

Care, control and the electroconvulsive therapy (ECT) ritual: Making sense of polarised patient narratives

Short title: Making sense of polarised electroconvulsive therapy narratives

Fauzia Knight¹, Damien Ridge², Rupert McShane³, Sara Ryan¹ and Laura Griffith⁴

¹Nuffield Department of Primary Care Health Sciences, University of Oxford, London, UK

²Department of Psychology, University of Westminster, London, UK

³Department of Psychiatry, University of Oxford, Oxford, UK

⁴School of Social Policy, University of Birmingham, Birmingham, UK

Corresponding Author:

Rupert McShane, Oxford Health NHS Foundation Trust, Warneford Hospital, Warneford Lane, Oxford, OX3 7JX, UK. Email: Rupert.mcshane@oxfordhealth.nhs.uk

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Bios

Sara Ryan PhD, is a sociologist and Senior Research Lead, in the Health Experiences Research Group, University of Oxford.

Fauzia Knight PhD is a private therapist and Senior Qualitative Researcher in Mental Health, in the Health Experiences Research Group, University of Oxford.

Damien Ridge, PhD, is Professor of Health Studies in the Department of Psychology in the University of Westminster, and also a psychotherapist in private practice.

Laura Griffith, PhD, is Lecturer in the Anthropology of Healthcare, and a qualitative health researcher interested in the experiences of mental health, University of Birmingham.

Rupert McShane PhD is a psychiatrist with specific interests in dementia and treatment resistant depression, University of Oxford.

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Abstract

Despite evidence of short-term effectiveness of ECT (electroconvulsive therapy), both positive and negative patient reports are common. However, research examining these polarized accounts has not adequately elucidated why such divergences occur. We thus sought to examine opposing patient narratives to better understand underlying meanings. Eighteen interviews were conducted with UK-based people who had experienced the treatment. Our analysis revealed that the quality of relations with staff, ECT artefacts (e.g. the ECT suite), and perceived outcomes all play a role in divergent accounts. Positive reflections on ECT emerged alongside narratives of trust in staff, comfort with ECT, and perception of sufficient personal control. Conversely, where negative evaluations of ECT predominated, there was anger associated with a lack of control, and a belief that ECT made little sense, and was linked to past abuses and/or the unacceptability of side effects. We discuss the implications of our findings for professionals.

Keywords: Abuse; Power, Empowerment; Mental health and illness; Psychiatry; User Experiences; Mental Health Nursing

Introduction

A growing body of research suggests that overall patient evaluations of ECT (electroconvulsive therapy) are mixed and even contradictory, with “extremes of opinion” both for and against the treatment (National Institute for Clinical Excellence, 2003). In a recent editorial, Rasmussen (2015) asked why enduring patient hostility to an apparently effective treatment such as ECT persists. Qualitative research on patient perceptions of ECT goes some way to explain this situation and is replete with details of patient concerns over memory loss associated with ECT, inadequacies of informed consent (Pedler, 2001; Rose, Wykes, Bindman, & Fleischmann, 2005), and traumatisation by ECT, that may only be recognized after treatment has ended (Johnstone, 1999). However, the literature also indicates that patient experiences are highly variable, with strongly positive assessments also prevalent, e.g. relating to satisfaction with the adequacy of information provision, safety of the treatment, and willingness to receive ECT again (Chakrabarti, Grover, & Rajagopal, 2010).

Understanding positive and negative personal responses to ECT is not only a matter of academic interest. There are real implications for treatment outcomes since, when patients experience memory loss and trauma in the context of ECT, their recovery is challenged, and they may feel that ECT has contributed to – not alleviated – suffering. Despite this, Rasmussen notes that there is little guidance for clinicians on the circumstances in which a patient is more likely to develop a hostile or a positive reaction to ECT.

Patient fears of – and sense of powerlessness about – ECT have long been documented in research (Crumpton, Brill, Eiduson, & Geller, 1963; Fisher, 2012; Pedler, 2001). Chakrabarti and colleagues’ (2010) review of research concluded that despite technological improvements over decades (e.g. the introduction of brief pulse machines,

and the use of anaesthetics and muscle relaxants), deep fears of ECT remain. They found that such fears frequently related to worries about the effects of the treatment on memory and the perceived risks, e.g. of permanent brain damage. However, the most distressing aspect of the procedure related to waiting for treatment, being given an anesthetic, and the way patients felt when they wake up. Interestingly, rates of distress were not very different from those of patients who received an anesthetic for routine surgery. However, evidence of the nature of the distress elsewhere suggests particular sensitivities to ECT itself.

Johnstone (1999) interviewed people who reported finding ECT upsetting. Alongside feelings of fear, participants told stories about shame, feeling vulnerable and powerless, as well as believing they had been abused by their treatment. Although they found it difficult to discuss such issues with staff at the time, participants described lasting traumas.

Given delayed assessments by patients, as well as enduring hostilities towards – and concomitant positive assessments of – ECT, our research aimed to better conceptualize what underpinned these varying evaluations. While most literature has focused on negative ECT experiences, some research does document positive patient accounts (Chakrabarti et al., 2010; Rajkumar, Saravanan, & Jacob, 2006), and some heterogeneity (Rose, Fleischmann, Wykes, Leese, & Bindman, 2003). We could not find any research that specifically attempted to interpret and connect these disparate accounts. We thus aimed to develop a more integrated account of patient experiences of ECT and to illuminate why and how reflections of treatment differ so widely. Narratives about mental health problems and approaches – including for ECT – are valued for providing rich reflections and insights into treatment (Ridge & Ziebland, 2006; Rose et al., 2003; Rose, Thornicroft, & Slade, 2006; Shepherd, Boardman, & Slade, 2008). Such narratives can provide “unmatched windows” into human experiences (Ochberg, 1988), while accounting for the stories that patients construct post-treatment (Frank, 1995).

Unstructured interviews – focused on generating these personal stories – allow participants to provide a broader context in which to interpret their clinical experiences, and the meanings given to those experiences. Here, the research interview itself becomes part of the individual’s construction of their story (Ridge and Ziebland, 2006). We show how polarized accounts of ECT go beyond efficacy (Koopowitz, Chur-Hansen, Reid, & Blashki, 2003) to reveal the significance of underlying meanings.

Method

Our article draws on an analysis of narrative style interviews with patients about their experience of ECT. The methods used were originally developed by the Health Experiences Research Group (HERG) at the University of Oxford as a rigorous way to collect and analyze personal experience to develop patient experience evidence (Soar, Ryan, & Salisbury, 2014). As a qualitative research method, this approach involves the use of unstructured “oral history” interviews as well as the collection of specific topics of interest to the study once the story has been collected (Herxheimer & Ziebland, 2004). All authors were involved in the original ECT project. While a discussion of the ethics of ECT itself is beyond the scope of this article (see e.g. Stefanazzi, 2013 for an in-depth discussion of ECT ethics) our research was covered by Multicentre Research Ethics Committee approval (Berkshire Research Ethics Committee REC Ref 12/SC/0495). Participants were provided with comprehensive information sheets, time and multiple opportunities to ask questions, and all signed written forms to consent to their interviews being used in the research. Participants were offered the choice of using either pseudonyms or their own names. Most chose pseudonyms, but some (particularly those who had spoken publicly about their experiences) preferred to use their own names. The researcher always obtained written consent regardless.

Sampling

Recruitment was via a combination of medical and user-group gatekeepers, including GPs with a mental health interest, hospital consultants, mental health charities, responses to advertisements in newspapers, stories about the project in charity newsletters (e.g. Bipolar Scotland) and on social media (e.g. Twitter). A maximum variation sample was sought to collect the widest range of experiences and views possible within the resources of the study. New interviews were sought until data saturation was achieved (i.e. no substantially new experiences and perspectives of interest to the study being uncovered, although every story is unique). The collection of these less structured narratives allowed us to uncover the relative importance of links between participants, others and “objects” in our analysis (see the discussion of actor network theory below). It also allowed participants to use more readily their own words and metaphors in relation to their experiences of ECT, therefore highlighting their own priorities and values (Chamberlain & Leydesdorff, 2004). Participants had to be 18 years or older, and a preliminary phone consultation with the researcher (experienced in mental health) took place in which an assessment was made as to whether the prospective participant was well enough to take part. Participants were recruited to include variation in gender, age, geographic location, ethnicity, and number of years since treatment. Ages ranged from 36 to 74. Although two participants were ‘Asian’, most described themselves as White (British, Irish and Scottish), broadly reflecting the demographic of people who have ECT. Four participants had a professional background in healthcare training (e.g. nurses, GPs, consultants, paramedics, mental health workers). Everyone had had a mental illness at some point in their lives, although diagnoses varied (e.g. major depression, obsessive compulsive disorder, post-traumatic stress disorder, personality disorder and schizophrenia). ECT was experienced at different ages (from 17 to 73 years old), and time

since first treatment varied from one to 43 years. Some had experienced ECT when the procedure was historically different to today (e.g. conducted in the old “asylums”). Patients had experienced varying amounts of ECT (from 6 to 39 treatment series), and the sample included those who had had ECT as inpatients and as outpatients. Some had maintenance as well as emergency ECT. A number of participants were under compulsory/involuntary care (i.e. taken into hospital and detained under a section of the Mental Health Act 1983 for treatment, a process known as being “sectioned”) when they had had ECT; others could not remember which of their treatments were compulsory and which were not.

Data collection

The aim of the larger study was to interview people with experience of ECT, either themselves or via a significant other, or who had been offered ECT. The analysis in this paper is confined to interviews (carried out in 2012–2013) with 18 people who could report on their direct experience of ECT in the previous 43 years.¹ Most interviews were carried out in participants’ homes, while some took place at local venues (e.g. a community centre, workplaces) chosen by the participants. The interviews usually began with an open question (e.g. ‘Tell me your story as you want to tell it’) to encourage storytelling. A topic list was used in the second part of the interview (once the narrative was collected) to ensure all areas of interest to the study were covered, e.g. life before mental health problems/services, experience of mental distress, experiences of ECT, the decision to have ECT, the effectiveness of ECT, consent, side effects, reactions to ECT (participants’ and others’). Interviews usually lasted under two hours, were audio

¹ In the larger study, 32 people were interviewed. Two had been offered ECT, but did not take it up and so have no experience of ECT, 12 people were carers and so did not have direct experience of ECT, while 18 participants had experienced directly ECT.

recorded, professionally transcribed in full, and checked for accuracy by the researcher. Transcripts are carefully anonymized, and form part of a University of Oxford archive, which is made available to other bona fide research teams for secondary analysis.

Analysis

The research question was: How do contrasting narrative accounts of ECT differentiate between positive and negative experiences of treatment? We were particularly looking for deeper explanations behind – and any links between – diverging accounts of ECT. Knight conducted a close thematic analysis of the data, taking a “constant comparison” approach to ensure rigour (i.e. each bit of data is repeatedly compared with other similar bits of data to develop concepts, understand their properties, as well as establish how they link with other concepts in the data) (Dye, Schatz, Rosenberg, & Coleman, 2000), using Nvivo software to aid comparisons (Bazeley & Jackson, 2013). Coding began by developing free nodes (open codes) in Nvivo applied to sections of the transcripts relating to people’s feelings about ECT, experience of the ECT procedure, and attitudes towards the success of ECT and subsequent experiences. New nodes were added where appropriate to reflect what was found in the data. Here, negative experiences (such as trauma, stress, anger, shame, fear, frustration), lack of consent or choice, lack of understanding and support were included. Nodes also covered positive and neutral experiences such as consent, indifference, absence of fear, managing mental health, surrendering to the procedure, making light of the procedure, success, support, recovery and trust. All nodes were examined especially to draw out a list of common or linked meanings.

The richness of the narrative data generated meant that people interviewed talked about their lives, and the ups and downs of the mental health and treatments they had had

over many years, thus contextualizing their experience of ECT. These related to the whole of their experience, and not only the ECT itself, and also included subsequent reflections on ECT. As analysis progressed and was debated with Ridge, we became aware that we needed to include the “constitutive role of objects” (Rinkinen, Jalas, & Shove, 2015). Thus our constant comparison was modified to include actor network theory, i.e. the material world and everyday relations that jointly constitute each other (Latour, 1999). We found that “objects” such as the ECT machinery, staff arrangements, and the physical circumstances in which patients experienced ECT all influenced constructions of ECT. As subjects and objects are constituted in a constant process of emerging, becoming and consolidating the everyday (Bennett, 2009; Latour, 2004), we especially focused on what people made of their relations (including those in the past) and “things” such as the anesthetic and the aesthetics of the ECT suite. Coding identified emotional tones (e.g. positive, neutral, indifferent, fearful) in the relevant sections of the transcripts (ECT and its assessment), and in the context of a broader reading of each participant’s story. Knight tested out emerging analysis by examining (and debating with other authors) the correlation between experiences, narratives and perceptions of success or otherwise. The discussion section was initially developed with Ridge, while all authors were involved in debating and contributing to multiple drafting of the manuscript over more than a year.

Results

Most participant accounts of ECT contained complex narratives about the treatment, and included both positive and negative reflections, yet most tended either towards positive (9) or negative (8) emotional responses (especially fear and anger), while one was neutral. Not unexpectedly given the clinical efficacy research on ECT, most participants (12) reported ECT as having some beneficial effect on their mental wellbeing (e.g. “it saved

my life”). However, other participants (6) described ECT as having a worsening effect on their wellbeing (especially due to its association with past trauma), claimed the effect was not noticeable, or focused their discussion only on side effects. Of those who reported ECT as having some beneficial effect, nearly all provided narratives that were rich with positive descriptions of comfort, receiving care, gratitude towards and trust in staff and/or the procedure. One participant failed to remember, and gave no detailed narrative of the ECT process or feelings before having ECT. Two had a negative experience of ECT, but claimed on subsequent reflection that the procedure had been successful. Among those who concluded that ECT was unsuccessful as a treatment, their narratives overwhelmingly described ECT as threatening, frightening, unnatural and illogical. Feelings of fear were strongly expressed here, and associated with frustration and loss of self. One participant gave no description of his ECT (circa 1960s), but his narrative focused on his lifelong struggle with memory loss. Strong feelings of negativity were, for some, linked to other traumatic personal experiences, sometimes from childhood.

Constructing divergent ECT accounts

Overall positive or negative accounts could be influenced by encounters with hospital staff, the ECT apparatus and suite, and the rituals undertaken (such as going through the anaesthetic procedure). In addition, individuals weighed up perceived outcomes and impacts of having ECT. Here, most (but not all) people adopted strongly held views about its effectiveness or lack thereof. Assessments about effectiveness could influence views on how problematic side effects were understood to be – and how ECT should be portrayed – to other patients.

While the effect of ECT could take time to become apparent, or appeared to decrease in effectiveness over time, many of those interviewed said that ECT had worked well for them. For some, this could literally seem instantaneous and/or lifesaving:

“It was as if I’d switched back on... I just woke up and the whole thing had lifted and it was quite incredible.” (female participant)

“...for me I think it was lifesaving and I became well again very, very quickly... I had got myself a Sunday job and I was back functioning normally.” (female participant)

Those for whom ECT had worked well tended to be enthusiastic and even advocate it as a treatment, e.g. *“I’ve seen dramatic effects of people improving... It is in the right circumstances a very effective treatment, a fast, effective treatment. It works faster than medication I believe, and it’s very safe”* (female participant). Here, participant narratives took into account negative media depictions of ECT – and real patients’ concerns – that the procedure was particularly dangerous, and positioned themselves as advocates of a misunderstood treatment:

“...there’s this idea that, that having ECT causes you to thrash about and, like in, yeah, *One Flew Over the Cuckoo’s Nest*, *A Beautiful Mind*... lots of people have seen and think, ‘Oh my God, you know, that’s, that’s a torture chamber’. I mean it’s nothing really like, well, from my experience...” (male participant).

“I would basically say three or four simple things: ‘This treatment works. We don’t know how. It is not barbaric. And this is what happens. And your head will not fall

off. Your brain will not be scrambled, and you will not lose your memory” (male participant).

These more positive outlooks on ECT seemed to facilitate a better acceptance of side effects. For instance, some weighed up the side effects of memory loss against the benefits of the ECT, and concluded that it was worth it “*if that was the price you paid for getting better*” (female participant). Others who supposed they had memories they would rather forget thought the memory loss was actually an advantage (e.g. “*I don’t mind not remembering*” (female participant)). One participant thought her brain was shutting off painful memories from her childhood and her son’s childhood “*as a protective thing*”.

Even though the ECT itself was reflected upon by those in the positive camp as something out of the ordinary, oddness here could be accommodated as something of a curiosity rather than danger:

“I guess there was also part of me, a small part of me was a bit intrigued. So there was probably a little bit of an interest there to see exactly what this was. So I guess I felt quite, quite okay with it. I wasn’t, wasn’t nervous...” (male participant)

“But I can remember going into the room where they do the treatment and looking at the machine that actually administers the, the, the shock... and you sort of think, ‘Oh, what’s all that about?’ And I suppose because of my background as a physicist I sort of thought ‘Well, yes, sounds very interesting.’” (male participant).

For those who reported negative experiences of the treatment, however, the use of electricity applied to the brain made little if any sense, and led to thoughts about the therapy as being unnatural, illogical, and ultimately unreliable, for instance, “[I] couldn’t

understand how electric shock was going to make me better”, or “treatment sounded horrific” (female participant), and “you’re passing 450 volts through the brain, how can it be good?” (female participant).

Side effects interpreted as profoundly negative could stain the experience of ECT, making it particularly difficult for participants to say anything positive about the treatment. One participant had ECT in the 1970s and 1990s and complained about losing seven years of memory, including the birth of her son, after her initial treatments, which she has never recovered. She says *“I feel like an incomplete person because of it... it’s rotten to not remember.”* She called ECT a *“terrible treatment”* and warned others, *“Don’t have it [under] any circumstances.”* Another also suffered long-term memory loss:

“...big chunks of my life are now missing, some of which were probably important or worth remembering [laugh]. So I feel quite sad about that, you know, round when my son was born... there’s big bits of it I don’t remember... I don’t remember some of his milestones... I think ECT is awful...” (female participant)

However, not all those who had a negative experience, or who felt that ECT had not worked, were entirely dismissive of the procedure. One participant who found the procedure “horrendous” and suggested it should only be used as a last resort, accepted with hindsight that it probably saved her life and might be worth a try. Another did not find the procedure effective for her, but her positive experience of the treatment and staff resulted in her becoming a strong advocate:

“I think I would want people not to be scared of the process itself. That it will be done, if my experience is anything to go down, I’m sure it is pretty well typical, it will be done thoughtfully, professionally and with care.” (female participant)

Good relations with ECT staff seemed an important consideration in final evaluations. Thus, many participant stories included messages for the health professionals carrying out ECT, which centred on the need for sensitivity to the sensibilities of the specific person receiving the treatment, and good communication as a prerequisite:

“[Sighs]. You know the negative experience you have with psychiatry is when you feel that your kind of just being sort of controlled within a system... One thing that can make even a really frightening experience a less frightening experience is just talking to someone as if they’re... a human being.” (female participant)

“I think it’s really, really, really important to... be empathetic in the way you deliver, how you explain about something like ECT...” (female participant)

Critical factors in positive and negative reflections

Throughout the narratives, where reflections on ECT were recounted, some common themes emerged that were pivotal in directing the tone and flux of stories about past experiences. While trust characterized the positive accounts, lack of control was a prevalent theme in negative experiences.

Feelings of familiarity, care, and trust in staff from the beginning often characterized the experience of those who reflected positively on the ECT procedure and its aftermath. Some mentioned that staff helped them make the decision to have ECT, and this was an important factor in accepting treatment. Here participants were made aware of the benefits and side effects of treatment, felt their own concerns had been heard, and trusted the clinician’s advice, e.g. “*The psychiatrist explained it perfectly*” (male participant). A few participants had medical training: one participant who was a GP and

another who was a retired nurse said knowing about the procedure affected their experience for the better; *“I knew about it. I knew it was safe”*; and *“I’d seen it done before. At least I knew what was going to happen, so it wasn’t [pause] totally unexpected”*.

For some, understanding the underlying process meant being more prepared to accept the downsides of their treatment, including side effects. Other patients were happy to hand-over self-determination in favour of staff control, taking difficult side-effects in their stride. One female participant said, *“If doctors recommend ECT, they must have good reason,”* and even on being sectioned, *“I supposed they’re just worried for my safety.”* On memory loss after ECT, another female participant said, *“It doesn’t really bother me... I think so long as you know that you are safe in that period and that you were looked after and cared for, that’s the main thing.”*

Experiencing care from staff could, on its own, play a specific role in positive experiences of ECT. Some people linked their positive ECT experiences to particular staff, and an environment they considered was caring: e.g. staff staying with them in the recovery room, asking them questions about how they were coping, or getting to know something about them personally – and communicated this understanding – despite participants undergoing an intense experience. Here, participants complimented particular staff they had met in the ECT suite (e.g. *“Sister an absolute delight”*, *“Very nice anaesthetist”* (female participant), *“I can remember two [nurses] giving a very warm welcome”* (female participant)). Experiences of individual attention, and even compassion, from staff in the ECT ward could contrast with experiences of staff in the general inpatient ward, where some felt not cared for or listened to, and that staff were not available when they needed them.

In contrast, those who had less positive experiences of ECT described staff as more disconnected and as not understanding their particular sensibilities. One participant found it frustrating that professionals - when trying to convince her to have ECT – did not seem to take into account how she felt about it:

“They wouldn’t listen to me and they didn’t understand what I was trying to tell them about how it made me feel. And I think yes, they need to listen more, listen to what people say and not just dismiss them as crazy depressed people who don’t have a voice because they’re depressed.” (female participant)

For another participant, the way consultants appeared to relate to her was critical in both her positive and negative experiences of ECT. Her first admission was the result of a referral by a private clinic. She had been on medication in a private hospital from which she had tried to run away, and had suicidal intentions, when a private consultant suggested ECT. She describes the consultant as *“Very angry that I’d, you know, I think it looked bad on him that I’d almost killed myself when I was supposed to be under his care... [he] essentially threatened me [with sectioning]”*. She describes herself as being *“overwhelmed”, “quite paranoid”* and *“terrified”* when she signed the consent form. She recalls one treatment under this consultant, and then it was stopped without explanation. Although she still felt unwell, she was eventually well enough to leave hospital. Things changed when her parents had a chance meeting with a psychiatrist at a funeral of a family friend and he recommended ECT. This time her experience was very different:

“And I ended up going into hospital actually under his care and he was a very... he was a very nice man and... he didn’t make it sound frightening at all. He just... explained the whole process. Explained that I have a choice in the matter...”

He felt that it would work, and it was definitely worth giving it a shot.” (female participant)

On this occasion the treatment was a success: *“After the seventh one I just woke up and the whole thing had lifted and it was quite incredible”*. This different relational experience – and good results – contributed to a transformation in her perspective on ECT: *“It’s nothing at all frightening... it’s not like having a major operation...”*

Both at the time of decision-making and during the ECT procedure, participants could be put at ease by staff who talked through things with them. The clear implication from the data is that the procedure could be frightening or calmative, depending on the support participants received to understand and undergo the process:

“The ECT nurse was very good. She was very good at telling you what to expect, taking you through everything, getting your consent each time.” (male participant)

“In terms of just the practicalities of it, I was overwhelmed by kindness... I really missed [the ECT] when it stopped because the two nurses who ran, effectively ran, the ECT department were both in their different ways, the warmest and kindest, and most lovely nurses you could ever hope to find.” (female participant)

Going to the ECT suite, seeing staff and undergoing the ECT ritual itself, and having that ritual become part of a routine in hospital, was something to look forward to for some.

Here, participants made strongly positive associations with the experience:

“I really missed it when it stopped... it almost became a treat, just thinking, ‘I can get out of this madhouse for a bit’ ... and [the nurses] make a fuss of me. And that wasn’t what was happening in the ward.” (female participant)

“I think it was kind of... know, there’s an expression, still point in a turning world, it was like almost my still point.” (female participant)

And metaphors of comfort were used to describe how participants passed over the threshold into the ECT suite to begin treatment:

“...and then you go into the room... and there’s a nice bed there, and you lie down and feel comfortable.” (female participant)

“Watch the telly for a bit, and then be taken into the first bit of the main room and I’d take my shoes off and get on the bed and have... ECG monitors attached and stuff.” (female participant)

More than this, the support and comfort provided by the ritual of the ECT could be narrated as integral to moving on with a better life:

“I must say that the people in the ECT department have been an enormous help. They are very good and supportive, and I just feel comfortable, if that’s the right word, being there, because I know that I’m well looked after there, and it’s been an enormous help to me, and helped me to get back to living a reasonable amount of life.” (female participant)

These descriptions of comforting rituals are in stark contrast to those of negative experiences, which tend to depict impersonal, stalled and failed rituals, e.g. the bed as an “operating trolley” and the room as “scary and sombre”. One participant compared the experience of being “trundled” over in a taxi in the afternoon, having had no lunch, and waiting for others to have ECT, to her expectations of something more “gentle”, and concluded, “I think they could have made it a lot easier for people.”

The anaesthetic was a focal point for some patients who found the experience positive, either providing some momentary relief from mental distress, or because of the feeling they had after the anaesthetic. Here, rather than anxieties, the narratives showed acceptance of the procedure, with a tendency to construct it as a minor intervention:

“nothing to worry about ... [the anaesthetist] just pops a needle into the back of your hand... very small shot of anaesthetic...” (female participant); or “light general anaesthetic... minor epileptic fit... very minor, they’re micro, micro volts... most of it is done by the houseman... like having a cataract operation” (male participant). Here, the anaesthetic itself could be ascribed positive, even therapeutic roles:

“because like if you think life is completely rubbish, then being woozy is actually really nice, because you’re slightly buffered from it... this sort of feeling of slight oblivion.” (female participant)

For others, the anaesthetic represented a point in their treatment where their will was overcome, which was particularly problematic in the narratives where lack of control was a primary concern (discussed below). Lack of communication or rapport with staff exacerbated fears of the ECT experience. Here, references were made to feeling disempowered: “They wouldn’t listen to me” (female participant). Some felt misinformed about treatments or misled or put at risk by staff (“trick psychiatrists”, “anaesthetist was

not qualified”), and felt they were not being informed about what was happening: “*I didn’t understand why it was going on for so long*” (female participant).

Interestingly, for some in this category, negative experiences of ECT were mitigated over time. One participant managed to find a positive side to her treatment on reflection, even though she had been unhappy about some aspects of it at the time, saying she felt ashamed of being in hospital. The staff stopped her going home one Christmas, and although upset at the time, she says in hindsight that she was unstable and it was probably the best decision for her: “*I understand now.*” At one point she was made to wear pyjamas so she wouldn’t escape, but reflected that it was “*to keep me safe*”. She also believed that ECT saved her life.

Thus familiarity, care and trust – or lack of it – in staff and the ECT as a ritual itself, seemed to be an important and potentially critical factor in mediating positive and negative experiences of ECT. Patients related to these experiences on an immediate basis so that each contact with staff and the specific artefacts of treatment (e.g. equipment, anaesthetic, ECT suites) and perceived outcomes, provided opportunities to improve patient experience. Sometimes, however, positive (re) evaluations only came after considerable time and reflection.

Dehumanisation narratives

Loss of power and control was a prominent theme in some of the narratives. People who generally felt in control, or found comfort in relinquishing some control, and were consulted about ECT, were more likely to have positive experiences of the treatment than those who felt they were not adequately consulted. These narratives revealed more ownership of the procedure *and* outcome, e.g. “*I definitely did respond,*” “*I’d switched back on.*” This was coupled with a sense of knowing (“*I knew about it,*” “*knew what was*

going to happen”), or of curiosity about ECT (“intrigued”, “sounds very interesting”). There were some exceptions, however, including people who were so ill they could not consent to the process, and were relieved, ultimately, that others had taken control.

Some participants were in hospital voluntarily when they had ECT, but others were there involuntarily. When people are very ill (e.g. there are serious concerns about their safety or the safety of others) they can be held in hospital and given compulsory treatment there, whether or not they agree to it – this is sometimes referred to as being “sectioned” because they are detained under a section of the Mental Health Act (England and Wales). Although the latter may still have been given information about their treatment, being sectioned could affect whether they were able to give their consent. If they were too ill to make that decision, the decision could be made for them by others (e.g. relatives, doctors). One participant said she was a “total zombie” when she was sectioned, and rather than feeling she had no control, she seemed to hand control over, and describes herself as “under the care of the doctors”. Another, however, wanted to understand what the treatment was about, and felt she wasn’t given enough information. When her husband consented for her to have ECT, she reflected, “I’m absolutely controlled by everybody.” She worries about being sectioned in the future: “huge fears about being incarcerated”.

People could feel they had little control over what was happening to them even if they were not under section. Consent is a complex issue, because even those who were not sectioned could feel they were somehow forced or “nagged” into consenting to ECT, and that they effectively had no choice. One participant remembers coming downstairs to find her GP and CPN waiting to section her and telling them resignedly, “I know what you’re doing, and I’ll go in voluntarily. I don’t want to be under a section.” Another wasn’t sectioned but said she was threatened with being sectioned if she attempted to leave the hospital.

Taking away choice could have profound implications. One participant describes her estranged mother as an alcoholic who threw her out of the house when she was a teenager. *“There was a lot of abuse within the relationship,”* she recalled. When her mother consented for her to have the treatment, the abusive relationship and the ECT became interlinked: *“ECT was something my mum did to me.”* Another participant, who had reported sexual abuse as a child by a family friend, said that aspects of the ECT she had experienced five years previously (e.g. not giving her consent, staff not speaking to her, the anaesthetic as *“a way of holding me down”*) had triggered feelings associated with this earlier abuse. She felt her history of abuse should have been taken into account by the staff carrying out the ECT.

“There was no consideration about why I’d ended up in the mental health system... This control thing about being manipulated, about being forced to sort of respond to my abuser, being sort of groomed, mentally scarred, and I don’t think anyone at the time took that background into... the whole procedure of ECT... was like, to me, I’ve used the word ‘abuse’, it [is] like another, but a mental abuse.”

(female participant)

Thus for participants with prior traumas, ECT could become part of a wider landscape of coercion. Loss of power did not only relate to the ECT itself, but to the system of psychiatric care which was portrayed as almost tyrannical by one participant:

“Psychiatrists have more power than the legal system... [They] stripped away my power and control.” This same participant described the process as dehumanising: a *“conveyor belt”* on which she was *“fast tracked”*. *“As human beings,”* she said, *“we need to feel we have some sort of control over our destiny.”*

In the narratives of those who were given the treatment in historic asylums, accounts of lack of control, trauma and fear were the norm. In these older accounts we did not see the mixture of negative and positive experiences that characterise later stories of ECT: they mostly tended to be negative. Asylums, which existed until the 1990s, were places where people could often live out a large portion of their lives. One participant who had ECT in the 1970s when she was 17 had been admitted to an asylum after the birth of an unwanted baby. In hindsight, she understands that she had unrecognized, severe postnatal depression. She experienced depression again after the birth of each subsequent child. She describes humiliating treatment in the asylum and being “*permanently doped*”. Here, the ECT procedure was described as debased (“*systematically lying us down*”). She has no memory of consenting and describes waking up after her first treatment unable to even remember who she was: “*I had no name, no nothing.*” Throughout her subsequent treatments she describes how she fought to maintain her sense of self – and thus a sense of control – at the point of the administration of anaesthetic:

“I was fighting for my name, fighting to remember my name... I knew I had to fight the anaesthetic to stay conscious. And I believe that [is] what I owe my sanity to now. And so I stayed conscious down to three and down to two which might [mean] I got the maximum pain and I’ve suffered from the maximum pain since, but I came out and in the end I recalled my name again.” (female participant)

For those who believed their experience of mental illness and/or recovery was meaningful, there was greater expectation that they, as experts in themselves, should have a say in their treatment. Instead, ECT seemed to be forced upon them in asylums, disrupting their ongoing story about themselves.

Discussion

Our analysis revealed that those who saw ECT as ultimately successful or relatively benign narrated their experience of the ECT procedure through stories of trust in staff, a sense of being cared for, of ECT rituals evoking a degree of comfort (including, for some, the ability to relinquish control), and frequently (but not necessarily) good outcomes. Where participants saw ECT as unsuccessful or harmful, however, the treatment was thought of as unnatural, traumatic, illogical, unfamiliar and unreliable. Where ECT was experienced as traumatic, it could trigger earlier traumas. Earlier abusive experiences in particular resonated with ECT as an implement of coercion.

There are complex issues involved in that some people are able to see themselves as having sufficient control over – or investment in – their treatment, or take comfort in giving over control, helpfully integrating the experience into their sense of self (Hyden, 1997). This is possible even in the face of an apparently alien procedure which, legally, participants are not in a position to avoid. Such narrative integration is helped by staff who treated participants in especially personal ways (Laugharne et al., 2012). A treatment that is traumatic for some is thus (re)configured through a relationship of trust (in staff and the ritual of ECT) and feelings of having the right amount of control (whether more or less is preferred), encouraging personal stories of ECT as relatively benevolent. This can be the case even when the treatment appears not to work. For others, however, for a range of reasons, including past trauma, severe side-effects, procedural traumas, and/or not having enough perceived control over the treatment, it is very difficult to integrate ECT into their narrative: ECT then easily becomes a narrative disrupter (Bury, 1982). Here, the procedure is remembered as dehumanizing and traumatic. This is particularly so in the context of severe and frightening conditions that warrant ECT. Many participants had been suicidal at the time. Stories and memories of past events are partly a product of the

current day telling of those narratives (Frank, 1995). These stories are important for securing a sense of self, and determining how we go on to form a relationship with things and people, yet they very much depend on our worldview and the frameworks of recollections available to us (Chamberlain & Leydesdorff, 2004). In consolidating any ECT “truths”, whatever the story told by participants, it was the recalled trust-control-outcomes (including side-effects) of the ECT ritual that was woven together in a narrative to draw out present-day conclusions about the treatment.

In a manner reminiscent of actor-network theory (Latour, 1999), what mattered for our participants was not just that they were treated with a hospital procedure while very ill. The interactions they recalled between participants and staff, as well as with the non-human things (e.g. the ward, the ECT suite, the anaesthetic administration) were elaborated as vital elements in the stories they told. Their narratives showed how specific artefacts and staff demeanours are suddenly foregrounded when they faced the reality of ECT (Rinkinen et al., 2015). Thus objects and relations are given special significance, woven together in participant narratives, and fused with past experiences, to produce a complex account of ECT, both at the time and after subsequent reflection. Thus we contend that the way people construct ECT, including their own personal history, trust in staff, the procedure itself (as a successful or failed ritual), along with the artefacts of the ritual, the perceived adequacy of control they felt, varying outcomes and subsequent reflections, combine to produce complex ECT evaluations.

Stories can be told, reflecting Freeman and Kendall’s (1980) findings, in which ECT is a “*helpful and not particularly frightening*” procedure even in the context of difficult experiences. Here, the ECT ritual could become positive and therapeutic, e.g. “[my] *still point in a turning world*”. Alternatively, accounts could also support Johnstone’s (1999) findings of disconnection, dehumanization and trauma. The treatment

and staff behaviours are constructed as “barbaric” in these stories of ECT. Here, there are clear links with “atrocious” accounts which patients invoke to understand especially poor encounters with health professionals (Baruch, 1981). Stories are never static, however, and even those with initially negative experiences could later revise their stories in more positive directions. Here, the way staff related to patients could make a positive difference, if only in hindsight. Conversely, where lack of control became a primary concern, and personal connections with staff were not made, the ECT experience remains potentially alienating and frightening. Thus, the anaesthetic, which for some was a welcome break, could be an instrument of abuse for others.

Interestingly, positive narratives also highlighted issues with personal control, but attempted to normalize the experience. Patients here played down the loss of control, and took more ownership of their particular personal experience of ECT, and of the outcome. The suggestion was of less judgment of themselves and of the treatment. These narratives projected a sense of ultimately being in control as a person, even in the face of an actual lack of control, or uncertainty, associated with ECT. Furthermore, for these participants, the procedure and personnel involved could be embraced like a friend (e.g. “*make a fuss of me*”) and the anaesthetic constructed as an escape (e.g. “*slight oblivion*”). There was a tendency here to play down the gravity of the procedure, which may have been a narrative way of taking control of their experience. Here the use of adjectives such as “*light*”, “*minor*” and “*micro*” constructed the procedure as more benign. Meanwhile, the ECT suite and the person’s interactions therein could be given homely qualities, e.g. “*nice bed*”, “*take my shoes off*” and “*watch telly*,” which further helped to put ECT on a normal footing.

Conclusions, limitations and recommendations

The data on which this article is based consisted of personal narratives of ECT and assessments of its success, but does not include professional judgements. As such it cannot be taken as a clinical account of whether ECT was deemed to be successful or not for each individual. Rather, we sought to examine whether participants themselves valued ECT as an effective and appropriate treatment. Memory loss – frequently related to ECT – was mentioned by some participants. This meant that in these narratives, descriptions of the ECT process itself were absent or vague. Additionally, some of those interviewed had had ECT decades ago, and struggled to remember what happened, or how they responded. And in all cases memories of past events are necessarily (re)constituted through telling the story (Frank, 1995). Despite this framing of our approach, we found that participants’ comfort in ECT relied on telling stories of themselves as respected individuals undergoing a reasonably personable treatment involving relating well to others, things and rituals. Here, the procedure could easily turn frightening and dehumanising. As such, our research is instructive for health professionals who seek to promote more balanced and helpful patient experiences of ECT.

More research is needed to understand how positive, normalising framings of ECT can be encouraged where helpful, to reduce the trauma involved in an otherwise effective treatment. Additionally, our narratives and analysis highlighted how interactions between humans and contextual factors (and not just the ECT treatment itself) were important sociologically, and potentially contributed therapeutically. Firstly, the use of actor network theory provided a useful “starting point for providing a proper rendition” of the complex patterns of relations between participants, others and things, which we might otherwise have overlooked (Sayes, 2014). As we found, it is useful to be open to contextual things (e.g. human relations, environment, technical administration, monitoring, ritual) as potentially influential in how ECT unfolds. Secondly, future research could usefully

examine the contribution of these elements therapeutically in ECT, rather than just confine them to the non-active arm of trials (Foot & Ridge, 2012).

The evidence we presented points to a strongly positive narrative when trust, feelings of ultimate control, and a sense of containable treatment can be maximized, even when the effectiveness of ECT is unclear. However, we acknowledge that in some circumstances (e.g. loss of years of memory), it may not be advantageous to encourage positive stories about ECT. Previously, memory tests that were used following ECT were insensitive to the sort of impairment that we now know occurs with the treatment (Sackeim, 2014). Complaints from ECT patients tended to be dismissed by professionals as consistent with depression. Now, the guidance is that people should be told about the potential for memory impairment, which may be permanent. Dismissals of patient experience have quite rightly contributed to negative perceptions of ECT. Our analysis reinforces the view that mental health patients should ultimately be the authorities on their own experiences (Fixsen, 2015). Nevertheless, as mental health professionals are able to treat and detain people against their will, patient-centred approaches do not always prevail. Additionally, past research has focused on “overt forms of pressure rather than encounters with a less immediate threat of coercion” (Quirk, Chaplin, Lelliott, & Seale, 2012, p. 96), and our participants highlighted these grey areas. More research is needed into the meaning given to control in these murky areas, where participants such as ours sometimes felt under pressure to undergo ECT, or were unsure about the decision-making process involved.

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