Tharunka acknowledges the traditional custodians of this land, the Gadigal and Bedigal people of the Eora nation, on which our university now stands.

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Letters from the Editors

A Message from UNSW LGBTIQ Champion Professor Mark Willcox

Corporate Image by Ash Rehn

Identity (photo series) by Jemima Waddell

Drag is for Everyone: Realising the Potential of an Art Form by Levent Dilsiz

How to be a Gender Explorer by Samuel Beatty

The 'In-between' of Sexual Assault: the Space that the Law Fails to Recognise by Nechama Basserabie

The Double-edged Ring by Sahana Nandakumar

Stayin' Alive: Dancing with Death by Shivika Gupta

Birds by Lachlan Bell
LUNGOL
MANAGING EDITOR

I called this issue ‘Binary’ because I wanted to challenge, explore, and examine the dichotomies we’ve sewn into the fabric of our society.

For as long as I can remember, I’ve always been pretty bad at fitting cleanly into one of two boxes. I was too messy. Too different. Too feminine to be one of the boys, too masculine to be one of the girls. Too exotic to belong where I lived, too foreign to belong where I was born.

I grew up dreaming of one day growing up, cleaning up, and making a home for myself comfortably in a box designed by someone else.

But now I have grown up, and I’m still too messy. Too different. I just don’t care anymore. And neither should you. Flourish in the boxes or spheres or cones your design around you.

I’ve learned that binaries are used to make things simple, comfortable. It’s simple to be either a boy or a girl. It’s comfortable to be either right or wrong. And maybe that’s because life is anything but simple and comfortable. Perhaps binaries are our way of navigating the firestorm we were all dropped into when we took our first breath. But in trying to escape the storm, have we inadvertently thrown gasoline into its flames instead?
MAGGIE
CREATIVES SUB-EDITOR

To define the term ‘binary’ seems like an ironic task. In essence, binary revolves around the premise of being composed of more than one; so how can such an intangible thing, be given one simple definition? In truth, it cannot. And that’s what I wanted to explore through this edition of *Tharunka*.

In my curation of content for ‘Binary’, I wanted to truly encapsulate the duality of what binary means, and not limit this exploration in any way. I’m very pleased with the end result and feel as though all of the contributors for this issue provide a unique and thoughtful perspective on what binary means to them.

Through a diverse assortment of visual and written works, I feel a true sense of binary has been conjured. Through the epistolary short-story written by Axel Nathaniel-Rose, we’re invited into a whirlwind of emotion as the story’s protagonists delve into a world of love, tension, confusion and identity. From the work of Ash Rehn, who paints an intimate and transformative portrait of the world, to the visual journey’s created by Lachlan Bell and Jemima Waddell who subvert traditional meaning to explore the limitations and impact of binary, and even with the beautiful and effortlessly cosmic comics created by Samuel Beatty.

Binary has a different meaning for everyone, and we have some exquisite reflections of these meanings throughout the creative works in this edition of *Tharunka*.

JACK
FEATURES SUB-EDITOR

It’s said that knowledge of a subject, or skill at a task, can be broken into one of four categories, the lowest of which is “unconscious incompetence” - the state of not even knowing how little one knows, or how poorly one is performing. I see this as the guiding state underlying Tharunka’s ‘Binary’ issue. This edition, more than any other this year, is an attempt by our team and our contributors to reveal the complexities and greyness of phenomena, such that we may, collectively, move to “unconscious competence”, where we can all, at the very least, learn how little we know.

This holds for the wonderfully broad range of topics in ‘Binary’. Sahana Nandakumar reveals the nuances of bipolar disorder, a condition so common that it warrants much better community understanding. Shivika Gupta explores the concept of brain-death, a physical limbo in which the body (with assistance) persists despite absent brain function, and its importance in our understanding of what it means to be a living human being. Levent Dilisz writes on the performance art of drag, and how the complexities of gender expression are not conveyed in the unidimensional representation of drag in the mainstream media. And Nechama Basserasie considers how our sexual assault laws inadequately account for cases like that of Saxon Mullins, who bravely participated in a *Four Corners* episode earlier this year.

In all cases, the articles invite further reflection and research, as each case reveals a deficiency in our collective knowledge, or in the workings of our laws or social environment. I think this is perfectly representative of the role of student journalism, and I am very pleased to present *Tharunka’s* fourth edition of the year for your reading and consideration.
SAHANA
DIGITAL SUB-EDITOR

“If there’s a right and a left then there definitely is a center, there’s the ‘he’ and the ‘she’ and so much more to gender”

A lot of us are ‘programmed’ to understand many aspects of life in duplex. The simple antonyms we learn in primary, the social constructs of ‘this is how you live’ and ‘this is not’ and the laws that very often label individuals as ‘good’ and ‘bad’ have led us to push all knowledge into two distinct classes and overlook the so-called grey area. Binary looks at the 1s and 0s in the computers and our minds to remind us the vast array in between. It’s okay to be confused, it’s okay to be messy and it’s okay if you don’t fall in the two ends of a spectrum.

On the other hand, the Tharunka team is super excited to produce our very first spoken word poetry web series, UNSWallowed. Send your expression of interest soon, to showcase your talents and learn new techniques in poetry presentation. UNSWallowed to follow your dreams! (I should stop).

LETTERS FROM THE EDITORS CONT.

AMY
DESIGNER

As a designer, it’s usually my job to make things as clear as possible and communicate a singular message constructed out of the familiar and palatable. But practicing design is different from the way of living we should practice in our daily lives.

We exist in an increasingly polarised world, where the complex multiplicity of things is dismissed amidst competitive headlines and general panicked apathy. We fall back on familiar binaries because we’re not ready to learn, not ready to grow, and not ready to be wrong.

We like the clean edges, the categories, and the clear corrections towards one or another definable stereotype. We seek the unreal, hyperreal, Instagrammable perfection. Our brains are geared towards pattern-recognition, and things which do not fit the pattern alarm our instincts.

But we can’t live in a constant state of alarm. And that’s why this issue of Tharunka is important. We must train ourselves to be at peace with the messy, the frayed, the half-full, the incomplete, the multiple, the inauthentic things that don’t quite fit.
A MESSAGE FROM UNSW LGBTIQ CHAMPION

PROFESSOR MARK WILLCOX

What a great idea to have an issue of Tharunka devoted to 'Binary'. Tharunka's editor put out a call for people to contribute to the issue – and I hope many people do. The issue of non-binary gender may be new to some, and having a discussion around this issue is timely. We live in a predominantly binary heteronormative environment – but not all of us identify as binary, and that can feel isolating and confronting, but also liberating and normal.

I am UNSW’s LGBTIQ Champion and an Ally. In the role of LGBTIQ Champion I bring issues related to the LGBTIQ community at UNSW into view and facilitate discussion on issues related to this group. I can bring to the attention of the Equity Diversity and Inclusion Board issues that affect your life at UNSW. I also have an Advisory Group that assists me. This Advisory Group consists of members of Academic and Profession Staff, students of UNSW, as well as representatives from Faculty Equity, Diversity and Inclusion committees.

UNSW is now a member of Pride In Diversity, and so we can learn best practice from other members and implement these. But every workplace is different, even within the higher education sector, and I am sure there are specific issues at UNSW within the LGBTIQ space in general and around non-binary participation in UNSW in particular.

I’m always interested to hear from you in relation to LGBTIQ, so that UNSW may better serve its employees and students. And I would welcome participation of people identifying as non-binary in my Advisory Group. If you would like to contact me please email: m.willcox@unsw.edu.au

3. HTTP://WWW.PRIDEINCLUSIONPROGRAMS.COM.AU/MEMBERS-LIST-2/
No one at work would like it, that was for sure.
They would say it was scruffy, unkempt. Not
suitable for the corporate image.
Fuck them.
They couldn’t do a thing.
Workplace diversity.

Four weeks in the Blue Mountains, living like a
hermit. No shaving. No carbs. Days of kettlebells,
sit ups, push ups, burpees. Running bush tracks.
She emerged a new man.
Midge was impressed. ‘Goatee?’

‘No, on the T. Full beard. I’m leaving it be.’
‘It’ll get thicker. Don’t worry.’
‘Do I look worried?’

A few things had to change at home.
Together they went through the wardrobe and
bagged up any gear that was too femme or didn’t
fit.
‘Salvos?’ queried Midge.

‘Screw them. Not with their attitude. Cat
Protection Society.’
‘There’s gonna be some well dressed cats in
Enmore.’

A dealer on Parramatta Road offered a good price
for the Barina.
‘She’s in great nick, buddy. Some little
sweetheart’s getting a nice surprise from daddy.’
Midge, on the other hand, was shocked when she
saw the replacement.
‘Holy shit! It’s a tank!’

‘No guts, no glory.’
‘Did you decide about your name?’
‘Keeping it.’
‘It’s gonna be a bugger.’
‘Bugger them.’

There were no other customers in the council
shop. The guy at the counter, friendly mutton
chops, asked if he could help.
‘Parking permit. I’ve got rego papers, electricity
bill, and lease. Need anything else?’
‘Hilux? Dude, that’s a beast!’

‘Sure is.’
Mutton Chops eyebrows wrinkled. ‘So who is
Ashleigh?’

‘I beg your pardon?’
‘It says here A. S. H. L...oh... sorry mate,
sometimes people fill them in for their partners.’
‘You think it’s a girl’s name?’
‘I just...’

‘It’s old English.
“The one from the Ash clearing.”’
‘Sorry dude, my bad. Stick this on the passenger
side windscreen of The Beast when you get home.’
Mutton Chops was staring now.
‘What?’
‘Hey man, just wanted to say I love the freestyle
you’re rocking.’ He stroked his jaw. ‘They won’t
let us go the Ned Kelly look here’.

‘Uh, thanks. Mate.’

There was only one space left in the street, right
in front of their terrace. Midge had rolled out the
bins and was on guard between them.
‘Big enough to drive a tank into. Welcome home!’

***

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Student Life and a part of the UNSW Ally Network.
IG & Twitter: @ashrehn / www.ashrehn.com
RuPaul’s Drag Race (hereafter referred to as Drag Race) has amassed a large and diverse fan base that continues to grow. A large part of its growing audience is due to the show’s emphasis on queer visibility and racial/transgender inclusivity. To see this focus, we need look no further than RuPaul Charles, the show’s founder and host, as he stated the show’s cast at the conclusion of every episode, “if you can’t love yourself, how in the hell you gonna love somebody else? Can I get an amen?”, to which the show’s cast of (mostly) gay men, in drag, reply “amen” before the credits roll. In one of the more poignant moments of the show, in season 5 episode 7, Roxxxy Andrews spoke of “not feeling wanted, and not feeling good enough”, going on to say, “I just feel like like my mom never wanted me”. RuPaul consoled Roxxxy with a heartfelt speech: “We as gay people, we get to choose our family… I am your family, we are a family here.”

These foundational values of inclusivity and sisterhood were recently debased by RuPaul during an interview with The Guardian.1 When asked about the potential inclusion of ‘bio queens’ (women who perform in drag) on Drag Race, RuPaul asserted that “drag loses its sense of danger and irony once it’s not men doing it”, before enforcing his personal philosophy of drag as “a big f-you to male-dominated culture”.2 Although many competitors have come out as transgender either during or after the show (including Monica Beverly Hills, Stacy Lane Matthews, Gia Gunn, Jiggly Caliente, and, most recently, Peppermint), RuPaul attempted to justify their inclusion on the show by claiming their being transgender didn’t factor into their performance at the time, as was the case, he claimed, for Peppermint: “Peppermint didn’t get breast implants until she left our show; she was identifying as a woman, but she hadn’t really transitioned”.1

Within contemporary Western drag performance, Drag Race plays a powerful role in defining unnecessary parameters to the art form. Choosing to reject contestants who had “really transitioned” indicates the limited scope of the show. This choice openly excludes drag talent which lives outside the drag category of ‘female illusion by cis-man’, the category considered by the show to be the solely valid form of drag expression. Outside of Drag Race, there exists a vast self-defined terrain of drag aesthetics and performance, ignored by the contemporary handbook of drag which chooses to televise and popularise only a single shade of an infinite spectrum of colours.

This single shade features cis-men imitating women, the “irony” of the act considered by RuPaul, as expressed in his Guardian interview, as a “social statement”. RuPaul’s mistake is assuming that drag is not politically and socially provocative at all times, no matter the sex or gender of the performer and the performed persona. Judith Butler notes the “dissonance” between “anatomical sex, gender identity, and gender performance” within drag.2 A man performing in drag as a woman demonstrates the social construction of gender through the ability of the individual to distinctly move between genders. If a man can act, dress, and perform like a woman, and then proceed to remove the costume, change their act, and “become” a man again, then the distinctions our society places on these categories are redundant.

Yet the performative nature of gender is not only demonstrated by performing across a gender boundary, but also by changing one’s performance within it. Just as a man may perform as woman, a single woman may mould her identity to perform as a different category of woman. For instance, the same woman can at different times perform as hyper-feminine or as a ‘tomboy’, and therefore, through altering behaviour and dress, fluctuate between feminine identities for performance. This is a similarly political act, as a woman performing in drag as a distinctly different woman dismantles the concept of there being a singular unquestionable female gender identity. Anyone in drag is “implicitly [revealing] the imitative structure of gender itself”.2

Even defining drag as simply an imitation of gender is inaccurate, and misses the self-expressivity of the style. This is a point made by many drag performers themselves, in their description of drag. Shangela Laquifa Wadley, a three-time contestant on Drag Race, describes drag as “a heightened sense of myself... it’s this extra-ness you add on, you put on the make-up you put on the wig”, adding that she likes “to give female illusion”.1 Lady Bunny, a seasoned queen, agreed that “drag is an expression, you are expressing something that you feel is in you”2 and, similarly, nineties New York nightlife extraordinaire Leigh Bowery described it as “expressing...ideas and having fantasies and making them all happen and also looking different and being a little bit subversive.”3 Peppermint, who was the Drag Race season nine runner-up, a trans-woman, and a drag queen, describes it as “heightened expression, heightened gender expression, for the sake of performance.”4 Outside of the framework of Drag Race, the clear consensus is that drag is a mode of expression, whether or not that includes playing with gender. This could be likened to an art gallery which only displayed expressionist paintings. Though the works of Kandinsky and Schiele are beautiful, they cannot speak for the entire history of the medium, which is exactly where Drag Race is failing its audience. As the only pop cultural platform representing drag performance, Drag Race is erring in single-handedly defining narrow parameters for the future of the art form.

The consequences of the narrowness of these parameters can be seen online. Milk, a drag performer who appeared on Drag Race in 2014, has displayed an artistic evolution from cis-man performing as woman to cis-man performing as,
Milk’s style of drag isn’t anything necessarily new. She is inspired by a long line of drag performers like Leigh Bowery, James St James, Kabuki, Walt Kassidy, Kenny Kenny, and Susanne Bartsch, all of whom did not prioritise gendered expression in their drag performance, but rather used the beauty of costumes, makeup, and wigs as their mode of expression. These performers did not allow the dualism of gender to permeate their aesthetics or performance, but rather used their own identities as the medium to mould.

There are countless contemporary acts who do the same: Ryburk, Hungry, Gott Mik, Jarry the Clown, and Lucy Stoole, to name only a few. These are some of the many performers who do not look and perform as distinctly man or woman, but rather play with gendered characteristics to express themselves. Once it is recognised that all drag is simply the creative, artistic expression of identity, infinite categories and styles of drag that deviate from Drag Race’s narrow scope of female illusion by cis-man become possible. Milk responded to the supposed invalidity of her drag style by stating that her critics “still live in a strictly masculine/feminine spectrum… embrace the gray area.”

Drag Race needs to be more inclusive of this grey area by diversifying its cast to include individuals who aren’t necessarily cis-men and aren’t necessarily impersonating women. Including drag kings, trans people, and performers who are stylistically unorthodox will encourage fans to escape the “strictly masculine/feminine” binary. It’s even possible that this change will come soon; following his comments in his interview with The Guardian, RuPaul received significant enough backlash for him to tweet an apology: “Each morning I pray to set aside everything I THINK I know, so I may have an open mind and a new experience. I understand and regret the hurt I have caused. The trans community are heroes of our shared LGBTQ movement. You are my teachers.” Hopefully, this “open mind” will help drag audiences transcend the binary imposed onto such a free and expressive art form.

References


3. Shangela Laquifa Wadley is out of the box and ready to snatch the crown, [online video], 2018, https://www.youtube.com/watch?v=1bJWFJo4AYM&t=2918s, (accessed 24 April 2018).


7. MILK (@bigandmilky) "For all those who have messaged me saying they are tired of my ‘boy’/line looks: 1. Hello, Happy New Year! 2. Do you just as easily tire of “fishy, traditional” makeup? 3. I doubt it, because you still live in a strictly masculine/feminine spectrum. 4. Embrace the gray area. xo,” 17 January 2018, 7:50PM. Tweet.
I wonder if the old star inside me is dying,
as the new star comes alive.
I hope that when they put me back together again, I'll know how to feel.
I feel chained by my own past. A cosmic link in space from a time I can’t forget.

I wonder if another me is out there, looking back on the progress I’ve made, and what is yet to come.
IF I LET GO OF ALL THAT I AM, WILL I STILL BE HERE.

I SACRIFICED SO MUCH OF MY SELF FOR THE COMFORT OF OTHERS.

I'VE BECOME SELFLESS IN THE RESPECT I'VE BECOME LESS OF A SELF.
One only had to watch Saxon Mullins speak on *Four Corners* to understand that Western society is being forced, with renewed urgency, to reckon with our understanding of sexual assault and the laws that govern it.

 Historically we have thought of sex in terms of a false dichotomy: either it reaches the criminal standard, and is classified as sexual assault, or it doesn’t. Saxon Mullins’ case demonstrates that there is really no avenue of recourse for the space in-between.

 In the wake of Mullins’ brave decision to speak out, the court of public opinion is holding the criminal law on trial for sanctioning this binary view of sex. Judge Tupman’s verdict in the Luke Lazarus retrial, in which she found Lazarus not guilty of sexual assault, supports this black-and-white conception. It’s evident that the law has a way to go in addressing the complexity and ambiguity of sexual assault. In the meantime, society can engage in activities and discussions that prevent assault from occurring in the first place.

 This conversation needs to address the grey, amorphous area that the rigid binaries of the law fail to recognise. While consent may sometimes be a matter of a straightforward ‘yes’ or ‘no’, it often doesn’t unfold that way. It might be a subtle application of pressure. It might be a pulling down of one’s underwear, as happened to Saxon Mullins.

 If a person resists and resists and resists and then finally acquiesces, does that amount to consent? If their final acquiescence means the other person could not reasonably have formed a belief that they were not consenting, and therefore is not guilty of sexual assault, does that make the encounter morally acceptable?

 There are some actions that should be illegal regardless of intent. There are others that, based on intent as a basis for culpability, should not. There are still some actions for which a person should be held morally responsible, and it is within this grey area that the Luke Lazarus case provides important instruction. In the #metoo era, it is true that society has begun to grapple more readily with the question of consent and sexual assault, but we could do better.

 What about formal education programs across a greater number of high schools, like the one introduced in Tasmania by the Sexual Assault Support Service and embraced enthusiastically by local schools? What about platforms that discuss consent in the public arena more frequently, as *Four Corners* did? What about greater inquiry into the reasons why sexual assault often goes unreported in the first place?

 We also need to look at the kind of conditions that create a culture of non-reporting. The 2016 Australian Bureau of Statistics Personal Safety Survey found that only 13%
of female victims of sexual assault by a male perpetrator (comprising the majority of sexual assault cases) reported the most recent incident of assault to police. It may have to do in large part with the fact that, as the same survey shows, in the majority of reported sexual assault cases the perpetrator is known to the victim – likely a partner or relative. It’s hard to imagine an acquaintance of Lazarus reporting him and risking becoming a community pariah had it been her in the alleyway that night. So whilst Mullins’ bravery in speaking out should be applauded, one can equally understand how hard it would be for other victims of sexual assault to do the same.

It is also our responsibility to continue picking at the question of consent. Mullins raised the idea of enthusiastic consent, a pretty compelling one, considering that Judge Tupman used the fact that Mullins was “moving back and forward” during intercourse and “did not stay ‘stop’” as support for the conclusion that Lazarus could not reasonably have known she was not consenting. A requirement of positive consent could bridge the gap between the ‘display of enthusiasm’ that Judge Tupman used to infer Lazarus’ state of mind and the absence of consent in Mullins’ own mind.

Sexual assault is like a wrecking ball. It swings through the life of a real person. Saxon Mullins lives with anxiety and is scared of walking down unlit streets at night. While the law deliberates on where fault should lie or whether it should lie at all, a person suffers from an encounter that could have been prevented by adequate education and a higher standard of moral accountability.

The law may have decided that Saxon Mullins is not a victim of rape. One can hardly imagine what hearing that verdict would have been like for her. But Saxon is also a victim of other things: of a system that failed to educate and demonstrate to a boy what consent looks like, or of a boy who knew but decided not to care. She is the victim of a system in which a person is either guilty or not, with no space for recognition of what might exist in between.

You can watch Saxon Mullins’ interview on *Four Corners* here: iview.abc.net.au/programs/four-corners/NC1803H013S00

References


As the fingers press harder on my carotids, I struggle to keep my eyes straight. I cough, and try screaming, only to realize that even I could hardly hear the little bit of air escaping my compressed trachea. I have around ten seconds before I lose my consciousness and a couple of minutes before I lose my soul. What’s the use of all this knowledge when all I can do is wriggle, a test to see if that powerful hold would ever leave my throat? My heart loses the race to match the oxygen void in my brain as I struggle…struggle…. and wake up.

Years later, I met a friend who’d gone through a similar incident. Although it wasn’t real for either of us, we shared the same panic and distress of thinking we were being strangled. I, however, got to wake up from my sleep; she was awake, in the middle of class, suffering an acute manic episode, and still doesn’t know how she survived. Although the diagnosis of having bipolar disorder gave her the comfort of at least identifying her condition, living with that label was a whole new challenge.

The medical concepts of mania and depression are as old as medicine itself. The descriptions of its features are fairly consistent, while our methods of treating them, and our understanding of the boundaries between and causes of them, have changed over time. Early writings from ancient Greece, Rome, India, and Egypt focused on demonic possession as the cause, while Hippocrates used the notion of an imbalance of ‘humors’ (bodily fluids) combined with environmental factors to explain ‘polarities’ in mental states.

Bipolar disorder is generally understood to be a chronic mental health condition with strong changes in mood and energy, but within the broad category of manic depressive illnesses, minute parameters are required to distinguish the many variations. The bipolar-unipolar distinction by Leonhard was a large step in the evolution of our understanding of these conditions, where he termed patients with mania and depression as bipolar and those with only recurrent depression as unipolar. As opposed to understanding these characteristics as independent, this placed mania and depression on the same affective axis, with hyperactivity, boisterousness, and euphoria on the one hand, and a lack of pleasure, hopelessness, and sleep and energy changes on the other.

It was and is a momentous struggle to help communities to understand that mental health disorders are "real health issues", and it’s equally important to accommodate them in our health and legal systems. Most importantly, we must understand that sufferers can live completely normal lives. Around 1 in every 100 Australians is affected by bipolar disorder. These numbers not only show how common the condition is, but also how impractical it is to stigmatize the pool.

Diagnosing and treating the condition can be a tedious process, with a very high rate of misdiagnoses. A comparative study showed that in the year 2000, over a third of bipolar patients had to wait at least 10 years or more before receiving an accurate diagnosis. After the (often long) wait to find the cause, patients embark on an extended journey to control the symptoms. From medications, talk therapy, support groups, and hospitalisations, symptomatic control is a continual, and taxing, commitment. Despite these hurdles, many individuals find the negative impact of bipolar disorder on their families, social relationships, and employment greater than the
exhausting medical process of diagnosis and treatment.\(^4\) This is why widespread communal knowledge of this condition could really help to make their lives better.

Often, our understanding of bipolar disorder is driven by popular media, and can become conflated with other psychiatric conditions. Common portrayals of bipolar individuals are serial killers wielding axes, awkward boys with dramatic hallucinations, or melodramatic girls with borderline caricatured PMS symptoms - and this is where the problem starts. The character Rebecca in The Roommate (2011) as a protagonist with bipolar disorder and schizophrenia, for example, was a violent murderer and a sexualised seductress; here, as in many other cases, it is not difficult to see where popular media contributes to the stigma around the condition. Importantly, not only are these portrayals inaccurate, but they are also one-sided. The condition doesn’t manifest in a universal way. Even the close friends of an affected person don’t get to witness the full range of emotional shifts the person will experience regularly. The most confusing presentation of bipolar disorder, for example, is the “mixed phase”, a combination of manic and depressive states, leaving the sufferer physically and emotionally disoriented.

After reading the above paragraph, if you are suddenly tempted to diagnose bipolar disorder in every reckless driver and grief-stricken person, you are again mistaken! The fluctuations are characterised by how difficult they are to control, and how extreme the induced emotions are, often being somewhat independent of the events in a person’s life (although this is not a strict rule).\(^5\) Additionally, these fluctuations don’t stop at the type of mood present in an episode; significant variations are also observed in the combinations of episodes and their regularity. Some experience multiple episodes of altered mood a day, while others experience a single episode that lasts for multiple days. Some have no signs or symptoms for many weeks. These extremities are why calling a friend who’s having a difficult day “bipolar” is an unfair and uninformed mischaracterisation.

The amount of variation in bipolar disorder is evident when we consider how the disease is actually classified by professionals. This gives a lot of insight into the need for treatment methods have been increasingly focusing on building adequate social support as the usual age of onset is late teens and early twenties, an age group highly impacted by social pressures.\(^6\) The disease, its effects, treatment, and its social impacts all sit on spectrums, which is why it’s much more than “crazy or depressed”. Trying to fit in the experience of bipolar into a binary definition is why widespread communal knowledge of this condition is much more than “crazy or depressed”. Trying to fit in the experience of bipolar into a binary definition is why it’s much more than "crazy or depressed". Trying to fit in the experience of bipolar into a binary definition is like trying to find the ends of a circle.

"I don’t blame myself for being Bipolar anymore. I believe that I have an immature child inside me, who needs a bit more care and attention.”

– The friend who shares a dream and opinion

References
This recent UK case shines a spotlight on the curious concept of brain death and the difficulty of balancing the various competing interests in brain death cases. Some may be familiar with the concept of the “persistent vegetative state” – medical patients who, usually subsequent to a severe brain injury, lose the areas of the brain responsible for conscious awareness, but maintain their own breathing and basic metabolic functions. Despite the loss of capacity for consciousness, we consider these patients to be “alive”.1 For patients in a persistent vegetative state, in the absence of an advanced care directive where the patient has outlined their preferred course of life, families may opt to withdraw or continue any aids which sustain life. This stands in contrast with brain dead patients, who, despite exhibiting signs of “life”, such as a beating heart and normal colouration of skin, are unable to breathe independently of respiratory support, and are therefore considered legally “dead”. Brain death seems to exist outside the certain binary of “life” and “death”, as patients sustained on life support are suspended in limbo. Family members may insist that they are alive, while medical professionals declare that they are dead. Sitting at the intersection of neuroscience, moral philosophy, and the law, brain death encourages serious contemplation of how we define death. The criteria used to diagnose death have evolved over time. Historically, simple observation of signs such as rigor mortis, decomposition, or massive physical injury indicated the end of life.2 Eventually, the medically accepted definition evolved into cardio-respiratory failure (where the heart and lungs no longer sustain breathing or the circulation of blood). However, as technology evolved to create machines capable of ‘cheating death’ through artificially supported breathing and circulation, doctors could no longer diagnose death exclusively using these standards. As an increasing number of permanently comatose people were surviving on ventilation alone, a new definition was constructed. A 1968 report of the Harvard Medical School3 set out a checklist of criteria outlining a new way to die: brain death, the essential factor being irreversible damage to the entire brain, including the brainstem. The brain stem is where our respiratory drive originates, meaning that our lungs will only breathe if our brainstem is functioning. Thus, despite a beating heart (which can function independently of the brainstem) and continued breathing (albeit artificially with the aid of a ventilator), death of the brainstem means a loss of capacity to breathe, and was deemed synonymous with death of the human body as a whole. The long and rigorous list of necessary prerequisites published in the 1968 report
has been adopted in most countries today as the criteria for brain death. As a consequence of the adoption of brain death as a form of death, one well-established opinion is that any definition of death will share two major criteria: the irreversible loss of capacity for consciousness, and the irreversible loss of capacity to breathe.⁴

Given this new definition of “brain death”, the question emerges of whether Alder Hey Hospital was justified in fighting against Alfie’s parents’ decision to try to prolong his ventilation. Legally, the answer is yes: there is an established principle that a Court can override parents’ decisions regarding their children. This is most commonly applied where parents refuse the administration of life-saving medical treatment to their children (think Jehovah’s Witnesses refusing emergency blood transfusions). The court, in its parens patriae jurisdiction, decide what is in the best interests of the child if the parents, influenced by, for example, their grief, may make a decision which favours other interests. The justification is that power is being exercised on behalf of the community, as the community is invested in the welfare of children.

The use of this power in brain death contexts is much less ethically than legally straight-forward. It is harder to convince the family of a child who appears healthy and “alive” that the removal of ventilation, which would render them visibly lifeless and “dead”, is in fact in that child’s best interests. It would seem more acceptable that a court can intervene in situations where parents are actively harming their child’s health. Keeping a child on life support, however, doesn’t inflict the same type of deliberate harm. It is certainly a futile act and conceptually inhumane, but it doesn’t appear actively harmful.

Therefore, when examining the situation from the parents’ perspective, it is understandable that they would find it difficult to accept the inhumanity of prolonged life support, despite being told that there is no chance of their child regaining consciousness. Brain dead people can progress through puberty, and some have even delivered children.⁵ Seeing a loved one still breathing, seemingly “living” for years in this way, combined with the fact that there is “symbolic and emotional significance of providing nourishment”,⁶ explains why so many families find it difficult to believe the patient is “dead” in the traditional conception and agree to the removal of life support. In fact, 20% of families of brain dead patients had doubts regarding whether their relative was actually dead, despite being given a full explanation of the diagnosis.⁷ It represents a sort of cognitive dissonance, in which a family can conceptualise death in its traditional form but continue to emotionally recognise life.

It is likely that many of these families are confusing brain death with coma or persistent vegetative state, which are themselves often misunderstood. Drawing upon popular representations of comas, many people are misled into thinking there is greater chance of recovery than in reality. An analysis of “soap opera comas” showed an 89% recovery rate contrasting with real figures of less than 50% survival and 10% full recovery.⁸ To overcome this gap in understanding, the best solution is to be compassionate and give the families a chance to grieve and say their goodbyes, which is often the justification for maintaining life support for a braindead patient in the short term.

The actual diagnosis of brain death can pose some inconsistencies, which can further the confusion and disorientation of families. Some brain-dead patients display ongoing motor functionality, for example moving their fingers or limbs. Generally, these movements originate in the spinal cord as reflex actions, not demonstrating consciousness in response to external stimuli. Claims from families that this proves their loved one is trying to “communicate” in response to commands are usually dismissed as being coincidental, or as the family reading meaning into these actions in their process of grieving. However, there are some rare cases of brain-dead patients regaining spontaneous breathing.⁴ Further, some cases have suggested the brain dead person in fact comprehends environmental information.⁹ Advanced neuroimaging techniques analysing these reflex movements, ostensibly performed in response to specific commands, open the controversial possibility that some of these patients are perhaps experiencing some level of consciousness and responding to their environment, contrary to the established definition of brain death which states an “irreversible loss of capacity for consciousness”.⁴ On the other hand, there are no documented cases of a brain dead person subsequently regaining full and normal brain function.¹⁰

Thus the question of sustained life support in brain death could, feasibly, shift from the support of a “dead” body to the support of a potentially partially conscious person. Yet even in this hypothetical case, given that an individual who is unable to communicate, or where meaningful communication is only perceptible through fMRI, would require a great burden of therapy, it is appropriate to consider whether prolonging life is in the patient’s best interest even in the presence of a degree of conscious awareness.
A further question can be raised: if Alfie’s parents were to pay for the costs of ventilation from their own pockets without drawing from public spending, would they be doing any harm? Most likely it would set a contentious precedent allowing families to rely on ventilation for years. This isn’t to stoke the controversial pro-life and deeply religious counter-position, which regards the end of life when the heart stops beating rather than when brain function ceases (the Alfie Evans case drew sympathies from the Pope himself). It rather indicates that the concept of death is not concrete across all cultures – there is a religious exception in two US states, and some countries including Japan, which allow ongoing ventilation for living bodies with dead brains. It would seem that the inclusion of brain death is by Western medical consensus, rather than universal agreement. Given the ongoing debate around brain death, and that death is a hugely personal experience, why shouldn’t families be allowed to choose if their choice has no disproportionate burden on public resources? In comas with very low chances of recovery, families are given the choice. It is certainly futile but arguably does not actively harm the individual.

The greatest concern about making this option available would be the negative impacts on organ donation. Defining brain death as the isolated loss of brain function has allowed the expansion of transplant programs by widening the ambit of patients considered dead. The medical profession has a very valid vested interest, in trying to save as many lives as possible, to declare patients brain dead such that their organs can be used for transplantation. Practically, allowing families to maintain ventilation for their relative would be unlikely to have a negative impact in Australia, because as the legal position currently stands, and similarly in the UK as seen in Alfie’s case, the court would intervene to order removal of life support if it wasn’t in the patients best interests. However, it would likely instigate unnecessarily taxing legal battles. In a society where there is increasing need for vital organ transplantation, recognition of brain death is a necessary step to allow this to take place.
Arguably the most pertinent ethical consideration relates to how we value human consciousness. Is consciousness a requirement for living? Does a lack of meaningful environmental interaction equate to a less meaningful life? The current definition of death suggests so, but this isn’t a shocking position. In all senses, the “individual” is gone from the body, even if the vital functions can persist with assistance. If an individual loses their ability to interact with the world and has no hope of recovery, they are not really “alive” in the human sense of learning, growing, feeling, and flourishing. As a tenuous analogy, although we recognise plants and trees as being carrying biological life, we perceive a lack of consciousness demonstrates there is no meaningful life. Derogatory references to comatose patients as “vegetables” also fit into this analogy. The existence of consciousness is a boundary in a hierarchy relating to what we deem “valuable” life. This gets to the heart of the definition of human death as a cessation of breathing and a cessation of conscious experience.

Clearly many families would find themselves in a position similar to Alfie’s parents, disquieted by the medical reality of death conflicting with their emotional belief of ongoing life. There is a definite medical grey area, reflected in discrepancies in criteria which may miss patients with residual neurological function, and in clinical cases of patients even marginally “recovering” from brain death. There are also competing interests at stake – those of families wishing to prolong their loved one’s life for as long as possible, and that of doctors and society wishing to save others and to be cost efficient with money and resources. But is it fair to decide for another the point at which life becomes meaningless? A deeply personal experience such as this arguably calls for greater autonomy.

References


“Through the inversion of colour we can see through new perspectives that challenge the notion of black and white to white and black. With this in mind I wish to examine the ways in which our relationship with nature in particular with our native birds is shaped under a colonial perspective and is primarily based on scientific observations that tend to overlook the cultural significance of animals in society.

“The work has four birds traditionally associated with being pests. The raven, the magpie, the ibis and the seagull. All are native to Australia and all have degrees of black and white within their bodies. Through the inversion of their colour, seen on a black background, our understanding of these pests are challenged by revealing a new reality.
“Crows – considered pests by farmers, are instead searching for new food sources as their habitat is lost. Magpies, considered dangers to society, are rather protecting themselves during mating season to defend from predators. Ibises ravage the cityscape due to the loss of their traditional wetland habitat, and seagulls associated with rubbish and filth are attracted to our waste as it serves their diet and traditional sources are dwindling.

“Each represent not only a consequence of human activity in Australia, they also represent degrees of whiteness and blackness, with the work examining the ways in which Aboriginal culture has been obscured and defaced by history. How can we view the world from an inverted perspective and renew our understandings of reality?

“Each of the images are named after the Horses of the Apocalypse – Death, War, Famine and Pestilence, which corresponds to the environmental context that these animals have faced and the stereotypes associated with these birds.”
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