anxiety fuel the hallucinatory states". And indeed in *Delirium Part 1*, PL's sense of doubt about her own condition, and her inability to identify the characters around her, appears to manifest itself in figures of the dead around her:

you're in so much pain, and you're not sure of what's going on; you know you've been injured but you don't know where – you're sort of in and out of consciousness; but I found that as I laid in bed, the nurses would come to see me or the doctors and all I would see was a skeleton, and I couldn't see their face; so every time I closed my eyes I thought "well, am I alive or dead?" [...] it was like *horror*, cause every time somebody came to me all you saw was this skull, the skeleton of these people. (PL, in *Delirium Part I*)

Here are two further examples of paranoias, from the present study and *Part 1*:

The nursing staff were the newspapers and they were coming to report on his case and the people around the table were all spies [...] he *completely and utterly* believed: reporters, spies, the charts, the TV had a camera in [...]. And the anxiety that went with the paranoia was *huge*. (S1)

Then my name appeared in the newspapers talking about me – and it was really derogatory, and it was picking out all the *worst* characteristics about myself in the newspaper, and I thought oh no; and then I kept wondering why my brother hadn't spoken to me and then I realise that my brother was going bonkers [...] publicity would not be good for him (LO, *Part I*)

It is notable that both people worry about the newspapers. The sense of being exposed to public disdain could easily be mapped back onto exposure intrinsic to ICUs: clothes gone, body revealed, outside and in: “you’re in that semi-conscious state, and before you know it the sheet is down, and [...] you’re lying there naked” (S2, Phase 3).⁶⁴ In the same vein, as we have seen on p.88, P3 believes “that the doctors had taken me to a shopping centre in Alberton and displayed me”; while in *Part 1*, MW was “sold as kebabs”, his exposure (as it often is in ICUs) being right down to the flesh. The image of the TV with a camera in (in S1’s testimony, above) is also telling. The watcher becomes the watched – a role-reversal that suggests immense vulnerability.

I note in my first day of observation that “Machines totally mysterious. Often with tentacles of tubes etc. Articulated arms”. I am also aware that much action occurs *behind* the patient: “Plastic bag behind me – not sure what [the nurse] is up to [...] nurse works behind patient”. On the second day I recognise “how I – a person sitting here, writing, in the eye line of the patient – might induce paranoia”. And on the third I note that “From the far end I can hear a man in distress. I could see him from reception, I could locate the cries. This woman next to me – in fact everyone here – can’t see him. They can only hear the wails”. As with P1 and PL, the facts are missing, and what sensory input is available, to say the least, invites suspicion.

If as S6 suggests, paranoia is “fuel” for hallucination, delirium could be seen as an extension of the baseline paranoia we all experience in the uncertain, uncontrolled space of hospital, where “You’re kind of suspended with very little control over what’s going to happen” (S10). In fact it can be hard to tell where ‘normal’ anxiety ends and delirium begins. S7 makes the point that “you can have a conspiracy syndrome in a normal work setting [...]; if your body’s under stress then it’s even worse”. And indeed some paranoias are relatively ‘domestic’. S1 says that in some cases, “the delirium’s not as obvious as having hallucinations, but it’s almost like [...] ‘why did you close all the doors here?’” P3, having undertaken some peer support work at the hospital, describes exactly this situation when he is asked to speak to a paranoid patient on the phone:

I said to him, “listen, what’s happening?”
“No, they’ve locked me in the room.”

⁶⁴ In my observation, I contrast descriptions of a glamorous nurse with a man “at the [nurses’] station. Nurse is tying up his gown at the back. Receptionist is trying to explain something to him. [...] he walks away very upright, holding the back of his gown together because it can only be tied at the top”.

I said to him, "OK. Do me a favour. Hold the phone to your ear, go to the door."
I said: "Open the door."
"I can't, it's locked."
So I said to him: "OK. Push the handle down. Have you pushed it down?"
"Yes."
"Pull on the door."
"It's open, they unlocked it?!"

P3 explains that the ICU staff had closed the door, but "you – that person, [...] pulls the handle, and [...] it's not open. He's not thinking 'push it down and pull it'. Just 'open the door because – it must open'. And [...] to him, then, it's locked". Paranoia, coupled with cognitive limitations (not thinking to try to push down the handle), seems to cause the re-interpretation of real events. I would characterise this re-interpretation (I use *re-* rather than *mis-* deliberately here) as elements of reality woven into an alternative narrative. P1 describes "about 75% dreamworld, 25% reality [...] blending what was occurring into this unconscious or subconscious view [of] reality". This tendency to blend two realities is also strongly evident in *Part 1*, where MW suggests that "you use part of your surroundings, and then your mind makes things up". And an interviewee in Wainwright and Wynne (2016) explains that "every hallucination, bar one or two [...] had a basis that happened, or something was said and then my mind took it somewhere else".

This reconstitution of reality also manifests as a re-casting of roles. Many interviewees in *Part 1* register the dominant presence of the nurses, for example, but understand them to be military police, terrorists, skeletons, or animals, and believe them to be an immediate threat. S7-9 confirm that patients often feel nursing staff are conspiring against them. P1 reads his nurses as "officers in the air force", involved in his subjugation. P4 gives them more benign roles, as "senior inspectors that were looking after us, the minister of defence, that type of thing". He remembers being tied up (in reality as well as hallucination), but "went to the head of the prisons department" and seems content with the explanation that "we're just doing this to protect you" (again, P4's attitude to persecution and threat may be somewhat anomalous).

Nor is it just the nurses who are re-cast: P2, for example, says that "mom I know at one stage had to come and sit with me, because I couldn't sleep, and I remember she was holding my hand. And I looked over and the devil was sitting next to me holding my hand". P1 experiences a particular version of this paranoid misidentification, believing himself and

his wife to have been cloned “I could tell that this was a clone, because she had a microchip in her neck” (this is known as a Capgras delusion; see for example Blom 2005, 84-85.).

As we have seen (on p.6) Robert Hughes, too, re-interprets reality, when “something weird [...] fixed to my right arm, driven into the flesh, immobilizing me” turns out to be a medical device (2006, 17). The misunderstanding of devices is a frequent problem – S5 says that “the normal act of putting up an antibody becomes a persecutory thing” – and may be part of why patients strive to remove what is keeping them alive: drips, and even tracheostomies (see p.84 above). A visitor to Hughes writes to him describing his ordeal thus: “You woke, a look of utter terror on your face [...] and then began trying to disconnect all the various tubes which were keeping you physically stable” (2011, 16).

Control and racism

In a few cases, interviewees note a relationship between this paranoia and latent racism.

I think it might also be racially motivated in a lot of cases. Because if you speak to patients during that time they’ll be quite derogatory about the black staff. [...] And then when they’re speaking to *you* [indicates self, a white woman] it’s quite – you know, you can hear the racist undertones. [...] Depending on the age group of the patient and stuff like that, I mean – we live in South Africa and we get a lot of the very staunch Afrikaans strong male figures; and you can spot it a mile away, you really can. [...] I’m not saying *all* the cases. [...] I think [in] some of the cases [...] they’ll be more paranoid of a black man than they will be of a white woman, for example. [...] I have seen that. Even from my days at a previous hospital when I was looking after patients. You’d see that. (S3)

S7, too, says that “racism comes out a lot for me when people are confused”, particularly in elderly patients. She describes one woman calling her over in ICU to say “she wanted to speak to the only human being here tonight. So the rest was just black people, and I was the only white person”. For S7-9 this is *not* specifically a South African phenomenon, the patient in question being English (“Quite a bit of racism over there too” – S9) but relates more to age: “it’s the way they’ve been *moulded* all their lives” (S9’s emphasis).

It is worth bearing in mind that this is S7’s interpretation of the patient’s statement; knowing that at least two other interviewees in this study and *Part I* have seen humans as skeletons, or the devil, it’s possible that ‘human’ means just that – human as opposed to

demonic or monstrous, not white vs. black. And later in the interview S7 expresses some doubts: “I don’t know if she meant what she said”. But assuming that there is something in S3 and S7’s initial assessment, racism may tie with the Allen and Sherman’s 2011 findings of a correlation between ‘ego-threat’ and increased prejudice against other races. Robert Hughes’ “fiendish Chinese doctors” may attest to this same phenomenon – even as he satirises his own racist subconscious for deploying such a cliché:

I realised (in the dream) that it had been implanted surgically implanted there by two fiendish Chinese doctors who were not only slave traffickers but Maoist spies. Their names were Dr Wong and Dr Fong.⁶⁵

Control and disinhibition

S3 and S7-9 all suggest that racism is the public appearance of something normally suppressed, something ingrained in these people’s personalities. But there is some inconsistency here in the data, as HCPs struggle to determine whether delirium is exposing fundamental characteristics or creating false ones. S2, for example, suggests that delirium amplifies existing traits: “if a patient has a tendency of being sad, they tend to get *very* sad [...] And if a patient has a tendency to get angry, they get *very* angry” (S2). S3 thinks that “their *real* personality comes out” when “some of them get really mean and really nasty and quite vile”. S8 similarly suggests that HCPs sometimes witness behaviour that “your conscience suppresses”. This familiar idea of a Mr Hyde evicted from his Dr Jekyll exterior by circumstance and drugs is countered elsewhere the data, however, by the sense that difficult delirious behaviour has nothing to do with the person’s ‘real’ self. S1 for example describes a patient as “aggressive, he was *rude*, he was swearing at us, he was [...] *agitated*; he was like the sort of human being that you didn’t want to help”, but swiftly explains that after his recovery he was “the *sweetest, kindest, gentle* man”. S8 empathetically places herself in the picture by saying “my personal feeling: any one of us can actually lose it one day and end up in a psychiatric hospital, because [...] it’s a fine balance in life, that tips you over”. And S5 says “they are dignified people in their way, and obviously they do not think that [...] they could have such episodes in their lives”. Here, the implication is that personality is a construct, involving agency; and the moral implications of a real self emerging from under a gag are gone. Finally, S7 points out that it is ultimately impossible for

⁶⁵ The satire is in the word “fiendish”. Later in the book he calls Australian illustrator Norman Lindsay an “execrable racist” for his images of “Australo-Aryan heroes protecting white womanhood from pigtailed Chinese hordes” (2011, 84).

HCPs to determine what is characteristic or not: “we don’t always know how they are beforehand, [...] a few people would say ‘yes he is aggressive like this at home’, [...] but not everybody would declare that. So you can’t really *know*”.

The relationship between delirium and disinhibition seems clear, however. In encephalopathy this is described as manifesting physically: S4 and S5 both describe nudity, S5 describes defecating in the ward passageway or in the bed, and again ‘aggression’ is mentioned frequently in relation to both psychosis and encephalopathy. S6 also relates this to *regressive* behaviours: “I felt her to be transgressing boundaries, and behaving in a way [in] which a three-year old would behave [...] wanting to play” (regressive behaviour is also noted in older patients by S7-9 – see p.111-112).

Some of the disinhibitions in relation to psychosis seem qualitatively different. In some cases it is verbal disinhibition – thus C1 says that “he would *never* curse in front of anyone”, and S9 describes the loose tongue of a teenage boy:

The first thing he did when we extubated him, he was going [smacks lips] –
and I said to him
“[Name], what’s wrong?”
“Where’s my scafe? Where’s my scafe?”
I said “your mother’s here!”
But he was so confused; all he wanted was his scafe.⁶⁶

In others, disinhibited sexuality is described. S7-9 agree that sexuality is “increased in ICU settings [...] even in the ward sometimes”. They “always say things to the nurses that [...] I don’t think they would have said [...] in a normal situation”. In a mild version of this, P1 jokes to a doctor that “I feel OK [...] but I’ve gotta quit hanging from the chandeliers when we have sex”. C1 notes this as a moment when both she and the doctor realise P1 is becoming delirious, and says “he would ordinarily *never say anything like that*, in public, to anyone”. For S7-9 this heightened sexuality is “not the women as such, [...] you find that more with the men”. As we have seen, however, S1 describes a reduction to “eating, drinking, sexual needs” in a teenage *female* patient.

Sexuality is entirely absent from the interviews in *Part 1*. But there are of course plenty of reasons for that other than its absence from the experience. The impact on the frontal lobe suggested by Yokota et al. (2003) and van der Kooi et al. (2015) (see p.11) confirms the

⁶⁶ A marijuana water-pipe.

likelihood that delirium brings with it sexual disinhibition. The nurses make a tentative association with testosterone, and thence with 'aggression'. It may be that the libido – in the broader sense of a life-force⁶⁷ – is asserting itself, through sexuality and violence, in the face of significant threat. But it would need a far more substantial research process to start to uncover these details with any thoroughness.

Loss of Self

In his essay "Sound and the boundless body", Tom Rice talks about the hospital as "producing a continuous soundscape to which the body contributes" (2008, 44). He explains how illness exposes us, our acute vulnerability, in this way:

Sounds that issued from within leaked and bled involuntarily into the world, transforming the body into a porous membrane. Suddenly there seemed to be no clear line between where the body ended and the world beyond began. The acoustic of the hospital made it hard for certain patients to preserve a sense of their bodies as bounded, self-contained entities (Idem., 43).

As I suggest above (p.100), ideas of containment and exposure seem to me to be vital to interpreting delirium. Through illness and trauma, our sense of self as a 'bounded' entity is exploded.

I spent quite a bit of time talking to her after transplant. And she used to say to me "I can see my feet there. I can see my arms there" [...]; she pulled her body apart in terms of a lot of pieces. And then as the confusion got better, she could see her whole body. So for me [...] that was very spooky and unnerving, because I kept thinking she was going to die and that she was almost perceiving her own death; and she really was minutes away from death. (S1)

The fragmentation S1 describes above could be interpreted from a Lacanian perspective – a shattering of the mirror that gives us our sense of self. It is interesting therefore that S7-9 mention using mirrors to help long-term ICU patients recover a sense of self:

as soon as you're giving them a mirror [...] to have a look at themselves, [...] you know they can look at themselves and they can see "Oh, OK, I've got a

⁶⁷ Merriam-Webster defines libido "as instinctual psychic energy that in psychoanalytic theory is derived from primitive biological urges (as for sexual pleasure or self-preservation) and that is expressed in conscious activity".

tube here, OK, I've got a line here". It just gives them [...] a bit more of a sense of *responsibility*, back to themselves again if they can have a look at themselves.

S2 says at one point that "they're encephalopathic – they don't know who they are or what they are" (S2). If, as Ramachandran says, our sense of self is dependent upon our senses of autobiography, agency, and personhood (2013, n.p.; see p.88 above), the compounding effects of the losses above are more than likely to result in a crisis of identity. Moreover, in both *Part 1* and this study, the majority of former patients describe experiencing *as real* something their loved ones do not experience: "it is realistic. *Very, very, very* realistic. And people don't understand how realistic it really is" (P3's emphasis). S6 mentions two patients "who've had a kind of body memory of their medical interventions, which they then are not sure of after [...] did it really happen or didn't it?"

Andrews 2013 and Hoffman 2013 both also speak to this clash between realities. It is a brutally isolating phenomenon, which curiously reinforces loneliness whilst upsetting the boundaries of the self. Robert Hughes says:

I knew that even if I had been able to describe these states and narratives, these loved ones could not have understood their import. [...] To explain the details, to show by what twisted, metaphor-ridden paths they led back to core experiences whose nature was barely evident even to me, would have been a hopeless task; I lay in the middle of these narratives like a man who has cut the binding strings on a coil of fencing wire which, springing anarchically from confinement, now has him in its tangled embrace. (Hughes 2011, 14)

Like P1, "in the blender", Hughes lies "in the middle of these narratives".

Theme 3: Humanity

Emerging from the whole body of interviews, this final theme depends on a sense of the interlocking roles of the three groups interviewed: the delirious person themselves, their carers, and the HCPs who treat them.

Delirium is in some ways a retreat into the self. The Capgras hallucination experienced by P1 (see pp.101-102 above) exemplifies the way in which loved ones may remain important figures in the psyche, but are no longer recognisable in external reality: “the real [C1] was supposed to rescue me”. S7, too, talks about “this guy, who loves his wife, and then the next minute he doesn’t know who she is”. In our “fight or flight” (P1, S7) state, we lose contact with everyone nearby. S7 also describes an episode in which a patient projects what he hears on the radio onto his own circumstance: “there was something on the radio about some attacks [... and] every time one of us walked in, he assumed we’re gonna attack him”. Delirium is a solipsistic state, in which the external reality we *can* perceive becomes a manifestation of our own fear, with the ironic consequence that we put ourselves at greater risk. Thus S3 says that for “the patients who’ve got that frantic paranoia, nothing else matters, apart from the fact that someone’s out to hurt them and somebody must come and save them. So they could be bleeding to death and they wouldn’t actually care”.

All of this is of course extremely challenging for families:

in general the family finds it extremely traumatising – very difficult, and that applies both to the psychosis, and the encephalopathy. So I’ve had husbands/wives say “we know the kind of physical symptoms, and they’re frightening, but when you come here and your wife can speak to you clearly one day and the next day you come and she doesn’t know where she is and who she is, that’s very difficult”. Equally, the psychotic behaviour they find extremely disturbing. So for family, that’s very distressing. (S6)

It may be worth reminding ourselves at this point that none of this is taking place in a psychiatric unit. This is acute care: a context to which families are conditioned to respond in quite different ways. From one HCP’s perspective, “I just think we’re all so used to it, it’s [...] par for the course” (S5), but for the families, “they become shocked” (S4):

So we see shock at first. And they get very anxious. Not knowing what exactly is happening. And only after a thorough explanation to say that this is what causes the problem and this is how we’re gonna correct it, and then with that understanding they internalise it and they are now able to cope. And

they will be the ones that are reporting to us that we are now seeing a change in behaviour. (S4)

Without this communication, the potential for conflict is clear. Trust is disrupted as soon as the parties cease to have common perceptions of events. S10 notes that delirious patients frequently accuse nursing staff of theft; and that families will then be put in the difficult position of not knowing who to believe. S5 confirms that families may be inclined to support conspiracy theories about HCPs “until we come in and say ‘no, it’s the drug [...] no-one’s tried to kill him, [...] the nurses didn’t do that to him’” (S5).

The impact on HCPs

S8 says “we get ICU syndrome ourselves”. S1 and S6 are the most vocal about the impact of others’ deliriums their own lives. S6 says “I feel quite traumatised by it actually [...]; it perhaps is trauma, it’s a kind of sense of fear, and vigilance [...] fear of being exposed to [delirium], because it appears to be so common”. And S1 talks openly about her emotional response: the “profound impact” of the young patient described above on p.78; her distress at a case of life-destroying, long-term post-transplant paranoia; the aggression, which is “the worst to deal with”; and the “spooky and unnerving” nature of some hallucination.

HCPs, moreover, are also subject to the pressures of the environment of care. S7 says that after ten years in ICUs, “I had to get out for my own sanity” (Phase 3). The sound of the ICU is of particular importance here; much of the discussion of the impact on HCPs is stimulated by hearing the draft music with hospital sounds embedded in it. Both S2 and S8 separately say that the sounds of the ICU return to them before sleep: “as you would get into bed, and you’d be drifting off, [and] the sound of alarms and fluster would still be in your head [...] because of that sensory input all the time” (S2, Phase 2).

Difference in understanding between HCPs and patients

For all that they occupy the same space, HCPs in this study are aware that they are missing much of the experience. Both S5 and S1 say that “we don’t pay too much attention” to the detail. S1 puts this down partly to its episodic nature:

[I]t's not hallucination and confusion for two weeks: it appears, you can have a rational conversation, and it appears again. So you're not witnessing the intense scope [...] we'll say to the doctor, the patient's confused, he'll go walk in there, he says "hello how are you?" Patient says "I'm fine", you know?

Looking back at my observations in ICU, I note that my tone changes across the three sessions. When I begin, "I like this space. It's open and oddly relaxed (to me as an outsider, but one who's not bothered by hospitals). Nurses are friendly and smiley to me – they don't seem bothered by my scribbling away, even if they don't know me". By the third short session I am increasingly conscious of the barriers under the surface:

While I was waiting at the front desk I could see all the interaction between staff – there's lots of it – questions, answers, general small acknowledgments. But nothing to the patients. They are like ghosts. For example, now, a nurse sits here at the charts, her back to [a patient], who regards her, for lacking in energy not to, perhaps? Now there's a gathering of four people round the chart. Cleaner, another nurse, a third nurse inside the isolation room. She watches them all but they don't acknowledge her. Too used to her. At last – lovely nurse – "are you still strong? How was your night?"

Communication is evidently a problem here. S6 says that "people just want contact in those states [...] human contact helps. [...] some people say that if they'd just [...] told me what was going on, or just that – could the nurse just talk to me, I wanted her to touch me or talk to me, or..." (Phase 3). Communication is repeatedly cited as a way to alleviate delirium. In some cases this is about HCPs describing their own actions: "we try and say 'we are gonna turn you now, we are gonna do this now'. And I think that always calms people, calms patients *more* than just coming and doing it" (S7, Phase 3). In others it is simple mechanisms (pictures and alphabets, S7-9) that allow patients to communicate despite tracheostomies or endotracheal tubes. S5 and S8 also describe the need to prepare families:

a confused patient can say harsh things. And you need to reassure the family that this is not a personal thing, [...] remember they're confused, they don't know what they're doing, they don't know what they're saying. So don't take it personally. (S8)

S5 states clearly that the impact of HE "depends on how well do we [*sic*] communicate back to them". But more often communication is poor, to the point of dangerous carelessness: "there was a patient recently who *heard* the doctor standing over him going 'this guy's gone'. [...] And he was aware of that [...] now he's very traumatised post" (S6). S7 confirms

that “they do speak like that, the doctors – well, us also [nursing staff], not just the doctors [...] sometimes you speak about a different patient, at that patient’s bed” (Phase 3). S2 says that “some of our patients comment that they would be examined, and the doctor doesn’t even say ‘good morning’”:

there’s a dehumanisation, I think that’s the word. Is that if you’re delirious, then you’re less than, then you’re not like me, then you’re not conscious, then you don’t need to be treated, you’re just objectified, cause you’re in a psychotic state, assumption being you don’t understand, you’re nonresponsive, you can’t hear. (S6)

Language is part of this, too. My observation notes ask whether “it exacerbate[s] the problem that (I assume) these patients don’t understand the language their nurses speak amongst themselves”. In answer to this, S10 (in Phase 3) says

if your language is not the language of the patient, I think it’s part of the dehumanising. So if it’s a patient that speaks x language, you’ll speak in another language *the whole time*; there’s this whole dialogue that’s going on and the patient’s completely incidental to that process [...] I’ve been on the receiving end of that and it’s a horrible feeling, cause you know that you aren’t the focus of it. And as a patient, you kind of should be, if they’re working on you – if they’re bathing you and sticking things up your nostrils...

But delirium is of course not exclusive to multilingual spaces, and the wider issue here is not so much linguistic as attitudinal. It is about acknowledging the *active* presence of the person in the bed, not simply the passive presence of a body, however carefully tended in those terms. Humanity here requires a leap of imagination. It is important to acknowledge that is not always easy to make this leap – to see a machine-dependent, and most importantly a *dying* person in the same terms as the active colleague beside you, or to recognise yourself in someone who is subversively pulling out a life-giving arterial line,⁶⁸ or coming at you “with his fists in my face” (S8). S2 tells me that “one nurse [...] couldn’t ever nurse again, that’s how badly injured she was”. Despite these manifest barriers, however, HCPs continue to behave in profoundly humane ways. Nowhere is it better exemplified than in S8’s story of a dying patient (also related in “Gloria and the Water”):

⁶⁸ S3 explains that patients – as is logical given the conspiratorial nature of delirium – will be deliberately secretive: “a lot of them quietly sit like this... and quietly nudge and slowly pull things out, so it’s not always something that you notice straight away; you’ll go back and you’re like ‘but I was just standing here and now the A-line out and the CVC [central venous catheter] line’s out’”.

he [knew] he was dying. [...] and then on the end of the day, he said “no more”. If anything happens now to him, it’s finished. We don’t resuss, no more antibiotics, I think he made up his mind, [...] we must leave him. So [...] I said to him “what would you like me to do for you today? If there’s *anything* you could choose. And it’s in my power, what would you like?” He says “I wanna go shower” [...] And I got him out of the bed – he couldn’t walk any more or anything – got him into a wheelchair, pushed him into the shower and I opened that tap, and I just left – obviously I was there with him, but I left him there; he sat about a half an hour, you know, water just running down him. [...] and then I took him outside; at [hospital], we’ve got a prayer garden, with a fountain. [...] and I put his feet in the fountain. And we sat there. And – we just sat. [...] You know when you’re just *there*. You don’t talk, you don’t ... you just embrace the moment. And then his wife came [and] said to me, “you know, he was a big swimmer, on [*sic*] his day; he loved water”.

Here, the patient’s dignity and identity is at least partly restored by S8’s treatment. Frank defines narrative medicine as “medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness” (2013, vii; see p.20, above). Clearly not all HCPs are equally sensitised. But if concerns about failure of empathy are threaded through this study, so are examples of its existence.

Reconstituting the self: Humanity and touch

As we have seen above (pp.105-106), S7-9 mention the use of mirrors in ICU, which seem to return a sense of self to patients. In other units, diaries have been used as a way of mapping the time lost to patients. In this study, the family plays a critical role in finding the thread back through the delirium. But during the delirium itself, there may also be a role for touch.

As I note above (p.87-88) and in Appendix 7, delirium is a multisensory experience. Within this, tactile sensations of various kinds play a significant role. As we have seen on p.71, for some HCPs tactile issues are diagnostic, since the skin is an area where we register interference with the body (cuffs and probes). But touch and its absence are also associated with care:

I read a interesting thing on Facebook the other day about a lady, [...] she says in the whole six weeks only one nurse actually came to her and told her things, who actually touched her. She said “nobody touches you, nobody – they come in, they go out”; she said [...] she’ll remember for ever and ever because he came in, touched her shoulder and said, “you’re fine today, this is how the weather is outside...” And this is what we *should* all do... (S7)

S6 also calls for “human contact” and “simple holding of the patient”. S7-9 suggest that for older people, the constant fiddling with the material around them⁶⁹ is about regression and security “we think of a child with a security blanket, what do they do?” (S7). And S1 also speculates about whether this need may relate to the absence of touch: “I almost wonder whether there’s that need [...] they touch the paper, and then they touch the clothes, and they touch their skin, and – you know?”

It is possible, given the widespread neurological impact of delirium, that touch is related to the use of the mirror described by S7-9. Shildrick (2008) links the Lacanian/Freudian sense of the integrated body, in which “we all rely on a constructed and imaginary anatomy that is dependent on a certain corporeal introjection” directly to Penfield and Ramachandran’s work on the ‘somato-sensory’ map on the cortical surface. Ramachandran says that

Even a normal person [...] can at times adopt a “detached” allocentric stance toward yourself [...] but this doesn't become a full blown delusion because other neural systems (e.g. inhibition from frontal [*sic*] structures and skin receptors) keep you anchored. (Ramachandran 2009, n.p.)

We know that delirium impacts the frontal lobe. If the structure of the body is profoundly threatened – by illness, operations, intrusive additional elements – and touch is then absent, might this exacerbate a difficulty in accurately mapping our own bodies – leading to hallucinations like that of S1’s patient, in which we are scattered across a room? If this is the case, the human sympathy offered in the gesture of touching someone’s shoulder may have a very specific, neurological ‘anchoring’ function for a patient at risk of losing bearings on themselves.

Humanity in this study is about mitigating the losses described above – to dignity, as well as orientation to time, place, and self – and restoring a sense of personhood. S2 gets to the heart of the matter in Phase 3 when she describes the treatment delirious children receive, which is “much gentler than adults who are in the same position”: “you always kind of orientate them to what they know: [...] ‘bring your blanket in, bring your teddy in, bring familial noise’ [...] but with an adult it’s like it’s a hostile environment, there’s nothing familiar”. Once we acknowledge the acute vulnerability of the delirious person, we may realise this need to provide the same levels of security and reassurance.

⁶⁹ “If it’s not the sheet, it will be their patient jacket, [...] or their pyjamas, and they will be continuously fiddling” (S8).

CHAPTER 5: RESULTS & ANALYSIS

How might music expand our insight?

To address the question of the role of music in this study and in understanding delirium more broadly, this chapter will explore participants' general sense of research in this area (5.1), followed by how music might fit into this (5.2). It will, finally, discuss initial responses to music, from participants after hearing drafts, and after its first performance (5.4). Again, all participant quotations below come from Phase 1 (first-round interviews) unless otherwise stated. The remaining quotes derive from Phase 3 (second-round interview and focus groups). (See p.36 for a summary of the data-gathering phases.)

5.1 PERCEPTIONS OF RESEARCH INTO DELIRIUM

We're doing what we *think* is the best. But we have no clue what the patient's actually going through. (S1)

All the participants in the study (except in the joint interview between P2, C2 and C3)⁷⁰ were asked directly (see the prompts in Appendix 4) about the idea of researching delirium. Both former patients and staff point to a lack of knowledge, a lack of prior research, and a consequent lack of clarity about treatment. S2 suggests that HCPs are basing their approach on too little knowledge: "I don't think it's ever been looked at [...]. So I don't think we've got anything to base our thoughts on". Several HCPs suggest that ultimately research "will benefit the patients" (S3): "this is a thing that's happening *so often*, that if we can have a solution to it..." (S7). S1 expands on this, drawing attention to the lack of a sense of the patient experience, and providing here the most concrete argument for qualitative research in this area:

If the patient can tell us what they're experiencing and how best to deal with them – because perhaps we're not dealing with them in the best way. [...] we're not really even acknowledging their confusion, because we're just orientating them. We're not engaging in "what is your delirium about?" or [...] "how real is it?" [...] we're just smoothing it over and carrying on and hoping it's gonna get better. [...] We're doing what we *think* is the best. But we have no clue what the patient's actually going through [...] I think there's a huge gap in our learning and we can learn from any research.

⁷⁰ The interview ran over time.

P1 agrees that delirium is “an understudied phenomenon”, and highlights particularly the deleterious impact of this lack on patients and families:

in terms of what individuals [...] and family members go through as a result, it’s traumatic, and [...] to have a better understanding of what’s occurring and why it’s occurring, and perhaps lessening it or helping individuals cope and deal with it more, in a better way – it’s needed.

P3 agrees that “the nursing, the doctor fraternities” should be more aware. He suggests that transplant specialists *are* likely to know about it,⁷¹ but “What about the other doctors? They need to *know* about that; need to know what *you’ve* been through”. S4 also suggests that better information will “help the families to cope”, as well as HCPs. He points out that delirium and HE were never part of his training as a nurse – he knows them purely through experience, and thinks “it needs a lot of research. [...] for the families, and I think for the patients it’ll probably make a difference”.

5.2 THE USE OF MUSIC AS A RESEARCH TOOL

Again, all the participants in the study except P2, C2 and C3 were asked specifically what they felt about using music. It is this question that elicited P1’s musical map of psychosis (see p.50). P3, too, takes it for granted that music can describe his experience: he refers to a song he has recently heard (“I Stand Amazed” – Tomlin 2014), a video for which strikes him as being just like one of his hallucinations, and says “I think music is a very important part of getting the message across [...] Everybody listens to music”. P4 suggests that classical music – in particular longer pieces (he mentions ballet) – might be closer to how he would interpret his experiences than songs.

The idea that its universality makes music a useful communication tool comes up again with S9: “I think it makes a lot of sense because – a lot of people listen to music”. She goes on to contrast it with ‘drier’ forms of research:

⁷¹ S1 and S2 also suggest that transplant patients are more likely to be prepared for delirium by HCPs (through the pre-transplant counselling process) than other patients. For more on transplant as a risk factor, see p.69 above.

if you stand in front of [an] auditorium and tell them “this is what I’ve found” and you get out your statistics and that kind of stuff, they’re like “oh, OK” [snores]. Whereas “oh this is a CD, shove it into my car while I’m on the road”, think “hang on a moment, there’s something here that could probably help me”.

In relation to this, S6 talks about the importance of accessibility: “if you can make it accessible it would be wonderful”, to create “a kind of openness to understanding – or having the experience represented to you” (see pp.28-30 on Communication, accessibility, and advocacy):

For me it would be the actual suffering of it, cause I think there’s a lot of torment in it, and suffering, and maybe people’s general way of dealing with that is to kind of create a wall, a defence, to not be able to see it, because if you do connect too much with it, it becomes a bit unbearable. (S6)

S10 echoes this almost exactly:

[M]usic occupies a space that you can’t get to through your head or through reading or through talking [...] it’s a very powerful space. And I think, when you use it, in the setting of healthcare professionals, you can get through boundaries and defences much quicker [...] I think it’s a way of short-circuiting our defences around things.

S10, referring to “I can’t find myself”, a short musical film about dementia (Allegranti and Halstead 2015), also refers specifically to music’s potential in medical education:

I think as a medical student if I had seen those things on dementia [...], I would have been completely different. It has taken me 20 years to understand that why demented patients are aggressive is because they don’t know who you are, and they don’t know where they are, and now you’re trying to shove a needle in to their arms. And I never thought about that as a student, I was just like “shit, I’ve got to get this drip up because I’ve got an infection and we have to treat it”. [...] I don’t know how you get that right in medical education, but I think it could be a very powerful tool.

S1, by contrast, says

It’s very foreign to me [...] How you’re gonna come out with some music, that’s gonna tell them about the delirium [...] it’s quite confusing to me how you’re gonna get to this piece of music, but I’m – I’m waiting in excitement and anticipation of what’s gonna happen!

S2 then immediately describes a musical mode for expressing delirium, at which point S1, too, gets into the spirit of it:

S2: I think we are gonna go from heavy metal to very soothing music...

S1: Or the other way around!

S2: Or the other way around.

But others struggle more with the basic concept of music as a research tool – S3, S5, and C2 in particular assume that the music is meant to be a therapeutic intervention, something that will be brought into the space to soothe patients. S4 says that the use of music in the study is “very relevant. And it’s proper”; but the context of this comment suggests that he, too, may be assuming a therapeutic role, relating it back to his own use of music as a “coping mechanism” which helps him “decompress” from his work. The association with therapy may be partly due to my running a separate live music project in the hospital at the same time as this study; but the idea of music as therapeutic is also deeply ingrained in popular culture, whether because of music therapy itself, or the ways in which much classical music has been marketed over the past two decades as an aid to relaxation. This may create a challenge in communicating the idea of music as research, but it is a challenge met in the open-mindedness of all the interviewees to other approaches. S6 is “surprised at some of the openness of some of the professionals, to the idea that you would put some of this to music. I thought they would find it bizarre, but they were open”. Having worked with music in hospital settings in various guises for 18 years, the openness of HCPs, while not universal, is less of a surprise to me.

5.2 INITIAL RESPONSES TO DELIRIUM PART II

For the participants, listening to the music acted as a prompt for further discussion, and in terms of this study brought out several things very strongly which had not emerged as clearly before. These were the fluctuating nature of psychotic as well as encephalopathic delirium; the impact of sound on HCPs; and lastly and perhaps most importantly, the importance of simple sympathetic gestures in the relationship between HCPs and patients in particular. The first performance stimulated yet further discussion, and one participant has since written to say “I have been thinking about, and have written up a case or two – so your

piece was profound for me”. (All quotes below are from Phase 3 unless otherwise stated; comments from the first performance of *Part II* are included as Appendix 6.)

Running through all the Phase 3 conversations is a discussion of the possibilities for using the finished music in training. S7 particularly mentions that the piece could help nursing staff understand the importance of the sound they make, and its amplified impact on patients. Other staff groups who might benefit from hearing the work were suggested as ICU staff more generally, anaesthesiology, surgery, and the allied medical professions. As we have seen above, S10 supports the idea of using work like with medical students.

Specific suggestions for the music include making it more “user-friendly” by splitting it into the smaller pieces (S3, 7, and 9) – hence the decision to divide it online into the sections described on p.45, above. S3, 7 and 8 also agreed that the *Prologue* was confusing outside the context of performance:

I was confused. [...] I listened to it while I was working, and then I got busy on the phone and [...] the third time when I listened to it I actually “Oh, that confusion in the beginning, it sort of starts making more sense”, and then I hear people’s voices... (S7)

S8 says “I first thought is there something wrong with my phone? I’m having interference here!” Once past the opening, however, all the HCPs in Phase 2 read this confusion as relevant. Although it was not the intention of the piece, the multiple voices become “how somebody’s brain might feel. That you’re hearing all of this stuff – noise – and you can’t really make out...” (S7). S9 confirms that “the noise in the beginning [...] just takes you back [to ICU]”. S9 “didn’t find it confusing – but you do have to sit down and concentrate”. And in fact S7 suggests half-jokingly it may be worth advising people not to multitask when listening: “please be advised, no multitasking – concentrate when you listen to this!”

Responses from Phase 3 were generally extremely positive: “For me I think it definitely fitted in to what I view as delirium [...] yesterday we were in ICU and there was a patient who was really delirious, and it was almost like I could almost hear the peaks and the flows of the music” (S2). The peaks and flows were a surprise to me, since I had not consciously intended to pull in and out of intensity in this way but, like the interpretation of the *Prologue* above, it suggests enough space in the music for people to find their own meanings – vital if it is intended to start a discussion (see also p.31 on diminishing exclusivity). Responses have been less full from the former patients who took part in the study. This is mainly due to the

difficulty of arranging meetings (see p.42 above). P4 has confirmed he is happy for his voice to be used, but has chosen not to listen to the piece. P3 and P2 have confirmed that they like the music, and P2 has said that she is keen to meet at a later date to discuss the work. P1 has responded more fully by email:

The emotions it brought out in me included depression, confusion, disorientation, paranoia, despair, and joy. It was very powerful, intense. After listening to this, I was transported back and relived the experiences. [...] You have captured the essence of the delirium.

Hospital sounds

The hospital sounds are also very important [...] what you did there to me in these few minutes was you actually took me through from [the] starting point: [...] it starts in craziness – absolutely crazy, being a nurse watching it, or being a patient in that situation, it's crazy. And then the emotion that you brought back to what that person's actually going through. And then connecting emotion to the craziness and then actually trying to bring it back to humanity. [...] in these few minutes this is what I've experienced. (S8)

As S8 states, the use of the hospital sounds has proved extremely important. It created instant recognition in the HCPs involved in the study. S9 says that "that's exactly how it sounds in ICU, I promise you! [...] that's absolutely the truth – the banging, the talking, the absolute craziness in there", which S6 suggests may make *Part II* particularly useful in addressing the issue of noise in ICUs: "it's a mirror – a *sound* mirror in a way", which may challenge the desensitisation S3 expresses: "I think we don't hear it any more because we learn to shut it out".

Here my foreignness in this environment is important. Like the majority of patients, I am unable to read the sounds. To me, the beeps are meaningless tunes. For an HCP each may have its own meaning, but they have been decontextualised through the composition, and represented to the HCPs as the complex, insistent, random sounds they are to patients:

in the beginning I noticed it, and it was like "oh, this is what you're in every day when you're in ICU". And then as it goes on it becomes noisy and intrusive. [...] I find myself going from recognising the familiarity of it to it then becoming intrusive and noisy, which I thought was quite interesting. (S10)

The advantages of music as a research tool

In Phase 3 I ask participants what the difference might be between the *Key findings* document I circulate (Appendix 3) and the music.

S9 says “yeah I’m gonna read it. Am I gonna read it and feel it? No I’m not”:

But to listen [...] you’re putting emotion there; and isn’t it that we should go back to emotion? [...] this is my perception, is that you want to bring emotion back [so] that staff will realise that there’s emotion attached to that person that is becoming aggressive, that is becoming completely loony in the bed. [...] don’t only see the crazy person in front of you, but see the person behind it. And that’s what your music is doing.

In a similar vein, S10 says that “if I wasn’t part of your study and I read this, it wouldn’t do anything. It wouldn’t mean a thing” (S10), and that

as clinicians, people get very saturated with information. So getting something like this [paper], you’re like “oh, god”. Nurses are up at 5 o’clock in the morning, they work from 7 to 7 and they have to go home and still be moms, and then to sit own at 11 o’clock at night and try and start reading this, you can’t. But to listen to something that’s beautiful *and* brings home to many things, it’s [...] a brilliant way of getting stuff across. I think. That’s what makes it powerful.

S10 further explains that “it was the first time I felt like I was in a patient’s head. [...] I have never come across seeing it from the patients’ perspective. And I think if that’s all it does I think it would go a long way to sensitising us about our practice. (S10)

CHAPTER 6: CONCLUSION

This chapter reunites the separate strands of narrative medicine and music with an overview of some of the themes covered above. It will address briefly the limitations of the study (6.1), before some concluding remarks about both research questions (6.2), and the implications for future research (6.3).

6.1 LIMITATIONS

As I have described above, the study population is limited both in number and in the way it reflects the broader context of Johannesburg and South Africa. The focus on HE should also be read as a consequence of the site of study (see p.36).

The self-imposed requirement of three months post-delirium prior to interview limited the number of former patients who could be interviewed. During the study I tried in various ways to encourage referrals – expanding the initial group of HCPs through whom I had hoped to reach people and, on advice, attempting a fairly crude written referral system in the ICU, to no immediate avail. The development of more formal guidelines for the length of time between delirium and qualitative enquiry would be welcome, but in their absence, I would design the initial approach to former patients differently, and more systematically – working with a small team of HCPs in advance of recruitment to establish a more feasible and more structured protocol, and allowing more time for the recruitment phase.

One possible model might be to ask a small number of ward or ICU staff to place a sticker on the chart of every delirious patient daily for a period of (e.g.) six months, reviewing these charts regularly from three months after their commencement of this process. This would make the three-month safe space easier to determine. I would also seek permission to make the initial contact myself with the approval of the patient's physician, rather than require an HCP to undertake this time-consuming task. It might also be preferable to introduce limited flexibility into the three-month rule, at the discretion of the interviewee's physician and psychologist, and of course their own and their carers' discretion.

Having said the above, the emphasis on HCPs' testimonies has had distinct advantages, and (particularly if read in tandem with *Delirium Part I*) provides a more comprehensive sense of the impacts of delirium in the round. Future studies might also benefit from a more detailed

appraisal of the experience of carers as primary sources of information, rather than in a supportive role.

The process of recruiting participants, by describing the narrative nature of the study and the use of music, may have led to respondents with a bias towards qualitative understandings of health, and a bias toward the arts, which must be borne in mind when assessing the positive responses to both qualitative and musical approaches in Chapter 5 above. (Further planned performances at both WDGMC and Wits' School of Public Health may access a less 'converted' group.)

My own time constraints also prevented me from spending as much time observing the hospital space as I would have liked. In particular it would be valuable in future research to include periods of observation during the night, particularly since the literature suggests that delirium levels may increase at night (e.g. Maldonado, 2008; Seymour et al., 2012). I would in addition allow more time for the follow-up focus groups and interviews – the six weeks given for this between early January and late February (the first performance being on 2 March) was demonstrably too little time to fit these into people's busy lives.

Lastly, while the sound recording equipment was deliberately chosen for its unobtrusive qualities, this also impacts on the quality of some of the recordings. Although this has not been prohibitive for the composition, more sophisticated recording devices might be preferable in future work.

6.2 CONCLUDING REMARKS

I specify on p.33 that the aims of this study are twofold: Firstly, to uncover the detail of delirium, valuing the subjective experience of hallucination and understanding what it can tell us about care. Secondly, to understand what role music may have in this project.

It is clear from the study that there is lack of detail in our understanding of delirium, which directly impacts the way it is experienced and treated in hospital. This is also manifest in the reported absence of qualitative understandings of delirium from clinical training. The very definition of delirium is a complex area and one that merits further assessment if we are to find appropriate ways of treating people. This study suggests that there is a fairly clear

difference between the encephalopathic and psychotic experience, which is not yet universally taken into account in the literature.

What this study uniquely brings to the fore, however, is the violence, loss, and humanity inherent in hospital care, and discernable through delirious experience.

Violence causes and drives delirium on in a cycle that holds both HCPs and patients within its grip in the broader medical culture. I argue therefore that we need to consider carefully the use of the word ‘aggression’ in this context (see pp.84-85) – and suggest in particular that the violence expressed by patients is rather a defence against the violence inside their own bodies, and with which they are treated. At the same time, if we are to tackle this cycle it is vital also to acknowledge the vulnerability of HCPs in this situation, the very real threats delirium presents both to their own and their patients’ safety, and the mistrust that the experience can sew between patients, carers, and HCPs.

Delirium is, moreover, characterised by losses of numerous kinds: orientation, dignity, control, and ultimately personhood. This study suggests, however, that it is within our grasp to limit significantly the impacts of these losses through re-evaluating our interaction and communication with patients and families, and challenging the dehumanising aspects of care. The need to mitigate the “shock” of delirium by discussing the possibility it will occur with patients and carers in advance, as well of course as reassuring them throughout, is clear (see p.107). Maintaining more general communication whilst treating patients, even when they appear to be unconscious or semi-conscious, is perceived by HCPs to alleviate distress (pp.108-111). This study strongly reaffirms the need for healthcare professionals properly to acknowledge the presence of *any* patient their vicinity, and consider more carefully what is said within earshot. (There may even be a case for concrete communication aids such as alphabets or pictures to support patients with compromised speech and cognition, although the limited data presented by this study is not alone enough to support this.)

Given the blank, sonically brutal spaces into which we place our sickest patients (and in which we expect HCPs not only to work but to sustain empathic practice),⁷² it may be worth considering in particular how we are able to create more humane space, in fact the *intimate* space appropriate to the intimacy of treatment. The physical environment plays a role here,

⁷² For descriptions of the physical environment, please see Appendix 5: Observation notes.

but it is also about behaviour. S6 calls for a “*simple* holding of the patient, soft voice, explaining”. This is the kind of space exemplified in S8’s testimony on p.111: “You know when you’re just *there*. You don’t talk, you don’t ... you just embrace the moment”.

None of these measures are expensive or complex, but they do require cultural change. As Bélanger and Ducharme (2015) point out, much of this is about realising “ethical knowledge” that already exists within the healthcare professions. Bélanger and Ducharme offer a strong model for achieving this kind of cultural shift through “narrative pedagogy” – a form of active group learning conducted with (in the case of their study) nurses. This study suggests that *Part II* might contribute to similar processes of learning in healthcare professions, particularly if paired with opportunities for group discussion.

Music

There are clear indications here of the potential for music to convey the experience of delirium for all those concerned; and confirmation that this would be a useful tool in training and education for a variety of HCPs (see p.117). One clinical interviewee writes in the comments book after the first performance that she finds it “sobering, real, and true [...] staff need to have a lesson in humanity and sensory input”. The “emotional” (S8) quality of the music is singled out as valuable in this context, as well as its capacity to convey “the patients’ perspective” (S10). S8 says that “I think the message that you’re gonna give out there is gonna be extraordinary [...] I think you’re definitely gonna reach your objectives”.

Several HCPs hint (p.93) at our reluctance to look at delirium. Part of this may be what S6 describes as a defence against suffering “because if you do connect too much with it, it becomes a bit unbearable”. In his essay on “The Uncanny and the Rest of the World”, Michael Kinnucan says that “Our everyday involvement with the world in which we feel most ‘at home’ is, among other things, a constant effort to keep the uncanny at bay” (2012, n.p.). My own early reactions (see p.5) remind me that delirium is existentially uncomfortable, “spooky and unnerving” (S1). The music, here, may provide safe passage through this discomfort, towards experiences we intuitively recognise.

The use of both voice and ICU sound plays a vital role in *Part II*, holding up a “sound mirror” to the care environment, and providing direct access to patients’ testimony in space that demands attention outside the normal frantic routine of care. More generally, I would argue

that the success of music in this study is indicative of the potential for all creative arts to engage with health research, bringing with them different qualities but universal in their capacity to de-contextualise familiar experience and present it to us anew.

Music has contributed centrally to the development of this research, as both an analytical tool (see Chapter 3) and a means of developing ongoing conversations with participants, and starting new ones with its audiences (Chapter 5.2). There are therefore plans to perform the *Part II* again at WDGMC and the Wits School of Public Health, with space for discussion afterwards. It will also be performed at the International Conference for Culture, Health & Wellbeing on 20 June 2017 in Bristol, UK.⁷³ It is hoped that more performances will be arranged for public and clinical spaces, in particular platforms for education and professional development.

Lastly, I would note that the suitability of music may be down to the fact that delirium itself is a creative act, however unbidden it may be – one which through its strangeness renders the business of care in hospital entirely new, allowing us to see it more clearly.

6.3 IMPLICATIONS FOR FUTURE RESEARCH

Given the relatively open field into which this research is emerging, I hope it will open up a number of topics for further discussion. These are given with the caveat that limitations of time, resource, and experience may mean that I have failed to source existing research in any of these areas.

Firstly, I would echo Peter's (2014) call for additional data – both quantitative and qualitative – on delirium from South Africa, in particular from the state sector, which might more accurately reflect the experience of the majority of South Africans. There is evidently also a more general need for data on delirium outside the 'global north'.

The differentiation I have tentatively made between encephalopathy and psychosis (see Chapter 4.2, and Figure 17) needs further exploration, which I would argue could best be undertaken with qualitative methods that would develop a more detailed understanding of the nature of the experience.

⁷³ <http://www.culturehealthwellbeing.org.uk/>

In particular it would be valuable to spend time assessing the cycle of violence described in Chapter 4.3, with a view developing our approach to breaking this cycle. More work is needed on the question of isolation and its relationship with delirium. And the obvious connection between delirium and religious belief would merit further exploration. As I suggest above on pp.104-105, sexuality in delirium should also be explored further.

The impact of sound on the health of ICU staff is an area that is hinted at throughout this study (see p.108) but one that I have been unable to explore in any depth.

Finally, it seems that there is a substantial gap in the literature pertaining to the relationship between our sense of control and our physical wellbeing.

As we have seen, the focus of the literature generally continues to be quantitative (p.14). I would argue that there is space for a considerable amount of qualitative assessment of delirium, which could refine some of the suggestions made by this study.

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Appendix 1: Programme notes and full score, *Delirium Part II*

[1 of 58 pages]

Delirium

Thursday 2 March 2017, 6.30 for 7pm
The Music Room, 8th floor, University Corner (above the Wits Art Museum)
University of the Witwatersrand

Piano, keyboards: Chris Letcher

Viola: Waldo Alexander

Composition, keyboards, voice: Victoria Hume

*For as long as I can remember I have had dreams about losing power over my life.
These nightmares of dependency [...] must have been reawoken by the systems of
intensive care, which dissolve the patient's will in a sort of therapeutic absolutism.*

Robert Hughes, Things I Didn't Know

Delirium affects huge numbers of people in hospital – from around one in five in normal care to up to four in five in intensive care. The music in this performance is based on and around conversations with people who have experienced or treated delirium. This research was conducted with the generous support of Wits Donald Gordon Medical Centre.

Overarching themes of violence, loss and restitution emerged from the conversations, and underpin the structure of the piece.

- I *Prologue***
- II **Violence & unreality****
- III *Interlude: 'Pleasantly Confused'***
- V **Loss & restitution****

This performance is in partial fulfilment of a Masters degree in Music and Health Communication, jointly supervised through the Music Division, Wits School of Art and Health Communication Research Unit, Wits School of Human and Community Development.

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Most of all, thank you to all those who have generously given their time and words to this study.

This is the second part of an ongoing project to understand more about delirium in hospital settings, using narrative research methods to create new music. Delirium (Part I) was written in 2013 and performed in clinical and public settings in the UK. You can listen to it in full online at victoriahume.bandcamp.com or contact info@victoriahume.com.
victoriahume.com/delirium

– In memory of Belinda Rossi –

I Prologue

II i. Cycle

$\text{♩} = 50$

Violin

mp *mf*

Piano (V)

$\text{♩} = 50$

mp

9

Violin

f

Piano

p *mp* *f*

mp espressivo *mf*

Synth

16

Violin

mp *mf*

Piano

Synth

22

Violin

f

Piano

Synth

27

Violin

mf *mf*

Piano

Synth

33

Violin

mp

Piano

the family... getting **out** of hand

and he would look at him and say '**no**'

the nurse, the male nurse... *f*

Voice pad

Voice (V) *mf*

40

Violin

mp *mf* *mp*

Piano

Voice pad

Voice (V)

43

Piano

and he's a very non-violent...

II ii. Expressed

♩ = 130

(punches) ...confused, and they **become** aggressive

glock (V)

organ (pre-rec'd)

4

viola

glock

organ

6

viola

glock

organ

8

viola

glock

organ

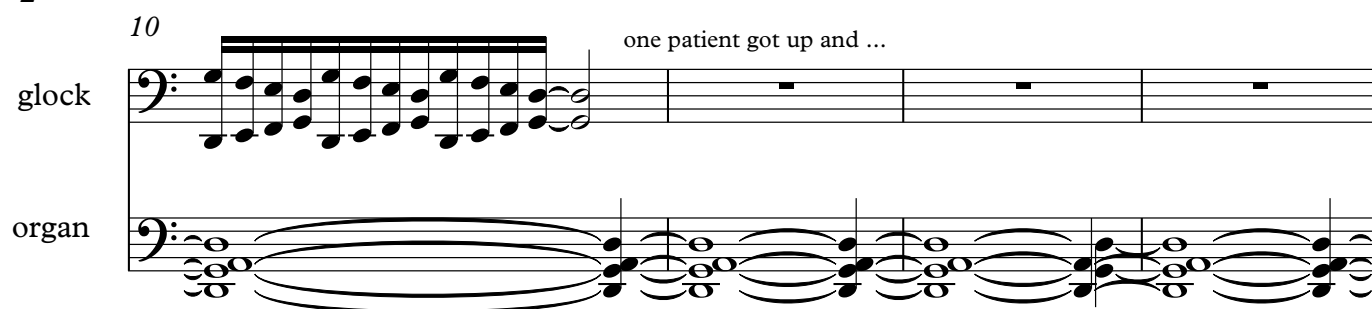
This musical score is for measures 4 through 8 of a piece. It features five staves: Viola, Glockenspiel (V), Organ (pre-recorded), Glockenspiel, and Organ. The tempo is marked as 130 beats per minute. The key signature has one flat (B-flat). The time signature is 5/4. The score includes dynamic markings such as *mp* (mezzo-piano), *mf* (mezzo-forte), and *mf legato*. The organ part is pre-recorded. The Viola part has a measure rest in measure 4 and a half note in measure 8. The Glockenspiel parts feature a rhythmic pattern of eighth and sixteenth notes. The Organ part features a sustained chord in the left hand and a melodic line in the right hand.

10

glock

organ

one patient got up and ...



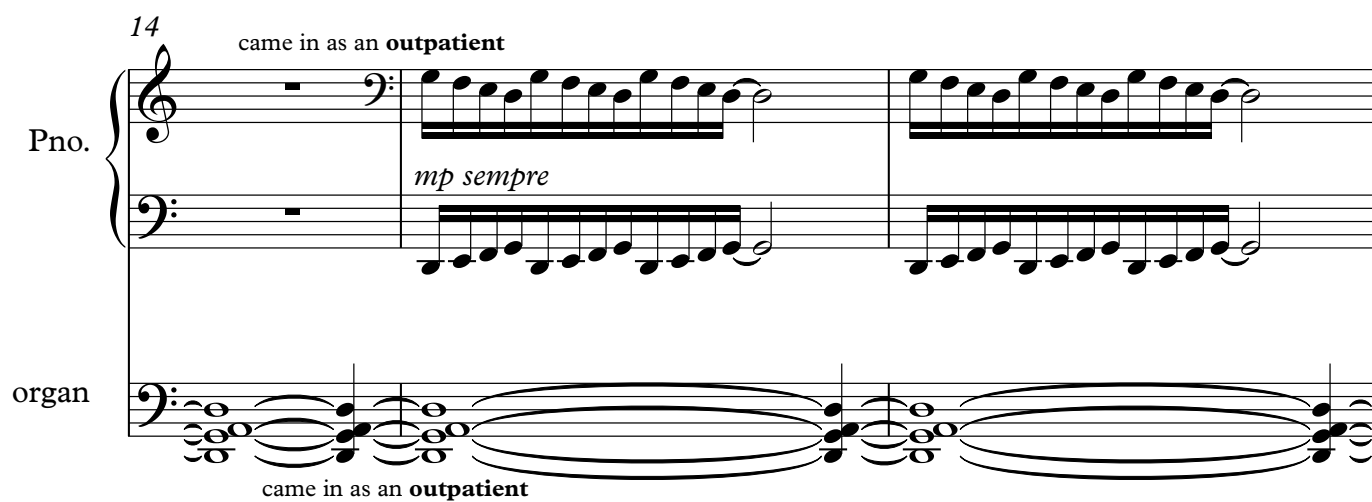
14

Pno.

organ

came in as an outpatient

mp sempre



17

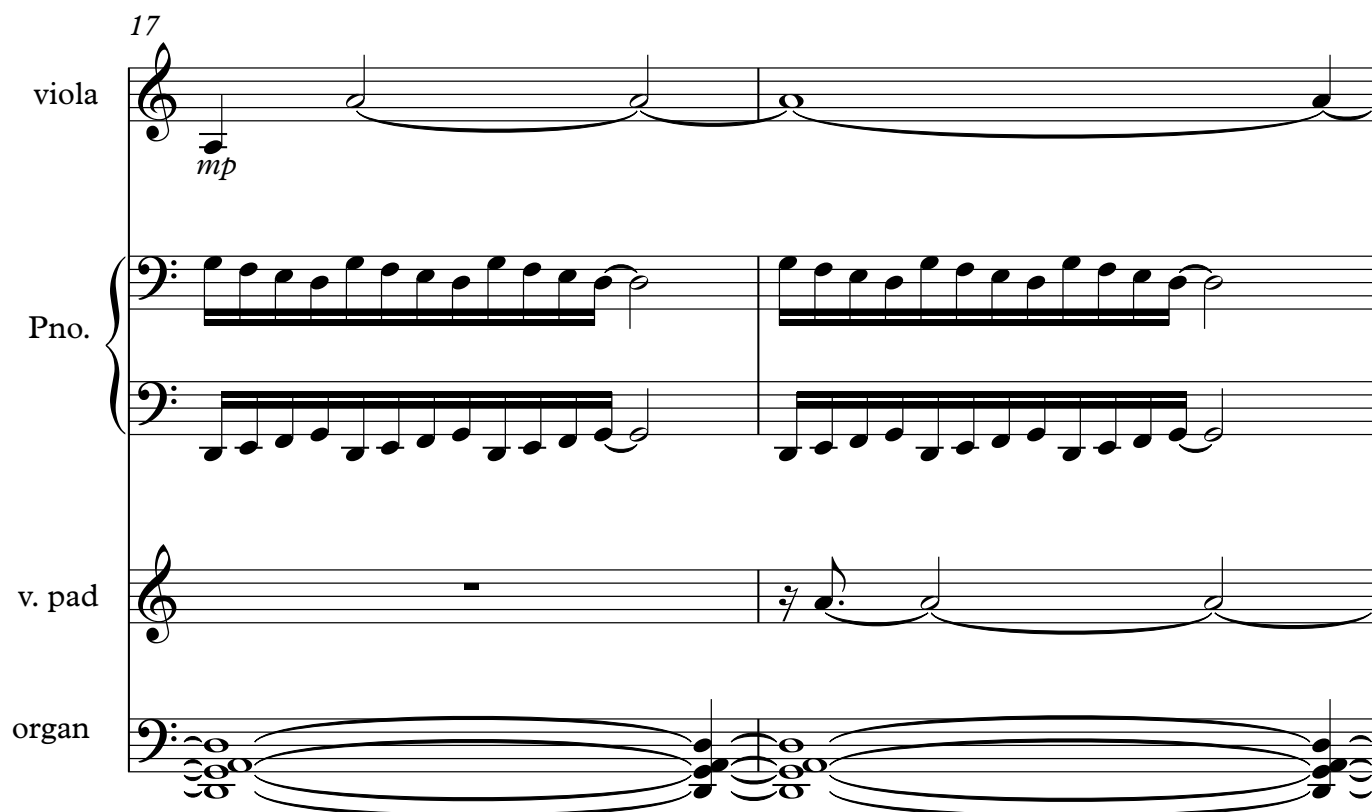
viola

Pno.

v. pad

organ

mp



19

viola

Pno.

v. pad

organ

Measures 19-20. Viola and v. pad have long notes. Pno. and organ have active patterns.

21

Pno.

organ

he was completely out of it and very aggress

Measures 21-25. Pno. and organ have active patterns.

26

Pno.

organ

Measures 26-31. Pno. and organ have active patterns.

32

...but he literally, he **broke** through

glock

organ

mf

Measures 32-35. Glock and organ have active patterns.

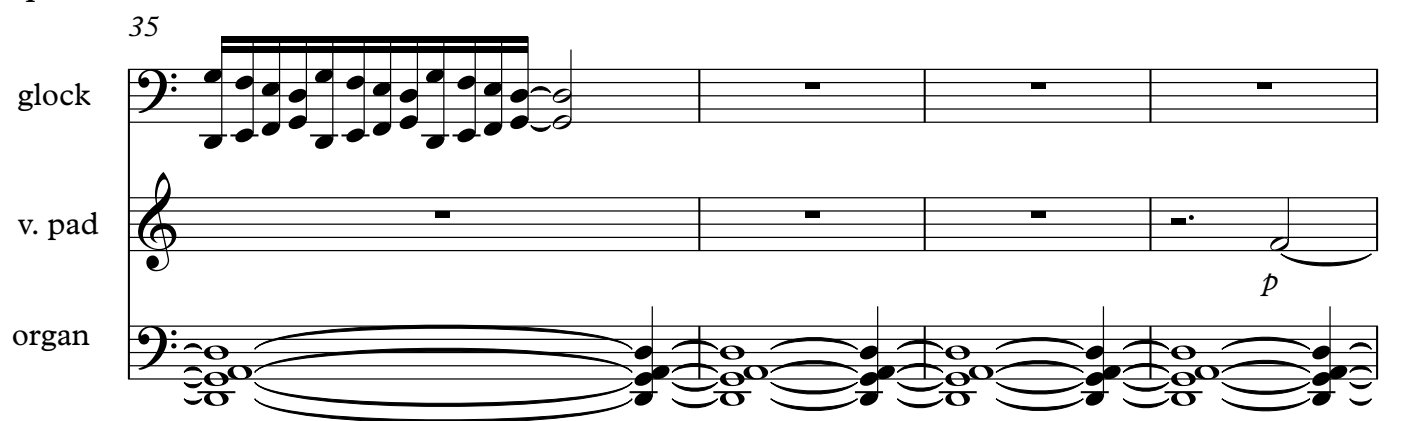
35

glock

v. pad

organ

p



39

viola

v. pad

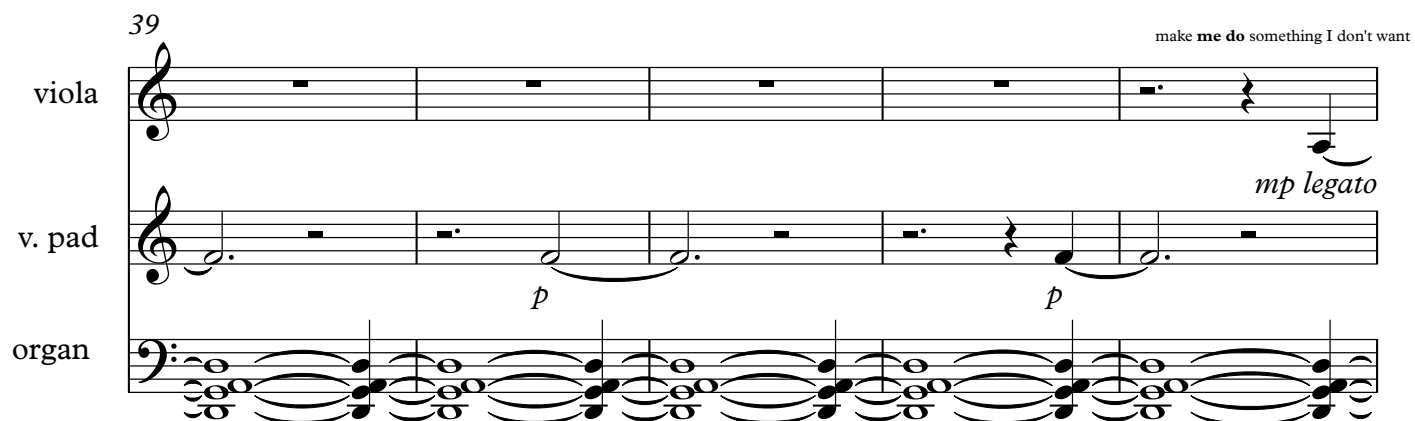
organ

make me do something I don't want

mp legato

p

p



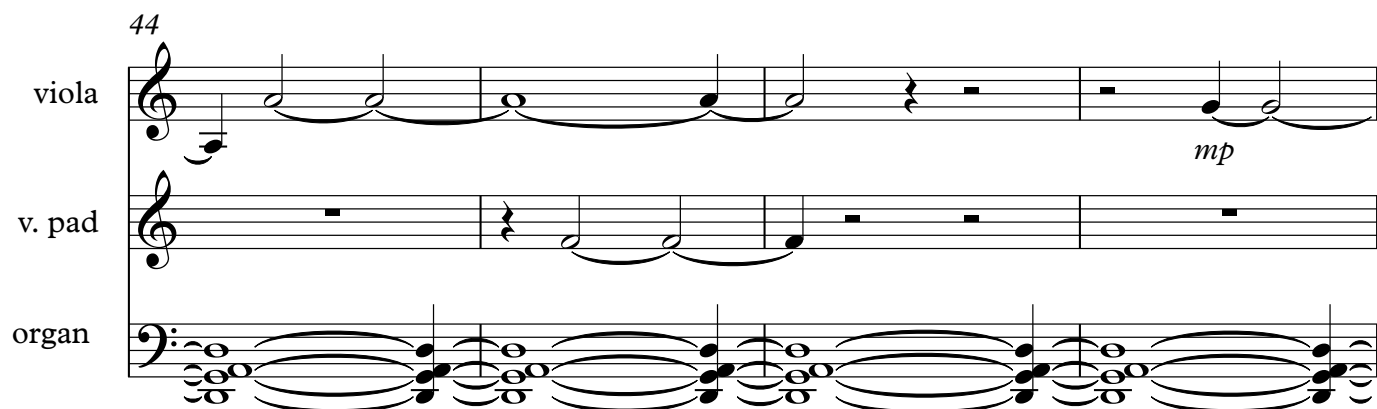
44

viola

v. pad

organ

mp

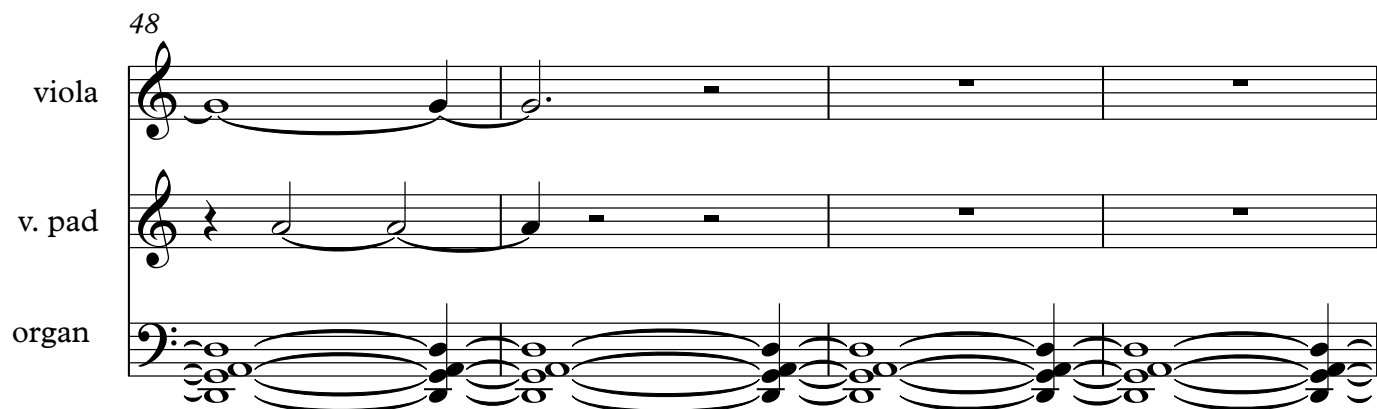


48

viola

v. pad

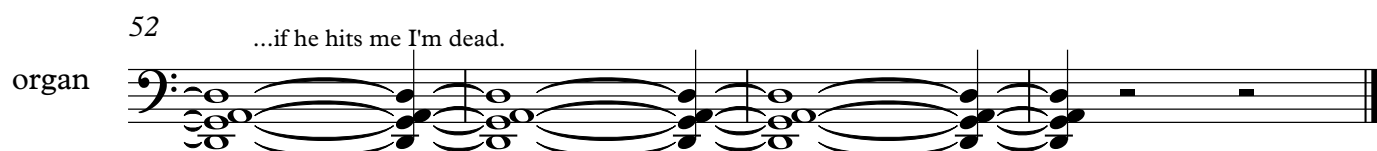
organ



52

organ

...if he hits me I'm dead.



II iii. Internalised (On Patrol)

♩ = 150

piano (C)

p gentle

piano (C)

9

I would go out
on patrol...

piano (C)

17

...to ensure that
nobody **got** injured

p

piano (C)

19

19

piano (C)

21

21

ethereal synth

mp

23

viola

piano (C)

Pno. 2 (V)

ethereal synth

mf

25

viola

piano (C)

Pno. 2 (V)

ethereal synth

27

viola

piano (C)

Pno. 2 (V)

ethereal synth

This musical score consists of three systems, each containing four staves. The instruments are viola, piano (C), Pno. 2 (V), and ethereal synth. The key signature has one flat (B-flat). Measure 23: Viola has a whole rest followed by a half note G4, quarter note F#4, and eighth notes E4, D4, C4. Piano (C) has a continuous eighth-note pattern: B3, A3, G3, F#3, E3, D3, C3, B2. Pno. 2 (V) has a whole rest followed by a half note G4, quarter note F#4, and eighth notes E4, D4, C4. Ethereal synth has a sustained chord of B3 and E3. Measure 25: Viola has a half note G4, quarter note F#4, and eighth notes E4, D4, C4. Piano (C) continues the eighth-note pattern. Pno. 2 (V) has a half note G4, quarter note F#4, and eighth notes E4, D4, C4. Ethereal synth has a sustained chord of B3 and E3. Measure 27: Viola has a half note G4, quarter note F#4, and eighth notes E4, D4, C4. Piano (C) continues the eighth-note pattern. Pno. 2 (V) has a half note G4, quarter note F#4, and eighth notes E4, D4, C4. Ethereal synth has a sustained chord of B3 and E3.

glock (pre-rec'd)

35

glock (pre-rec'd)

37

II iv. Sleepless

$\text{♩} = 75$

viola

I also don't think they sleep properly...

9

synth (pre-rec'd)

rhythm rhythm rhythm

voice pad (pre-rec'd)

...patient,
lying there myself

p

mp

16

viola

...hearing -
hearing noise

p

synth (pre-rec'd)

voice pad (pre-rec'd)

22

viola

and then they gave me
morphine

mp

voice pad (pre-rec'd)

mp

28

synth (pre-rec'd)

...battle the whole time
inside of myself

organ (V)

rhythm from here...

34

...but I always wanted
to break away...

viola

synth (pre-rec'd)

organ (V)

...but I always wanted
to break away...



38

and I can't be in here...

viola

mf

synth (pre-rec'd)

organ (V)



41

viola

synth (pre-rec'd)

glock (pre-rec'd)

organ (V)



44

opening piano chord
of 'Theatre'

viola

organ (V)

opening piano chord
of 'Theatre'



II iv. Theatre

♩ = 55

piano (C)

and she
opened up
the curtain... ...what I have seen
not what is true

pp

9

viola

...you show them it's
not the wife, but... *pp ad lib.*

pp ad lib.

glock (pre-rec'd)

...I **slipped** back into that
hallucinatory state...

p

13

glock (pre-rec'd)

3

15

piano (C)

p legato

p legato

glock (pre-rec'd)

3

organ (pre-rec'd)

3

17

piano (C)

glock (pre-rec'd)

organ (pre-rec'd)

6 6 6 6

18

piano (C)

viola

glock (pre-rec'd)

organ (pre-rec'd)

mf

6 6 6 6

19

piano (C)

viola

glock (pre-rec'd)

organ (pre-rec'd)

p *mf*

21

piano (C)

viola

glock (pre-rec'd)

organ (pre-rec'd)

mf

23 *p legato*

piano (C)

viola *mp legato*

mp

glock (pre-rec'd)

organ (pre-rec'd)

6 6 6 6

24

piano (C)

viola

glock (pre-rec'd)

organ (pre-rec'd)

6 6 6 6

25

piano (C)

viola

glock (pre-rec'd)

organ (pre-rec'd)

3 3 3 3

27

piano (C)

viola

glock (pre-rec'd)

organ (pre-rec'd)

28

glock (pre-rec'd)

organ (pre-rec'd)

29

glock (pre-rec'd)

The musical score consists of three systems of staves. The first system (measures 27-28) includes staves for piano (C), viola, glock (pre-rec'd), and organ (pre-rec'd). The piano and viola parts are identical, playing a whole note chord of D#4 and F#4. The glock and organ parts play a sixteenth-note triplet melody. The second system (measures 28-29) includes staves for glock (pre-rec'd) and organ (pre-rec'd), continuing the sixteenth-note triplet melody. The third system (measure 29) includes a staff for glock (pre-rec'd) playing a sixteenth-note triplet melody ending with a whole note D4. The organ part is pre-recorded and spans measures 27-28.

II vi. Struggle

footsteps

piano $\text{♩} = 85$ Paranoia set in

10 *slaps* where was it, in the blood? *slaps become rhythm*

piano (V)

viola *slaps* *mf* *slaps become rhythm*

synth (pre-rec'd)

17

piano (V)

viola

synth (pre-rec'd) *p*

21

piano (V)

viola

The musical score is written for four parts: piano, piano (V), viola, and synth (pre-rec'd). The key signature has one sharp (F#), and the time signature is 3/4. The tempo is marked as 85 beats per minute. The score is divided into three systems. The first system (measures 10-16) features the piano part with a series of rests, the piano (V) part with a series of rests and a triplet of eighth notes, the viola part with a series of rests and a triplet of eighth notes, and the synth part with a series of rests. The second system (measures 17-20) features the piano (V) part with a series of eighth notes, the viola part with a series of eighth notes, and the synth part with a series of eighth notes. The third system (measures 21-24) features the piano (V) part with a series of eighth notes and the viola part with a series of eighth notes. The score includes lyrics and performance instructions such as 'slaps', 'slaps become rhythm', and 'where was it, in the blood?'. The piano part is marked with a tempo of 85. The piano (V) part is marked with a tempo of 85. The viola part is marked with a tempo of 85. The synth part is marked with a tempo of 85.

25

piano (V)

viola

f

Detailed description: This system covers measures 25 to 28. The piano (V) part is in the bass clef, playing a continuous sixteenth-note scale with a slur over the entire phrase and fingerings of 6 and 3 alternating every two measures. The viola part is in the treble clef, playing a series of eighth notes with a slur over the phrase. A forte (*f*) dynamic marking is present at the beginning of the viola part.

29

piano (V)

viola

organ (pre-rec'd)

Detailed description: This system covers measures 29 to 31. The piano (V) part continues with the same sixteenth-note scale pattern. The viola part continues with eighth notes. The organ (pre-rec'd) part enters in measure 30 with a sustained chord in the right hand and a single note in the left hand, both sustained through measure 31.

32

piano (V)

viola

organ (pre-rec'd)

Detailed description: This system covers measures 32 to 36. The piano (V) part plays the sixteenth-note scale for measures 32-34, then rests for measures 35-36. The viola part rests for measures 32-34 and then plays a series of eighth notes in measures 35-36. The organ (pre-rec'd) part plays a sustained, arpeggiated chord throughout measures 32-36.

37

organ (pre-rec'd)

Detailed description: This system covers measures 37 and 38. The organ (pre-rec'd) part continues with the sustained, arpeggiated chord in both hands.

II vii. Imposed (eagle/restraint)

♩ = 85

blender blades

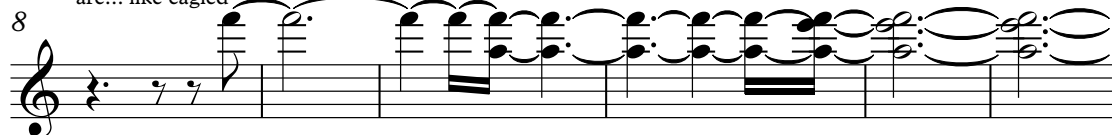
ICU synth (pre-rec'd)



So we'll go to the ICU and the patients
are... like eagled

8

synth (pre-r'd)

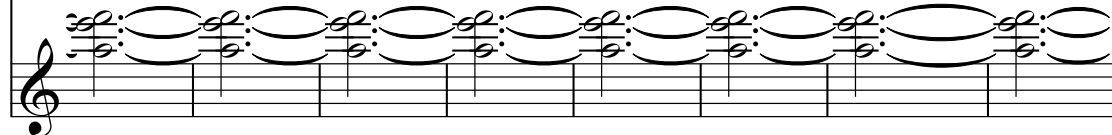


14

v. pad (pre-r'd)



synth (pre-r'd)



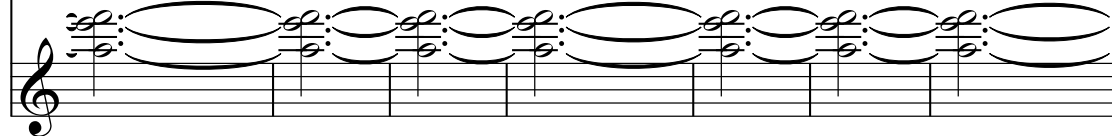
22

The nurse, the male nurse
would say... (blender blades)

v. pad (pre-r'd)



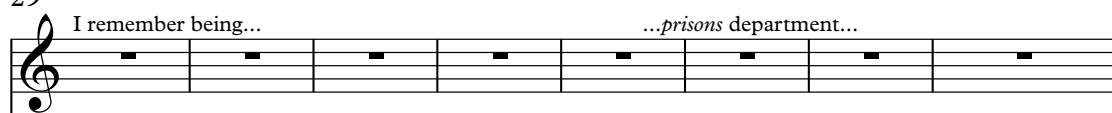
synth (pre-r'd)



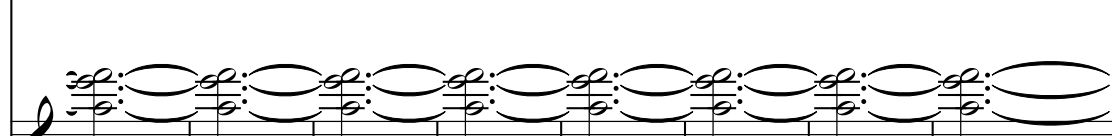
29

I remember being... ...prisons department...

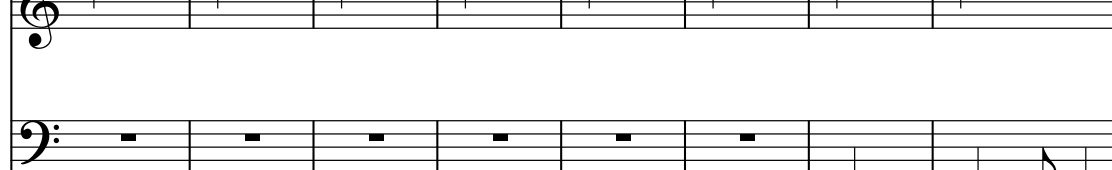
v. pad (pre-r'd)



synth (pre-r'd)



organ (V)



mf

37

v. pad (pre-r'd)

synth (pre-r'd)

organ (V)

42

v. pad (pre-r'd)

synth (pre-r'd)

organ (V)

glock (pre-rec'd)

...and I believed I was part of the police
at that stage; ...

48

synth (pre-r'd)

glock (pre-rec'd)

mp

52

v. pad (pre-r'd)

synth (pre-r'd)

organ (V)

glock (pre-rec'd)

I was protecting people. |

56

v. pad (pre-r'd)



organ (V)



glock (pre-rec'd)



60

glock (pre-rec'd)



64

v. pad (pre-r'd)



organ (V)

*rhythm back in*

glock (pre-rec'd)

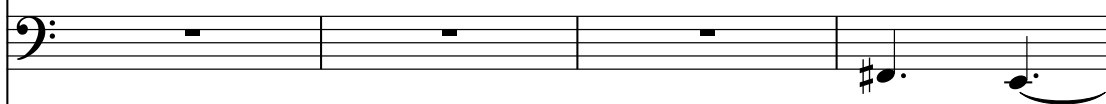


68

v. pad (pre-r'd)



organ (V)



glock (pre-rec'd)



72

viola

*mf ad lib.*

v. pad (pre-r'd)



organ (V)



glock (pre-rec'd)



76 we go round untying patients, [laughter], **going...**

viola

glock (pre-rec'd)

mf ad lib.

80

viola

synth (pre-r'd)

glock (pre-rec'd)

82

synth (pre-r'd)

glock (pre-rec'd)

The musical score is written for five staves. The first staff is for Viola, the second for Glockenspiel (pre-recorded), the third for Synth (pre-recorded), the fourth for Synth (pre-recorded), and the fifth for Glockenspiel (pre-recorded). The score is divided into measures 76-79, 80-81, and 82. In measures 76-79, the Viola plays a melodic line, the Glockenspiel plays a rhythmic pattern, and the Synth plays sustained chords. In measures 80-81, the Viola plays a melodic line, the Glockenspiel plays a rhythmic pattern, and the Synth plays sustained chords. In measure 82, the Viola plays a melodic line, the Glockenspiel plays a rhythmic pattern, and the Synth plays sustained chords. The score ends with a double bar line at measure 82.

III i. Naked

III ii. Pleasantly confused

The normal injection is fine...

oh I got so excited when...

piano (V) $\text{♩} = 110$

p leggero

6 you can feel it
as it goes in

and everything just...

viola

mp legato

you can feel it
as it goes in

and everything just...

piano (V)

10

...straight away? / Yes...

viola

...straight away? / Yes...

piano (V)

14

...and you can feel...

...the drip, the...

viola

...and you can feel...

...the drip, the...

piano (V)

18

But the ones that are
pleasantly ... out of it are fine.

viola

beep beep beep

But the ones that are
pleasantly ... out of it are fine.

piano (V)

The musical score is written for piano (V) and viola. The piano part is in 3/4 time with a tempo of 110 beats per minute. The key signature has three sharps (F#, C#, G#). The viola part is in the same key and time. The score is divided into measures, with measure numbers 6, 10, 14, and 18 indicated. Lyrics are placed above the staves. The piano part features a recurring rhythmic pattern of eighth notes with a sharp, dissonant quality. The viola part provides a melodic counterpoint, often with long, sustained notes. The overall mood is one of playful confusion, as suggested by the title.

27

...we call them pleasantly confused [laughter]

piano (V)

ICU sound (C)

mp gentle

34

ICU sound (C)

37

viola

piano (V)

ICU sound (C)

39

viola

piano (V)

ICU sound (C)

42

...she was knitting, OK? There was **nothing** in her hands

piano (V)

mp

I was still a student once, and I nursed...

ICU sound (C)

Detailed description of the musical score: The score is written for three parts: piano (V), ICU sound (C), and viola. It is divided into five systems. System 1 (measures 27-33) shows piano (V) with a whole rest and ICU sound (C) with a melodic line starting at measure 27. System 2 (measures 34-36) shows ICU sound (C) with a melodic line. System 3 (measures 37-38) shows viola with a whole note and piano (V) with a complex rhythmic pattern. System 4 (measures 39-41) shows viola with a whole note and piano (V) with a complex rhythmic pattern. System 5 (measures 42-48) shows piano (V) with a whole rest and ICU sound (C) with a melodic line. The score includes lyrics and dynamic markings like 'mp gentle' and 'mp'.

49

piano (V)

musical score for piano (V) starting at measure 49. The staff shows a series of chords in the bass clef, mostly consisting of a major triad with a flat second degree (e.g., F#-A-C, G-A-Bb). The treble clef has whole rests.

54

viola

glock (pre-rec'd)

piano (V)

musical score for measures 54-58. The viola part has whole rests followed by a half note G# and a half note A. The glock part has a triplet of eighth notes (F#, G, A) followed by whole rests. The piano (V) part continues with the same chordal pattern as in measure 49.

59

viola

piano (V)

ICU sound (C)

grungry organ

musical score for measures 59-63. The viola part has a half note B, a half note A, a half note G, and a half note F. The piano (V) part continues with the same chordal pattern. The ICU sound part has whole rests followed by a quarter note G# and a quarter note A. The grungry organ part has whole rests followed by a half note G# and a half note A.

64

glock (pre-rec'd)

piano (V)

So I remember
they were draining fluid...

71

piano (V)

p
from my lungs and they have
given me morphine

piano (V)

78

piano (V)

ICU sound (C)

see my fairies they're my friends

83

piano (V)

88

piano (V)

91

piano (V)

96

piano (V)

99

piano (V)

IV i. HE

$\text{♩} = 75$

...unfortunately they're not.

Piano

p very freely

6

Pno.

9

Pno.

12

Pno.

17 ...out of the blue, they become **so** delirious

viola

Pno.

mp a tempo

Synth

The image shows a musical score for three instruments: Viola, Piano (Pno.), and Synth. The score is for measures 17 through 20. Measure 17 has a Viola part with a whole rest and a Synth part with a sustained chord. Measure 18 has a Viola part with a whole rest and a Piano part with a melodic line in the right hand and a bass line in the left hand. Measure 19 has a Viola part with a half note and a Piano part with a melodic line in the right hand and a bass line in the left hand. Measure 20 has a Viola part with a half note and a Piano part with a melodic line in the right hand and a bass line in the left hand. The Synth part has a sustained chord in measures 17-18 and a melodic line in measures 19-20.

21

viola

Pno.

voice pad

Synth

The musical score for measures 21-23 is as follows:

- Measure 21:** The viola part begins with a half rest, followed by a quarter note G4, a quarter note F#4, and a half note E4. The piano part features a complex rhythmic pattern with eighth and sixteenth notes in both hands.
- Measure 22:** The piano part continues with a similar rhythmic pattern. The voice pad part has a half rest, followed by a quarter note G4, a quarter note F#4, and a half note E4.
- Measure 23:** The voice pad part has a half rest, followed by a quarter note G4, a quarter note F#4, and a half note E4. The synth part has a half rest, followed by a quarter note G4, a quarter note F#4, and a half note E4.

24

viola

Pno.

Glock

voice pad

27

viola

Pno.

30

viola

Pno.

Glock

33

viola

Pno.

Glock

This musical score consists of three staves: Viola, Piano (Pno.), and Glockenspiel (Glock). The Viola staff is in treble clef and shows rests for the first two measures, followed by a half note G4 and a dotted half note G4 in the third measure, with a final quarter rest in the fourth measure. The Piano staff is in grand staff (treble and bass clefs). In measure 33, the right hand plays a quarter note C4, an eighth note D4, and a quarter rest, while the left hand plays a quarter rest, an eighth note C3, and a quarter rest. In measure 34, the right hand plays a quarter note D4, a quarter note E4, and a quarter rest, while the left hand plays a quarter note C3, a quarter note D3, and a quarter rest. In measure 35, the right hand plays a quarter note E4, a quarter note F4, and a quarter rest, while the left hand plays a quarter note D3, a quarter note E3, and a quarter rest. In measure 36, both hands have whole rests. The Glockenspiel staff is in treble clef and shows a quarter rest in measure 33, followed by eighth notes G4, A4, and B4 in measure 34, eighth notes A4, G4, and F4 in measure 35, and a quarter rest in measure 36.

IV ii. Psychosis

♩ = 50

...well it seemed | that there... ... and it built up x4 and it built up x4

one long cresc. one long cresc.

piano (V)

8

Vla.

p

and it built up > x1 short cresc and it built up > x4 v short cresc - on 4th, and just after the next one

piano (V)

f mp

14

Vla.

short high tune | and it built up |

piano (V)

mf

'ahh' / peak of cresc. |

20

Starting out slowly softly a little bit different ICU tune

piano (V)

| backwards 'ah'

29

slaps, beats

piano (V)

extraneous... ...beats

The musical score is written for three parts: piano (V), Vla., and piano (V). The tempo is marked as ♩ = 50. The key signature has one sharp (F#) and the time signature is 4/4. The score is divided into measures, with measure numbers 8, 14, 20, and 29 indicated. The lyrics are written above the piano (V) staff. The piano (V) staff has a dynamic marking of pp at measure 8 and a crescendo leading to f and then mp. The Vla. staff has a dynamic marking of p at measure 8. The piano (V) staff has a dynamic marking of mf at measure 20. The score includes various musical notations such as rests, notes, and slurs.

38

piano (V)

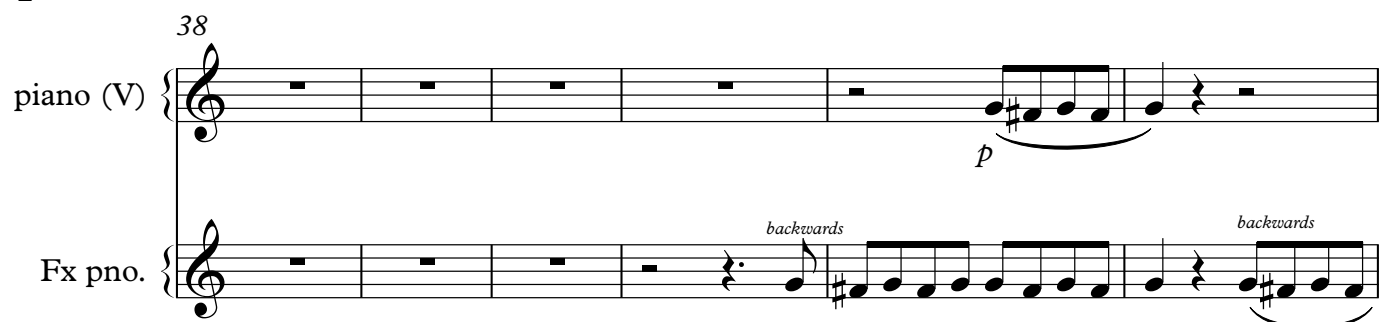
Fx pno.

p

backwards

backwards

slaps



44

Vla.

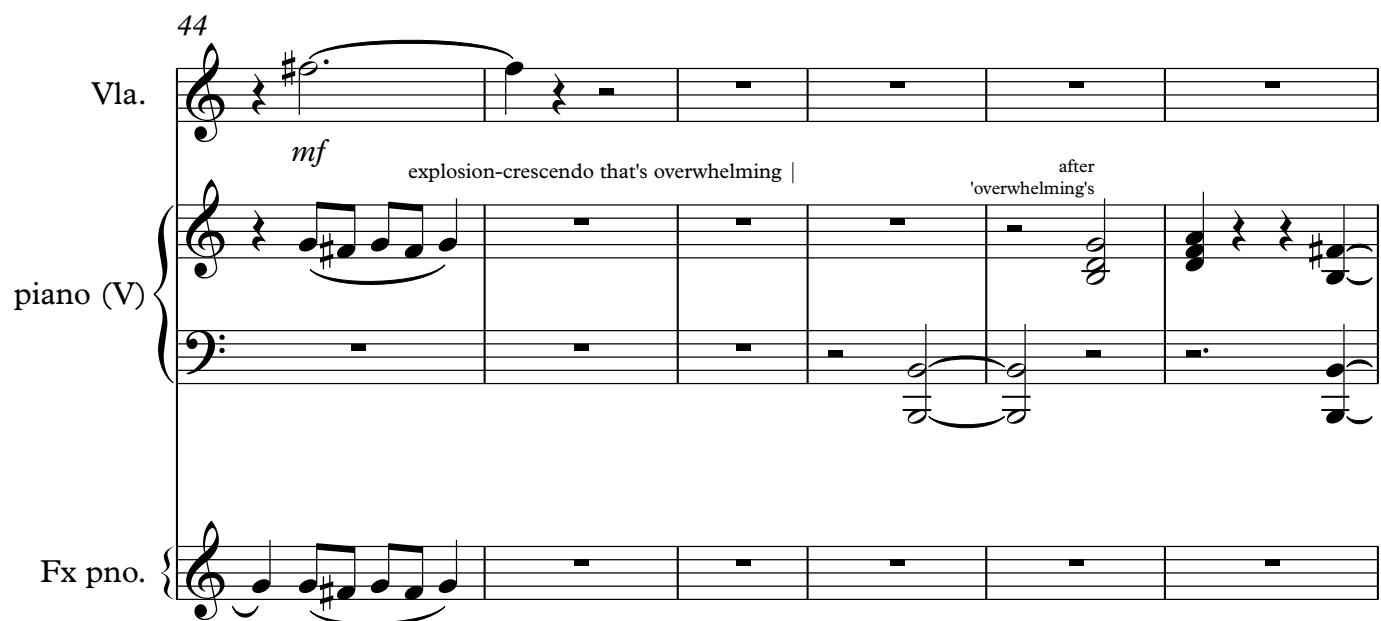
piano (V)

Fx pno.

mf

explosion-crescendo that's overwhelming |

after 'overwhelming's



50

piano cue

Pno. (C)

Vla.

piano (V)

f ad lib. espr.

Pno.



54

Pno. (C)

piano (V)

you know, reality

Detailed description: This block contains measures 54 through 58. The piano (V) part features a melodic line with lyrics 'you know, reality'. The Pno. (C) part provides a rhythmic accompaniment with chords and single notes.

59

Pno. (C)

Vla.

piano (V)

my perspective, um...

piano cue

f

Detailed description: This block contains measures 59 through 63. The Pno. (C) part has a melodic line with lyrics 'my perspective, um...' and a 'piano cue' marking. The Vla. part has a melodic line with a forte (f) marking. The piano (V) part provides a rhythmic accompaniment.

64

Pno. (C)

Vla.

piano (V)

mp

6

Measures 64-66. Piano (C) features a complex melodic line with many sharps and a sixteenth-note run. Viola has a single note at measure 64, a rest at measure 65, and a phrase starting at measure 66. Piano (V) provides a simple harmonic accompaniment. The dynamic *mp* is indicated for the Viola part.

67

Pno. (C)

piano (V)

blender blades cresc

Measures 67-73. Both Piano (C) and Piano (V) have rests in the treble clef and a simple harmonic accompaniment in the bass clef. The instruction *blender blades cresc* is written above both staves.

74

piano (V)

there's **peace** afterwards

Measure 74. Piano (V) has a single note at measure 74, a rest at measure 75, and a phrase starting at measure 76. The instruction *there's peace afterwards* is written above the staff.

IV iii. Taken to Tampa

$\text{♩} = 90$

they put you un-der

Piano

Organ

...rested for that little bit of time

Measures 1-8. The Piano part has a treble and bass staff. The Organ part has a single bass staff. The Piano part has rests in measures 1-5 and then plays a triplet of eighth notes in measures 6-8. The Organ part has rests in measures 1-5 and then plays a sustained chord in measures 6-8. The lyrics 'they put you un-der' are above the Piano part and '...rested for that little bit of time' is above the Organ part.

9

piano

voice pad

organ

Measures 9-15. The piano part has a treble and bass staff. The voice pad part has a single treble staff. The organ part has a single bass staff. The piano part has rests in measures 9-12 and then plays a melodic line in measures 13-15. The voice pad part has rests in measures 9-12 and then plays a melodic line in measures 13-15. The organ part has a sustained chord in measures 9-15.

16

piano

voice pad

Measures 16-20. The piano part has a treble and bass staff. The voice pad part has a single treble staff. The piano part plays a melodic line in measures 16-20. The voice pad part has rests in measures 16-20.

21

piano

Musical score for piano, measures 21-26. The score is written in a grand staff with a treble and bass clef. The key signature has one flat (B-flat). The melody in the treble clef consists of eighth and quarter notes, while the bass clef provides a simple harmonic accompaniment with quarter and eighth notes.

27

piano

ICU synth

Musical score for piano and ICU synth, measures 27-33. The piano part continues in the grand staff. Measures 27-32 feature a sustained chord in the bass clef. The ICU synth part, shown in a single staff, plays a melodic line with eighth and quarter notes, including a triplet in measure 30.

34

piano

Musical score for piano, measures 34-37. The piano part continues in the grand staff. Measures 34-37 show a more active bass line with eighth and quarter notes, while the treble clef maintains a steady melody.

38

piano

Musical score for piano, measures 38-41. The piano part continues in the grand staff. Measures 38-41 show the final progression of the piece, with a sustained chord in the bass clef and a melodic line in the treble clef.

IV iv. ICU

$\text{♩} = 70$

ICU synth (V)

beeps

mf (stately)

organ (pre-rec'd)

mf

7

ICU synth

piano

organ

10

ICU synth

piano

organ

13

ICU synth

piano

organ

This system contains measures 13 through 16. The ICU synth part features a melodic line in the treble clef with eighth and quarter notes, and a bass line in the bass clef with chords and rests. The piano part has a treble line with eighth notes and a bass line with chords and a whole note. The organ part is in the bass clef, playing a whole note in measure 15 and a half note in measure 16.

17

ICU synth

piano

organ

This system contains measures 17 through 20. The ICU synth part continues its melodic pattern. The piano part maintains its eighth-note melody. The organ part is in the bass clef, playing a whole note in measure 18 and a half note in measure 20. At the bottom of the organ staff, there are four vertical lines of varying heights, possibly indicating a pedal point or a specific organ registration.

21

ICU synth

piano

organ

25

ICU synth

organ

The musical score is divided into two systems. The first system (measures 21-24) features three staves: ICU synth (treble clef), piano (grand staff), and organ (bass clef). The ICU synth part consists of a continuous eighth-note melody with a dotted quarter note, primarily in the range of G4 to B4. The piano part has a treble staff with a melody of eighth and quarter notes, and a bass staff with a simple accompaniment of eighth and quarter notes. The organ part is in the bass clef, mostly silent, with a single sustained octave chord (marked #8) in measure 23. The second system (measures 25-28) features two staves: ICU synth and organ. The ICU synth part continues its melody for four measures before ending with a double bar line. The organ part, in the bass clef, begins with a sustained octave chord (marked #8) in measure 25, then changes to a treble clef in measure 26 to play a sustained octave chord (marked 8) in the range of G4 to B4 for the final two measures, ending with a double bar line.

IV v. Brokenness

$\text{♩} = 90$...a lot of time talking to her after the transplant.

viola

piano (V)

$\text{♩} = 90$...a lot of time talking to her after the transplant. *mp espressivo*

p *mf* *p*

Ped.

piano

glock

3

7

viola

...I can see my arms there

p *mf* *p*

piano

Ped.

...I can see my arms there

mf ad lib. leggero

glock

12

viola

piano

glock

Measures 12-15. Viola: whole rests. Piano: Treble clef has eighth notes, a triplet of eighth notes, and a half note. Bass clef has whole rests. Glock: Treble clef has a half note and eighth notes. Bass clef has eighth notes and quarter notes. Pedal points are marked in the piano part.

16

viola

piano

glock

Measures 16-20. Viola: whole rests. Piano: Treble clef has a half note, eighth notes, and a half note. Bass clef has whole notes and half notes. Glock: Treble clef has whole rests. Bass clef has eighth notes and quarter notes. Pedal points are marked in the piano part.

21

viola

mf $\leq$ *f* $>$ *mf*

...she could see her
whole body

piano

glock

21

viola

mf $\leq$ *f* $>$ *mf*

...she could see her
whole body

piano

glock

IV vi. Gloria and the Water

$\text{♩} = 85$

I saw

viola

mf

Pno.

I saw

p

glock



5

viola

Pno.

I can still vividly see

2nd pno.

glock

7

viola

Pno.

2nd pno.

glock

9

viola

Pno.

2nd pno.

glock

mf
...corn or...

f
...corn or...

...corn or...

11

viola

Pno.

2nd pno.

...lavender or something.

...lavender or something.

13

viola

Pno.

2nd pno.

...end of that field

...end of that field

...end of that field

15

viola

Pno.

p

17

Pno.

organ

...opened a total...

19

viola

Pno.

organ

...blanket of flowers

mf *f*

...blanket of flowers

...blanket of flowers

21

viola

Pno.

2nd pno.

organ

mf

musical score for measures 21-22. The viola part has a half note G4, a quarter rest, a half note F#4, a quarter rest, and a half note E4 marked *mf*. The piano (Pno.) and second piano (2nd pno.) parts have continuous eighth-note patterns. The organ part has a whole note chord of G4 and F#4 in the first measure, then rests.



23

viola

Pno.

2nd pno.

I saw there

I saw there

I saw there

musical score for measures 23-24. The viola part has a half note G3, a quarter rest, and a half note F#3, with the lyrics "I saw there" under the last two notes. The piano (Pno.) and second piano (2nd pno.) parts have continuous eighth-note patterns. The organ part has a whole note chord of G3 and F#3 in the first measure, then rests.

25

viola

Pno.

glock

27

Pno.

glock

29

Pno.

2nd pno.

glock

organ

Gloria cont...

Gloria cont...

...I love her

33

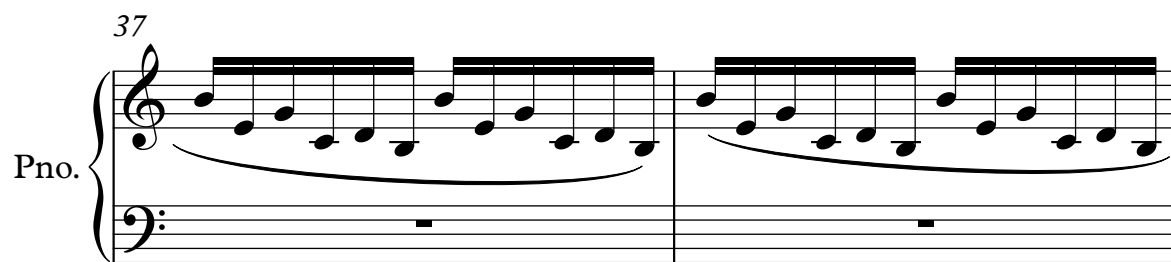
Pno.

organ

final sung 'Gloria'

37

Pno.



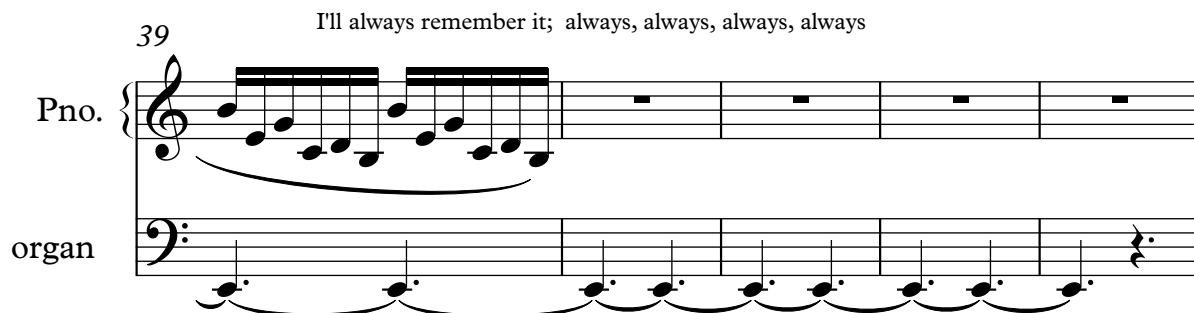
That to me is...

organ

39

Pno.

I'll always remember it; always, always, always, always

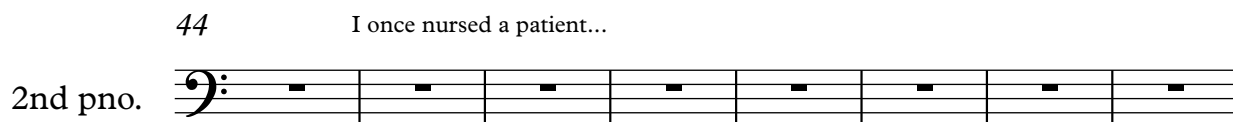


organ

44

2nd pno.

I once nursed a patient...



2nd pno.

52

viola



viola

60

2nd pno.

resus him today | then he's...

mp freely, espressivo



2nd pno.

64

2nd pno.



2nd pno.

68 ...you really get a bond with **people**

2nd pno.

73 ...anything you could choose | ...I wanna go shower |

2nd pno.

78

2nd pno.

83

Pno.

2nd pno.

...half an hour |

glock

86

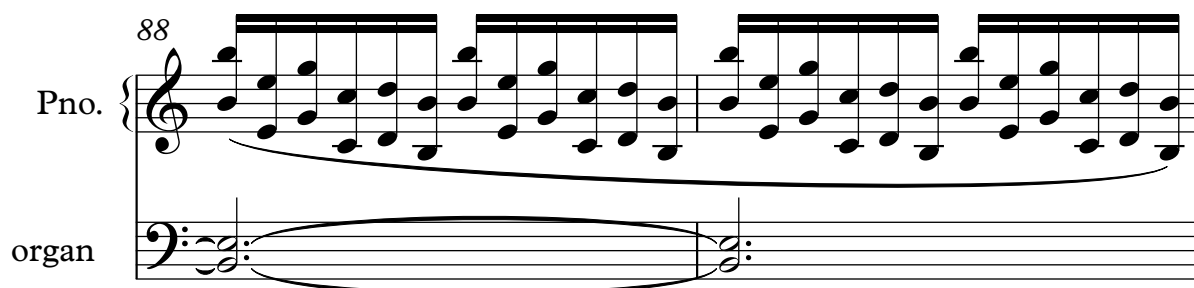
Pno.

organ

88

Pno.

organ



90

viola

Pno.

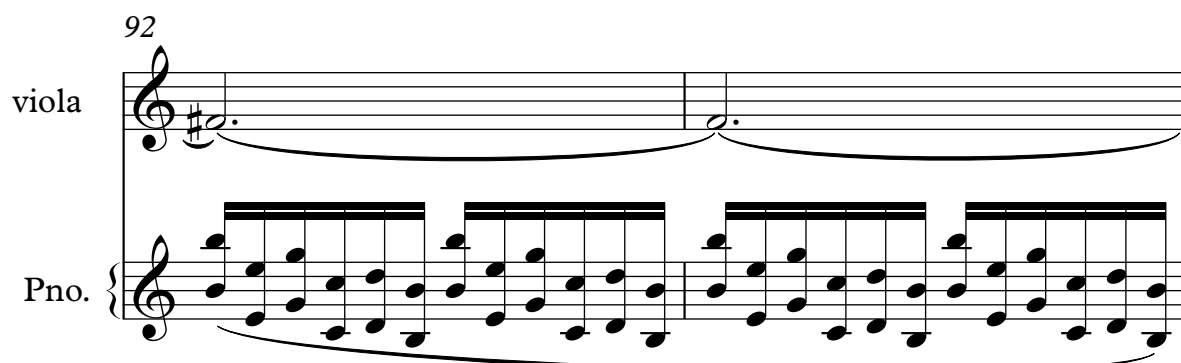
f



92

viola

Pno.



94

viola

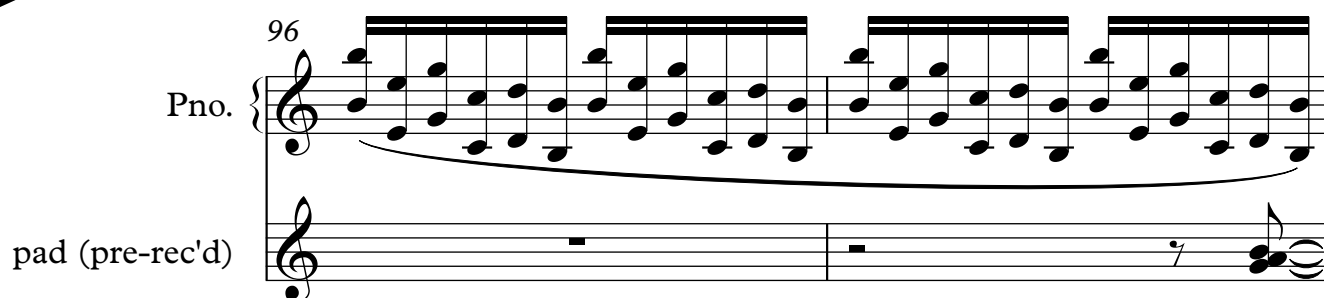
Pno.



96

Pno.

pad (pre-rec'd)



98

Pno.

pad (pre-rec'd)



100

Pno.

2nd pno.

pad (pre-rec'd)

At Olivedale they've got like...



103

Pno.

organ



108

viola

Pno.

organ

mp *pp* *mp*

...embrace the moment.

114

Pno.

organ

freely

120

Pno.

glock

122

Pno.

glock

Detailed description: This musical score consists of three systems. The first system (measures 114-119) features a Piano (Pno.) part with a melodic line in the right hand and a sustained chord in the left hand, and an Organ part with a sustained chord in the left hand. The second system (measures 120-121) features a Piano part with a melodic line in the right hand and a sustained chord in the left hand, and a Glockenspiel (glock) part with a rhythmic pattern in the right hand and a sustained chord in the left hand. The third system (measures 122-123) features a Piano part with a melodic line in the right hand and a sustained chord in the left hand, and a Glockenspiel part with a rhythmic pattern in the right hand and a sustained chord in the left hand. The score is written in treble clef with a key signature of one flat (B-flat).

Appendix 2: Approval certificates



R14/49 Ms Victoria Hume

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160336

NAME: Ms Victoria Hume
(Principal Investigator)
DEPARTMENT: Speech Pathology
Wits Donald Gordon Medical Centre

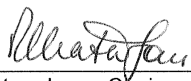
PROJECT TITLE: Exploring the Experience of Delirium in Hospital, and
How Music Might Expand Our Insight into This
Phenomenon [Phase 2]

DATE CONSIDERED: 01/04/2016

DECISION: Approved unconditionally

CONDITIONS: Phase 1: M150714

SUPERVISOR: Prof Claire Penn

APPROVED BY: 
Professor P Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 15/04/2016

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004, 10th floor, Senate House/2nd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in March and will therefore be due in the month of March each year.

Principal Investigator Signature

Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES



R14/49 Ms Victoria Hume

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M150714

NAME: Ms Victoria Hume
(Principal Investigator)

DEPARTMENT: Speech Pathology and Audiology
Wits Donald Gordon Medical Centre

PROJECT TITLE: Exploring the Experience of Delirium in Hospital, and How
Music Might Expand our Insight into this Phenomenon

DATE CONSIDERED: 31/07/2015

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Prof Claire Penn

APPROVED BY: 
Professor P Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 02/10/2015

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.**

Principal Investigator Signature _____

Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES



R14/49 Ms Victoria Hume

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M161123

NAME: Ms Victoria Hume
(Principal Investigator)
DEPARTMENT: Speech Pathology/School of Human and Community Development
Wits Donald Gordon Medical Centre: Intensive &
High Care and Liver Unit
PROJECT TITLE: Exploring the Experience of Delirium in Hospital, and how
Music might expand our Insight into this Phenomenon
DATE CONSIDERED: 25/11/2016
DECISION: Approved unconditionally
CONDITIONS: Phase Three
SUPERVISOR: Prof Claire Penn

APPROVED BY:

Professor A Dhai, Co-Chairperson, HREC (Medical)

DATE OF APPROVAL: 20/12/2016

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in November and will therefore be due in the month of November each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature _____

Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Delirium: Key findings for discussion

February 2017

Draft music: <https://soundcloud.com/victoriahume/delirium-full-draft-for-sharing/s-VXqNN>

All quotes below are from interviews from this study unless otherwise stated.

1. Organic and inorganic deliriums

The interviews describe two distinct types of delirium: encephalopathies and psychoses. Although much of the clinical literature conflates the two, or at least puts them in the same experiential bracket, they appear to have distinct characteristics, and quite different impacts on patients. Since renal encephalopathy (caused by kidney disease) rarely becomes extreme, thanks to dialysis, the discussions mainly refer to hepatic encephalopathy (caused by liver disease). I have interpreted the difference between encephalopathies and psychoses as being that between organic (of the failing functions of the body) and inorganic (derived from treatments and the impacts of the hospital environment).

What is common between these two branches of delirium is losing orientation to time, place and self; changes in behaviour (inappropriate talk or action); and often aggression. What separates them is the following:

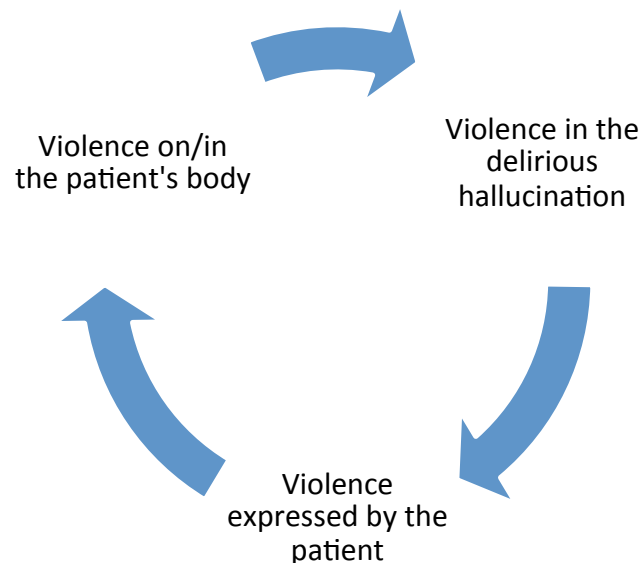
- Psychosis is often marked by paranoia and persecutory hallucination. Hallucination seems to be rare (non-existent?) in encephalopathy. Psychosis as a consequence can be 'horrificing' and 'terrifying'; while encephalopathy is certainly 'disturbing', but appears to have a less extreme emotional impact on the patient (and perhaps family).
- Encephalopathy is episodic, with episodes increasing in frequency and duration without treatment, but responds quickly to the correction of chemicals reaching the brain. Psychosis lasts for different lengths of time, from momentary hallucinations to days spent in other worlds. During a psychotic episode occasional flashes of reality are reported; people do move in and out of psychosis, but it is not episodic in quite the same way.
- Encephalopathy is described as mimicking a mild stroke – the brain is 'foggy' and confused. Psychosis is more often characterised by hyper-vigilance and the 'wild eyes' of absolute focus – albeit on things that are not externally verifiable.

There can be crossover between the two; it is possible to experience both HE and psychosis during the same hospital stay (possibly at the same time?). This can be further complicated by additional deliriums such as delirium tremens (characterised by formication – scratching the skin for invisible insects). Patients can move through these different states in ways that are hard to split apart; nonetheless each is its own condition, with different causes and symptoms.

Since none of the former patients interviewed had experienced HE or delirium tremens; and since my own interest is particularly in delirium generated by treatment, the main focus of the dissertation and music is psychosis (although one piece of music does deal quite specifically with HE – see 23:25 to 25:10 in the sound file).

2. Violence

Delirium is part of a cycle of violence:



Here is a salient quote:

P1: I wanted to be out of there [...] I think I was becoming very physically agitated, and trying to remove all the lines from my arms. I remember the people who were the nurses, but they were part of the hallucination [...] They were officers in the air force [...] And part of the hallucination was that they were trying to control me and keep me in that subjugated, enforced type of state, but I always wanted to break away, I wanted to get out of there.

C1: And he's a very non-violent, non-physical person when it comes to those kind of behaviours, [so...] it was terrifying for *me* to watch this [...] I would have to call for the nurse, and they had one large male nurse that would come in and [...] say 'Do you want me to have to restrain you?' And he would look at him and say 'No.' And then he would calm down. So he would listen to commands, and go back into reality for that moment when he was forced.

To break this down: first, P1 begins in a pained, confused state on his admission to hospital (experiencing violence on/in his own body). Second, his hallucination of being subjugated by the military mirrors a sense of being trapped/controlled in hospital (violence in his delirium). Third, he tries to pull out the lines that are keeping him alive (expressing violence). Fourth, the nurse steps in and threatens him with restraint (the second instance of violence on/in his body – at which point the cycle starts again).

Physical restraint is generally described by HCPs in the interviews with great discomfort, as 'almost barbaric' – although interestingly this emotional discomfort is less evident in the patients and family members who mention it. Chemical restraint carries less of a moral

burden and may be more (although perhaps not entirely) 'benign'. But the flipside of restraint is the real risk unrestrained patients present to themselves and others through their own expressions of violence, most often by pulling life-saving medical devices out of themselves, but in other cases punching staff or other patients, or even cracking their own sternum by lifting heavy objects.

3. Loss

People experiencing delirium lose contact with key elements of consciousness: a sense of **time, place, memory** (linear autobiography), **identity** (self). (This is interesting in relation to the DSM-5 definition of delirium, which has removed the term 'disturbance in consciousness' and replaced it with 'disturbance in attention'.)

These losses are all connected with an overarching loss of **control**. A loss of control is often discussed in tandem with illness and hospitalisation generally, but in delirium it is internalised in a particular way, and expressed through disinhibition (aggression and other 'inappropriate' behaviours – both verbal and physical) and paranoia, which can manifest as beliefs about and accusations of theft or conspiracy, directed at staff and/or families. It is also hard to discern the point at which the baseline paranoia characteristic of hospitalisation, particularly intensive care, becomes psychotic delirium.

There is also a loss of **dignity** – this is intrinsic to hospital care, especially of a more intensive kind, where we are powerless and subject to exposure of all kinds – but of course dignity is impacted more extremely by disinhibited behaviours, and people can be horrified by their own actions when they are explained back to them:

'No! I didn't do that!!' (C1)

'They are dignified people ... and obviously they do not think ... they could have such episodes in their lives, they are so embarrassing. So it's got some negative effect on them' (S5)

Dignity is further challenged by the use of physical restraint, which inspires 'an *intense* discomfort with your human rights, and your dignity' (S2).

These various losses can be extremely painful, and can lead to conflicts in key relationships between staff, family and the person experiencing the delirium – as well as psychological crises after the fact. How does we reconcile experiences that are entirely different from those around us, with others, and how do we reconcile our own strangeness with a sense of a self belonging in the 'real' world?

4. Humanity

In response to these losses, various types of restitution are discussed.

One healthcare professional, for example, reports a patient seeing parts of her own body distributed across a room at a time when she was ‘minutes away from death’. At the end of the delirium, her body-image reintegrates (she also recovers physically). Other HCPs also talk about the use of mirrors in ICU, which seem to return a sense of self to patients (there are links here to psychoanalysis, in particular Lacan, who emphasised the importance of the mirror in our development of a sense of a bounded self). In other units, diaries have been used as a way of mapping the time lost to patients. The diaries can take on huge significance in the process of recovery, since they provide a roadmap to help reconnect the self now to the self before delirium.

One interviewee talks poignantly about the experience of giving a patient – ‘he was a big swimmer ... he loved water’ – access to a shower, and of putting his feet in water – returning him quasi-religiously to his former identity. This is also of course a return of dignity. Not only through the recognition of his identity as a swimmer, but through the simple act of cleaning himself (‘for four months, he couldn’t get into a shower, couldn’t get into a bath ... [they] just get a basin and you wash them quickly, and you need to rush to all the patients’).

Another describes a shift in his own delirium from paranoid delusions to a profound experience of love – which he relates both to his wife, and to religion. In this person’s case there is a kind of restitution *in* his delirium. And in other cases there is a rebalancing of power relationships. Thus the doctor in one hallucination becomes a patient, who is treated by the *actual* patient. And in another case an interviewee hallucinates being in the police and ‘protecting people’.

But overall the data in this study suggests that there is potential to mitigate against some of the initial losses, and to do more in terms of restoring a sense of self after delirium.

Additional findings

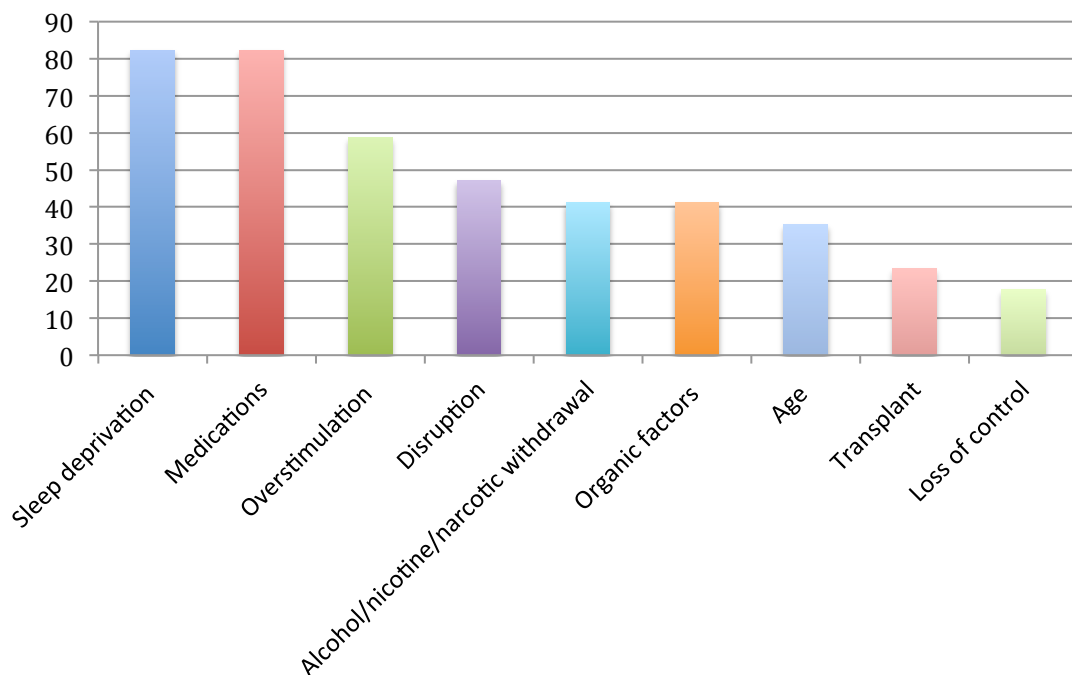
- Delirium is ‘under-researched’ and more research could improve outcomes for patients.
- There may be differences in the perception of delirium between HCPs, patients and families, particularly in terms of its impact – but the data is inconsistent here: ‘it doesn’t distress us, but it distresses the patients’ vs. ‘It’s horrible. It’s horrible. To watch someone go through it is horrible’.
- Delirium is not simply about visual or aural hallucination. It is multisensory – it affects sight, sound, possibly the olfactory system, and has a particular relationship

with touch, in terms of both hallucinated skin sensations, responses to on-skin devices, and tactile actions – like ‘knitting’, or pulling at sheets and clothes.

- Although the primary focus of the literature in recent years has been on diagnostic tools and discerning prevalence/incidence, no-one is using formal tools to diagnose delirium. Staff have no trouble recognising it, however, although it remains a loose term that covers a panoply of different experiences (is it recorded in patient notes?).
- Not all delirium is unpleasant. Some ‘happy hallucinations’ are reported – some even transcendent.

Risk factors

Risk factors are multifarious and overlapping. The main factors mentioned in interviews are given below (by % of interviewees):



Additional factors mentioned by one or two interviewees are sepsis, length of stay in ICU, lack of daylight, hepatitis C, pain, fear of death, and paranoia itself.

Appendix 4

INTERVIEW SHEET:

MEDICAL & ALLIED STAFF

STUDY TITLE: Exploring the experience of delirium and hallucination in hospital, and how music might expand our insight into this phenomenon.

(NB This sheet will not be given to interviewees; it will be used as a guide for the researcher)

The opening question will be

- Have you experienced patients under your care being confused or hallucinating while they are in hospital? Tell me about that.

Probes:

- How common would you say this is? (What *approximate* percentage of your patients experience this?)
- Why do you think this happens?
- How does it affect the patient more generally?
- How do you respond to this when it happens?
- How does it affect your relationship with the patient and their family (or that of other members of staff)?
- Do you use any special tools to diagnose delirium?
- What do you think about doing research into this experience?
- Tell me about the last piece of music you enjoyed listening to.
- What do you think about the idea of using music to document this experience?

Staff interviewees will also be asked for the following background information at the end of the session. It will be made clear that they do not have to give any of this information, and that these questions may compromise their anonymity. If they would prefer not to answer this will not preclude their interview from being included:

- home language
- primary area of work (intensive care, high care or transplantation unit)
- profession (e.g. doctor, physiotherapist etc.).

INTERVIEW SHEET:

PATIENTS AND CARERS

STUDY TITLE: Exploring the experience of delirium and hallucination in hospital, and how music might expand our insight into this phenomenon.

(NB This sheet will not be given to interviewees; it will be used as a guide for the researcher)

1. Tell me about your time in hospital

Probes:

- How long were you in hospital for?
- Do you remember (them) being confused while in hospital? (If yes) Tell me about that.
- Do you remember (them) experiencing things that weren't real while you were in hospital? (If yes) Tell me about that.
- Do you remember (them) doing anything strange while you were in hospital? (If yes) Tell me about that.
- Why do you think this happened?
- How did you feel when you (they) left hospital?
- How do you feel now about the time in hospital?
- What do you think about doing research into this experience?
- Tell me about the last piece of music you enjoyed listening to.
- What do you think about the idea of using music to document this experience?

I will also ask participants (both patient and carer) for their home language.

A note on carers:

Carers will only be interviewed with the patient, and at the patient's invitation. Should a carer be present, the opening question will be directed first to the former inpatient, and then opened to the carer for their additional thoughts (if they have not already engaged with it). Other questions will be addressed to both parties and care will be taken to ensure both voices are heard.

Appendix 5: Notes from observations

(All observation takes place in the intensive care unit at WDGMC with the written permission of the unit's director and the verbal permission of the senior nurse on duty at the time.)

Day 1: 27 May 2016, 14:33

"You should have been here this morning ... lots of people coming in, lots more *trying* to get in". It's now extremely calm. Lights off between 12 and 3. Light levels are lower than in other wards, but lots of daylight. Only the main overhead lights have been knocked out. Constant noise – beep – beep – beep

phone phone phone
nurse calls something

NB when I came in through the main doors the other day I was struck by the thank you card on the desk, facing you as you come in.

I like this space. It's open and oddly relaxed (to me as an outsider, but one who's not bothered by hospitals). Nurses are friendly and smiley to me – they don't seem bothered by my scribbling away, even if they don't know me. S— [nurse in charge] seems to have a good relationship with them. The now familiar SA mix of languages - Zulu; English.

Nurses' station has a blue flycatcher light by it, Ecolab stickers on it. Behind the station a clock, old-fashioned and cheap but on time (cf —)¹ and a picture (by a patient? Abstract – reminds me of a patient pic in Reading that MG showed me),² on a recess above the area where noticeboards and filing is [*sic*]. Two lightboxes, side by side.

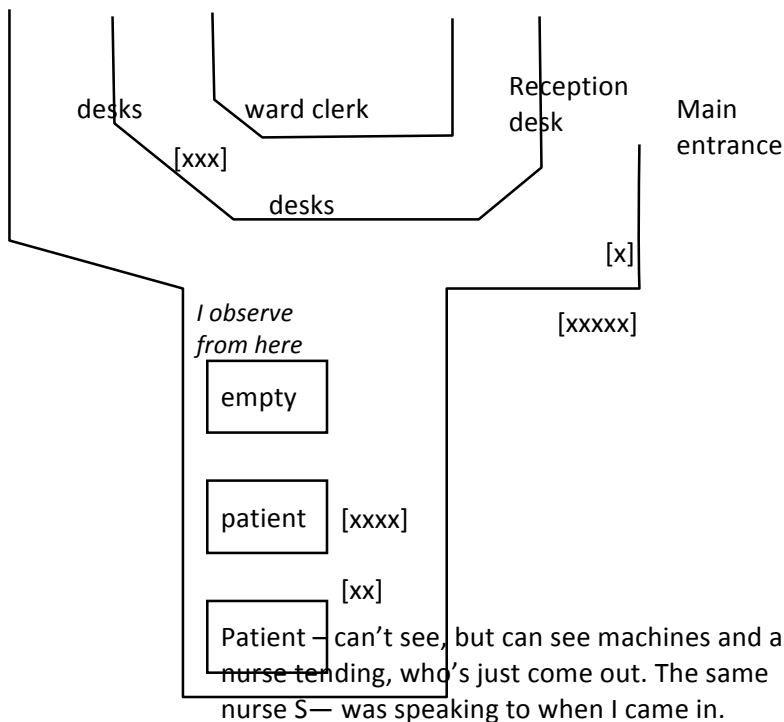
Occurs to me that it's odd to face the station. Normally they are the watchers.

¹ In another project at a different hospital clocks were not on time.

² This was part of *Part I* – a picture depicting ICU psychosis shown to me by a senior nurse as a prized possession.

A nurse comes past – holds up 4 fingers to a colleague. I can't see round the corner. Whispers 'patient 4'. Conscious of keeping noise down.

Also a cleaner working here [x].



A new sound ♪ ♪ □ ♪ □. SS responds. It's the machine in this room [xx]. The invisible patient.

Young nurse walks past again.

Struck by constancy of work. *Responsiveness*. Do you make a plan or do you just respond all day? Are there set things you want to achieve by a certain time? Obviously there must be regular checks etc. A ward clerk in a b/w cardigan is sitting here now [xxx] [14:49].

"...beep"

"been a problem the *whole* day" (nurse)

Ceiling: regulation tiles. 120x60cm, not 60x60cm. Now a man in a khaki roundneck sweater sitting with ward clerk. Dr?

Ward clerk moves off, nurse standing w Dr. or is she also a Dr? Probably – also blue scrubs but no piping.

Relative? comes out of one room and into another. Can't be relative. No, it is, she went out of the entrance, cleaning her hands with alcohol gel. Tall, white, dark hair piled up on head, leggings, trainers, dark ?blue top. Nurse brings yellow plastic bag around – sounds noisy out of context. Can hear curtains being drawn back. Very little talk.

Yes, he is a Dr. 'how's she doing now, sister' Standing at patient chart here [x]. Male voice stands out.

Ward clerk red nails.

Young nurse is now opposite the clerk sitting at a desk, writing up a chart. Plastic bag behind me – not sure what she's up to.

[drawing of nurse writing on chart]

Snippets of conversation: "...don't think that's *safe*". Something about driving. Ward clerk louder than nurse.

Patient here [xxxx] extremely ill. Bald.

V odd slapping/clapping noise next door.³ I can see a hoist faintly through opaque windows.

Am opposite a weird machine [drawing]. Hospital beige. Minijacks at end of leads.

15:02 first visitor arrives. Middle-aged, perm? Slim. Carrying 2 bags. Yellow linen bag an echo of the plastic earlier.

V sick patient [xxxx]. Nurse works behind him. Redness on the neck. Thin. Head faces upwards, knees raised, eyes closed?

Another relative by entrance. Stands diffidently waiting. Has she been asked to leave a room for a sec?

A man with quite bad scoliosis walks into [xxxxx]. Relative by door – bright red cardigan, smarts. Joins him with another older woman, grey-haired. Though they could be sisters? Same sort of face/build. He wears an anorak and [is] grizzled. They're smarter, but all grim-faced.

"was this in the blood? ...Bed 15"⁴ I see this nurse a lot. Senior. Works with [a colleague]. Smart low heels [drawing]. Noisier than others' shoes [15:09].⁵ Asian man pinky red trainers. At [x]. Staff? Relative?

Hubs of activity: [x] and [xxx]. Desk opposite ward clerk. Dr in dark blue scrubs with pink/white headscarf.

Machines totally mysterious. Often with tentacles of tubes etc. articulated arms. [drawing]

Maybe that's not a ward clerk. She seems to chat to drs and senior nurses and have a [?]. Dr says "1.67" to her.

Lights seem to be getting brighter but it may be an optical illusion.

Beige floor, beige walls, metal crash rails, beige machines. Some blue plastic. Off-white everywhere else. Pale fake wood desks with grey blocks. Above nurses' station – flourescents. Man at phone.

15:17 tired. Going now. ♪ □ ♪ □⁶

³ I learn later this is the physiotherapist. This sound is used extensively in the composition.

⁴ This also makes it into the composition.

⁵ As does this.

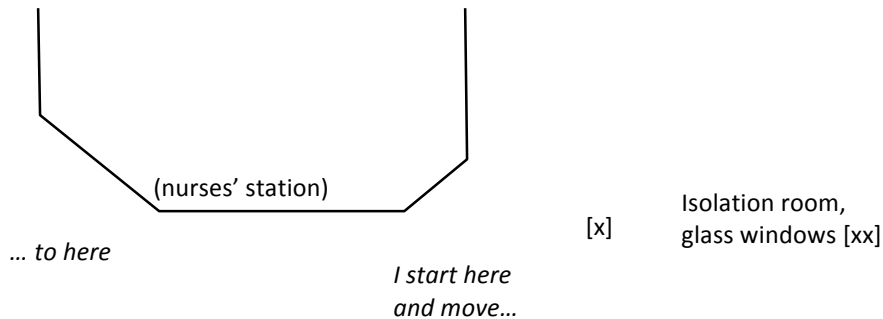
⁶ All of the bell/"parp" noises I transcribe in this document are in the composition.

Day 2: 13 June 2016, 10:32

Harder to find a place to sit this morning.

Volume not noticeably louder than last time, during quiet time.

Small child in bay behind where I was before.



“Yes my love.” Elderly lady, relatively upright in bed “...sore?”

Sound of towels being pulled from holder; handwashing.

Can see how I – a person sitting here, writing, in the eyeline of the patient – might induce paranoia.

Nurse wheels a large machine slowly past me.

Gas.

Electricity – again the spidery machine plugs. Odd that these two inherently toxic-seeming things are so central to care.

Cheerfulness again.

I’m going to move, not a good spot.

More children today.

Trolley in front of me.

Charts themselves are very noisy. Like sails in the wind though.

Together with the breathing machines.

[drawing of two nurses] Hand on her colleague’s back – supportive – as she looks at the chart [x].

in here [xx] a bald man. Could he perhaps be the man who was behind me last time? He’s sitting up now. It seems very unlikely he could have survived. No, I don’t think he’s the same – he just looked up and looked completely *compos mentis*.

There’s — [colleague]

The machines in this room – they’re familiar, but in such a particular way – like 60s sci-fi. Beige and primary colours. [drawing] No wonder people interpret all these foreign/familiar objects as they do “I was on a spaceship”... even a nurse.

On the trolley in front of me, a huge yellow set square – with a smaller one attached. Why a set square?? [drawing]

10:44 a new noise [transcribed] – parp-ish. And again about a minute later.

Patient up and walking around, back of gown open – grizzled, white hair, late '50s/60s? hair on his back. But not intimate, more like a beach.

Nurse in dark red scrubs, not seen that before.

The soundscape would drive you mad – because although it's varied within itself, it's also unchanging, and constantly *blurring*, with the odd word coming into focus. Exacerbated for me by the accents, different languages code-switching. Same for patients? Patients seem very mixed – young black boy, older white man, white man opposite me in his late 30s, 40s?

Nurse to my left behind me is *glam* – furry boots, writing on chart, black tights, green skirt, matching headscarf (douk?) with black piping. Green like my tank top – what's the word? I the turquoise range... short black hoodie winter coat. Dr? behind nurses station clocks me, wonders who I am. Dr – woman – short hair- padded waistcoat jacket. Man is at the station. Nurse is tying up his gown at the back. Receptionist is trying to explain something to him. She has a short red wig on today. The man is slimmer than I would have guessed, he walks away very upright, holding the back of his gown together because it can only be tied at the top. Seems very in control, doesn't really seem ill, from this distance, for that minute. Yet he's in ICU. Was about seeing the Dr. Receptionist told him what time it was.

Wife arrives to see man behind me to the right. Her husband is about to be taken to x-ray. Relatives must adapt to whatever greets them when they get here. Gaggles of 5 ppl at station. Youngish Indian woman in dream coat. Nurse with lilac shirt and *very* styled hair.

Smell. This is something I struggle to perceive. I'm too used to hospital smells. But if I make an effort I can smell disinfectant.

He's on the move again. Back of gown open below the top. Exposed buttocks. Nurse gently steers him round the desk. It seems he just wants exercise. She's taking him round.

"I'm asking you all the wrong questions" – wife to ?nurse watching her husband from the outside – they both laugh – "yr face is so familiar..."

[drawing of how nurse sits outside isolation booth at high stool with chart]

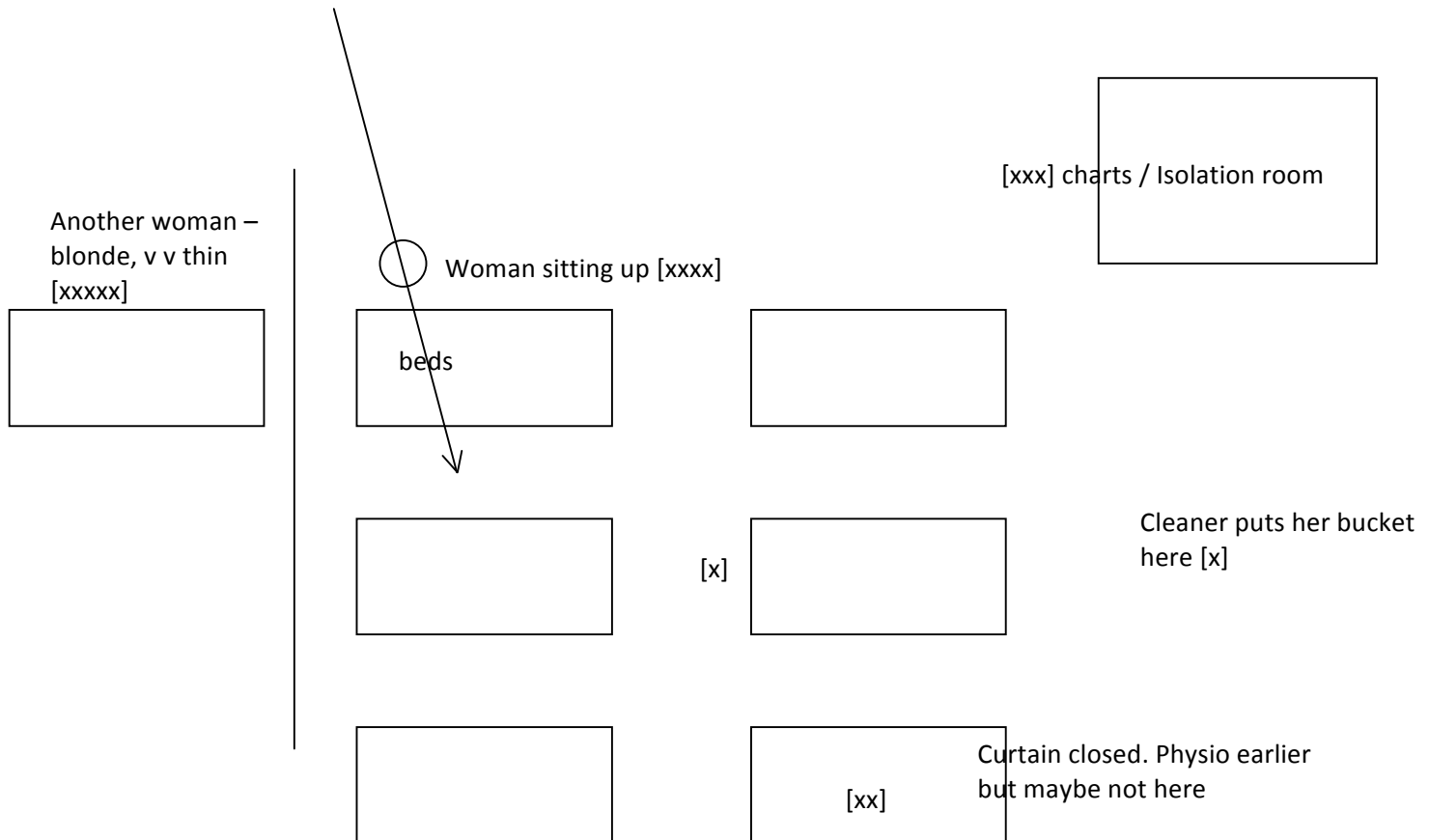
the man opposite has a visitor now. Also wife? Mother more likely. Oh, there's a younger woman in there to – sister? He's drinking tea/coffee? Or water? From a polystyrene cup. The two women are in aprons and masks. Mother fiddles with the tie on her masks. Are they habituated to them or is it awkward and irritating?

I'm going to go – and ask S— to explain I'm not assessing staff. [11:08]

Day 3: 18 June 2016 (Saturday), 10:32

Been here for 10 mins though it felt much longer. Started recording at desk.

Positioned self between 2 beds.



Sound quality quite different here from in the previous space around the nurses' station where it is more open. Here it is denser, quieter in some ways, more domestic. But there's some sort of oxygen/breathing machine operating here [xx] which fills the upper-mids/high frequencies.

While I was waiting at the front desk I could see all the interaction between staff – there's lots of it – questions, answers, general small acknowledgments. But nothing to the patients. They are like ghosts. For example, now, a nurse sits here at the charts [xxx], her back to this woman [xxxx], who regards her, for lacking in energy not to, perhaps? Now there's a gathering of 4 people round the chart. Cleaner, another nurse, a third nurse inside the isolation room. She watches them all but they don't acknowledge her. Too used to her. At last – lovely nurse – “are you still strong? How was your night?” Interesting – her bed is *facing* the machines. With this other lady, here [xxxxx], I was struck for the nth time by stuff happening behind her head. She looks around. I meet her eye for a second from the reception desk. I smile, she looks away immediately. It's hard not to feel you're assaulting people just by being here.

Now they're changing her bed, 2 nurses both speaking to her. One says “not long...40 minutes now” in answer to an unheard Q. But her brother was at the desk with me. He smiled at her very sweetly when he came in, mouthed a question of two. Waited patiently

after being told someone would attend. Nothing... nothing... eventually (only 5 mins but feels forever)

[I have to break here to explain what I'm doing to a Sister]

Does it exacerbate the problem that (I assume) these patients don't understand the language their nurses speak amongst themselves? Or are they used to it in an SA context? Street voices are always un-understood.

From the far end I can hear a man in distress. I could see him from reception, I could locate the cries. This woman next to me – in fact everyone here – can't see him. They can only hear the wails.

The male physio earlier acknowledged both this woman and the other. It was a great relief. I could see the other woman needed to be seen, though perhaps not by me. Distant, observing.

The wailer is in *great* distress. When I saw him he had his eyes closed, I think. He was lifting himself up and falling back down, only a matter of inches. He's quiet again now. Not for long.

I replicate the ignoring when I talk to the Sister about my project, but not the patient, who I sit to the right of and *behind*. I deliberately don't want to be in her eyeline so she won't see me observing and writing, but does she know I'm here? Do I make it worse? I'm just another hidden figure in a space she can't move around. She has one angle – forward. Can she see me in her peripheral vision? Could I? I test it. Probably. I think I'll move.

Now am back where I was last time. Distress acute.

Blood tests.

No-one's attending him. I feel like a spy.

Sound totally different. Space opens out.

God it's unbearable.

Like a child. Dr laughs. What else can you do?

Steroids.

Dr says he needs a walk. Brave.

Too intrusive. Leaving.

Dr: "How strong is Mr —?" Through the glass: "Mr —! They don't make them like that any more, huh?"

Nurse: "No, he's my celebrity".

Mr — looks *awful* to me.

Same Dr says "I can see he's getting a little bit antsy. He's a bit steroidy". Seems like the understatement of the century – he's been *wailing* for 45 minutes. Dr says "I've been speaking to him. He says he wants a walk. So I said 'OK, walk'."

"They're putting him in high Care".

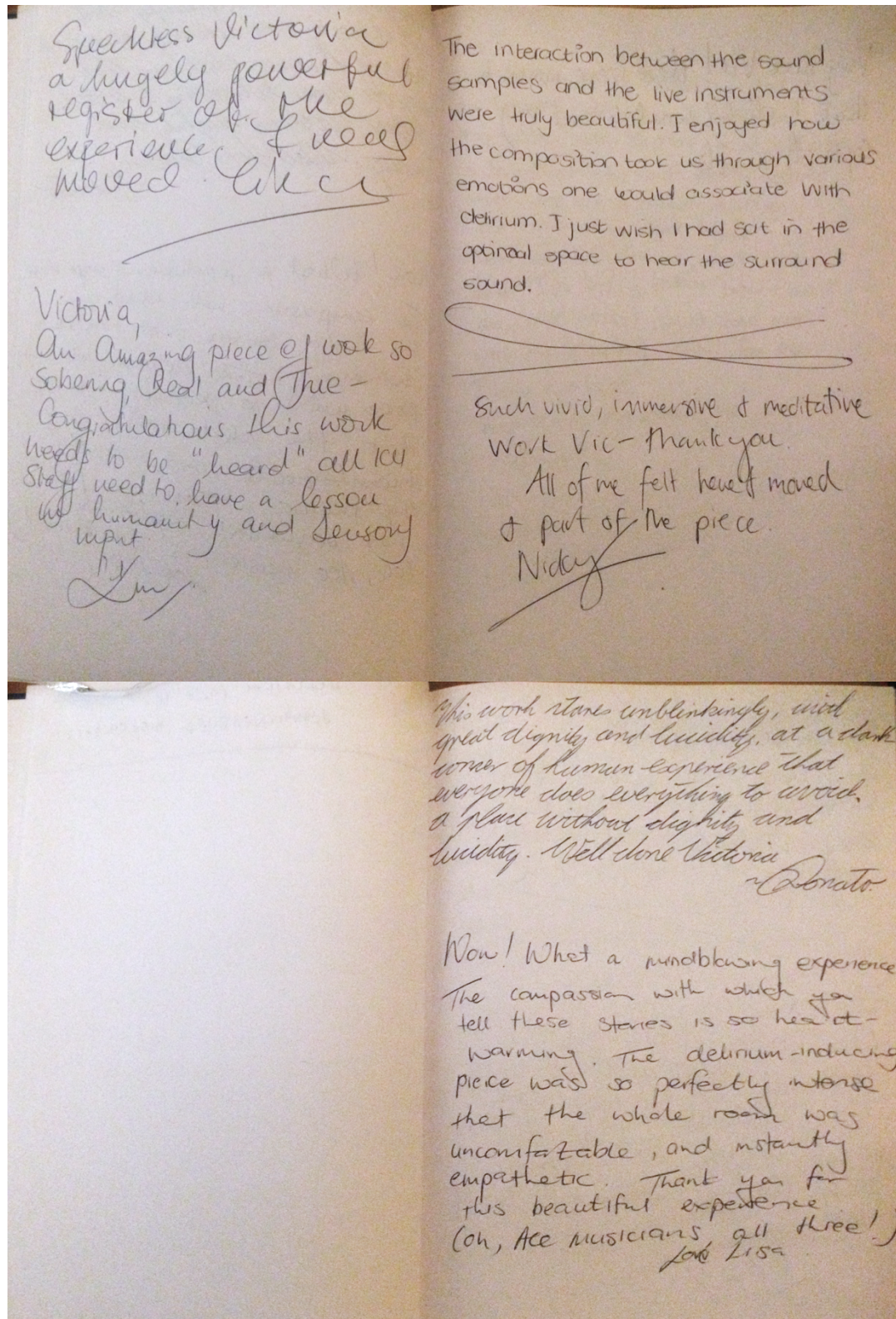
"OK, perfect".

The other Dr/nurse says she's asked for "a room with a window". Dr: "and a TV".

I would never have imagined he was getting *better* [i.e. able to move to High Care from ICU].

I was imagining he was near death. Assumptions of the non-clinician. I'm in the waiting room outside High Care now. Bit of a relief. Gonna buy a coffee and head home.

Appendix 6: Comments from the first performance (2 March 2017)



Appendix 7: Specific hallucinations, and the multisensory nature of deliriums

Table 4: List of hallucinations – as described in first and second-round interviews and groups (NB The chart below represents only what came up in conversation and should not be read as a comprehensive list of all the hallucinations interviewees have experienced.)

TYPE OF HALLUCINATION	REPORTED BY FORMER PATIENTS / CARERS	REPORTED BY HCPS
General / other		
HCPs as military or political figures, or spies, or engaged in conspiracy*	P1, P3, P4	All HCPs
Existing in another location entirely	P1, P3, P4	S1/2, S7-9, S6
Experiencing being transported somewhere*	P1, P3	S6
Absent family members (including deceased) – visual*†		S3, S5
Absent pet†	P2	
Being on display, made an example of*	P3	
Idyllic spaces: cornfield / field of flowers (P3) / “beautiful trees” (S6)	P3	S6
‘Sci-fi’ locations* ¹	P1	S5
Transformation of self		
Being in the police / army (“saving people”)	P4	S7
Becoming a “doctor”	P3	
Dismembered body		S1
Transformation of others / space / objects		
Loved one as clone (Capgras)	P1	
Loved one as the devil	P2	
HCPs as gardener, grandfather, witch		S1
Hospital room as patient’s “bakkie”, ² and workshop	P3	
Room losing proportions		S6
Machines misconstrued (e.g. TV as oxygen pump or camera)*	P3	S1
Poison in the drip*		S5
Other characters		
Insects (NB <i>not</i> the same as formication, below)		S9, S5, S6, S2, S10
Monsters, demons		S6
Snakes		S5
Crocodiles	P2	
Catwoman	P1	
Isabel Jones ³	P2	
Fairies*	P2	
Aural		
New music*	P1	
Music*†	P3	S6, S8
Absent family members – aural*†		S3
Hearing a tap running or other absent sounds		S7, S1
Tactile / physical		
Physically interacting with invisible objects / people		S7, S1
Feeling insects on the skin (formication)		All HCPs (DTs)

* = also present in *Part I*. † = also present in *The Isle*.

¹ I note in one observation that “the machines in this room – they’re familiar, but in such a particular way – like 60s sci-fi. Beige and primary colours” (see Appendix 5).

² Afrikaans slang for large car/small truck, widely used in South Africa.

³ A South African consumer affairs champion and a staple of a restricted televisual diet in the ‘90s (see <http://mg.co.za/article/2008-03-11-consumer-rights-champion-isabel-jones-dead-at-72>). Jones was feted for her tough attitude to consumer rights, something that perhaps reflects P2’s own intractability in relation to her care: “I was, like, well, that’s what doctors do, they fix you; [...] they’re doctors, they’re trained, they must make it right”.

Touch

Five different issues relating to touch are mentioned in this study.

- i) Formication – a physical sensation of insects crawling on or under the skin – is strongly associated by all ten HCPs with DTs (alcohol/narcotic withdrawal – see p.78 of the main dissertation). Hallucinations of insects (ants, scorpions, spiders) are also described as common, but the interviews and focus groups confirm this is absolutely distinct from formication, and happens across different deliriums.
- ii) Older patients are reported to be hyper-tactile in their behaviour, “continuously fiddling” with, folding, or picking at material on and around them: “If it’s not the sheet, it will be their patient jacket, you know [...] or their pajamas” (S8) – S7-9 speculate that this is equivalent to a “child with a security blanket” (S7).
- iii) Grabbing at things in the air which are invisible to others “often there’s this plucking feeling – they’re either moving something away, or they’re grabbing things in the air [...] almost like they can see things” (S1).
- iv) Hyper-sensitivity to small medical devices touching the skin. This is described by S5 and S3 as an early sign of an emerging delirium.
- v) Itching skin from liver disease “a lot of the liver patients, because they get very itchy, and – so everything sort of is quite tactile, and alive and moving” (S2).

It may also be worth noting that P2 describes the devil she sees as having “black, sharp, pointy hair” – there is an element of the tactile here, too.

Sound and music

S6 reports patients hearing taps dripping. S3 that they will hear the voices of absent relatives. P1 and P4 both specifically describe hearing music, however – and S6 and S8 also report this in patients under their care. P1 describes *composing* music, which he can recall in some detail, although the experience dates back three years from the interview.⁴

P1: My brain was creating new music.[...] mostly instrumental, [...] rock guitar music [...] it wasn’t like, you know, *heavy* music. It was just you know very melodic type of music that you know was – it was more like rock-jazz. [...] I enjoyed it.

This is strongly reminiscent of an interviewee in *Part 1*:

⁴ As we have seen, this clarity of recall is also typical of psychotic delirium, see dissertation p.94.

there was always music playing – always [...] I think that basically my brain must have been keeping me company. And creating [...] structure and form, and distraction. (LM)

P4 mentions that the music “currently being played” in his hallucination was R&B and light jazz; he suggests that this is the music he would use to describe his delirium, because this is the music that appeared in it. Again he recalls it in some detail: “for example in the store, the radio would be on. And Percy Sledge would be singing ‘When a man loves a woman’.”

Smell

In *Part I*, one interviewee talks about her extreme sensitivity to smell – detergent and coffee in particular.⁵ I ask some interviewees here directly about smells; none of the people who have experienced delirium have specific memories of this, barring P4, who remembers “a bit here and there”. S5 does discuss an encephalopathic patient who, losing the “concept of what’s normal and what’s abnormal”, is found “putting lotion on a sandwich and covering it and eating it”. It’s possible here that the olfactory system is compromised in some way.

⁵ Possibly hyperosmia, which is known to be related to anxiety, head injury, and drug withdrawal and could therefore have a relationship with delirium:
<http://www.sciencedirect.com/topics/page/Hyperosmia>.

Appendix 8: Themes used for coding

NB: The following headings were developed during data analysis and are included here in no particular order; the quantity of data relating to each heading differs significantly.

1. Definitions/characteristics of delirium
2. Differing perceptions between HCPs, patients, and carers
3. Theatricality
4. Impact of physical environment
5. Unpredictability/randomness-vs-predictability
6. Patterns, rhythms, fragmentation
7. Time
8. Memory
9. Death
10. Violence
11. Loss of self
12. Control
13. Racism
14. Multisensory nature of delirium
15. Psychosis as creative response to trauma
16. The value of music
17. Religion
18. Sanity/insanity
19. Longer-term impacts

Five Key Findings

