Exploring the emergence and disappearance of transableism on transabled.org: Digital ethnography of a transient mental illness

Submitted by Elena Sharratt to the University of Exeter as a thesis for the degree of Doctor of Philosophy in Sociology

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I certify that all material in this thesis which is not my own work has been identified and that any material that has previously been submitted and approved for the award of a degree by this or any other University has been acknowledged.

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Abstract

Transableism is an historical condition that originated in an online community named transabled.org, existing between 1996 and 2013. Transableism manifested as the desire to be disabled, arising out of a felt sense of incongruence between one's inner sense of identity as disabled, and one's bodily reality as abled. During its existence, transableism attracted clinical attention and was proposed for entry into the Diagnostic and Statistical Manual of Mental Disorders (DSM) under the descriptor Body Integrity Identity Disorder (BIID). However, despite its growing visibility, in 2012 BIID failed to enter the DSM and the online transabled community disappeared. The aim of this thesis is to explore transableism's rapid emergence and subsequent failure to achieve formal medical recognition. The key questions underpinning this thesis are (1) why did transableism emerge and (2) why did it disappear? Taking a qualitative approach, this thesis uses digital ethnography to analyse all content posted to transabled.org in its active years. The originality of this thesis lies in the way it uses the theoretical lens of an ecological niche of 'transient mental illness' (Hacking, 1998) to examine the historical, cultural and social factors which informed transableism, opening up a new, never before explored perspective.

Use of the ecological niche of transient mental illness model provides a nuanced and holistic answer to the questions which underpin this thesis. I argue that transableism emerged because it reflected and expressed broader cultural understandings and tensions surrounding authentic versus inauthentic disability. Its emergence was also facilitated by a centralised model of community leadership which, for a time, successfully fostered a coherent group identity and enlisted the interests of clinicians. On the other hand, transableism disappeared because BIID failed to conform to an accepted authenticity politics of disabled identity and was policed accordingly. In addition, although the centralised model of community leadership initially facilitated transableism, towards the later years, this model collapsed, leading to conflict, community attrition and moderator burn out. Overall, this thesis makes 6 original contributions to knowledge by advancing understandings within (1) extant transableism scholarship, (2) broader medical sociological literatures, (3) the disability studies literature, (4) scholarship that explores claims to authentic identities, and the limits of such claims, (5) the

literature on leadership and moderation practices within online communities and (6) the health advocacy community literature.

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Chapter 1

Introduction

Chapter outline

Although a pathological fascination with becoming disabled has been noted within the clinical literature since the 1800s (Bruno, 1997), it wasn't until the late 1990s that this phenomenon became reconceptualised as a disorder of identity incongruence, termed transableism. In this introductory chapter, I describe the characteristics of transableism and outline how it originated in an online community named transabled.org. I describe how it rapidly emerged online in the late 1990s, garnering academic and clinical interest, only to disappear just as suddenly in 2013. I then introduce the primary aim of this thesis- to explore this emergence and disappearance. The research questions underpinning this project are (1) why did transableism emerge and (2) why did it disappear? I then introduce the theoretical lens used to explore these questions, namely Ian Hacking's theory of the ecological niche of transient mental illnesses (1998). Following this, I describe the methods used in this project, and outline its scope, both in terms of location and chronology. I then discuss the key contributions to knowledge made by this thesis. This chapter concludes with a description of the structure of this thesis.

What is transableism? Origins and characteristics

A pathological fascination with becoming disabled has been noted within the clinical literature since the late 1800s (Bruno, 1997). These accounts were mostly of individual cases, observed by psychiatrists in clinical practice, and were explained via reference to either sexual perversion or emotional disturbance (Bruno, 1997; Money, Jobaris & Furth, 1977). Because of its rare and sporadic occurrence, little attempt was made to formally classify the desire to be disabled and it attracted relatively sparse attention from broader medical communities, academia and the general public. In the late 1990s, this changed. With the advent of the internet, an increasing number of individuals expressing an interest in becoming disabled were revealed. These individuals gathered in their hundreds on listservs[1] and forums, which had been set up with the sole purpose of discussing an interest in, or attraction towards, becoming disabled (Charland, 2004; Elliott, 2003). Not only did the presence of these platforms challenge the presumed rarity of the desire to become disabled, they also revealed changing explanations behind this phenomenon. No longer was the desire to be disabled exclusively situated as a sexual or emotional disturbance; instead, individuals began to indicate that their desires to become disabled were related to aspects of their ‘identity’ (Charland, 2004; Davis, 2012; Elliott, 2003). For example, individuals described feeling like their ‘true’ or ‘authentic’ selves were meant to be disabled (Elliott, 2003).

Although a number of these types of online platforms existed, one soon became the centre and hub: an online community named transabled.org. This community had originated as a solo authored blog set up in 1996 by a man who went by the alias ‘Sean’. In his earliest blog entries, Sean wrote about his fascination with disability, disabled bodies and disability aids; he also discussed vague desires to experience disability, albeit on a temporary basis. As time went on, Sean wrote more prolifically and outlined feeling increasingly distressed as his interest in disability evolved into an obsession. In the early 2000s, Sean began to describe actually wanting to become paraplegic, situating this as ‘who he was supposed to be’. Sean’s candid, articulate and frequent blog posts soon led a number of individuals, many of whom were regulars on the other disability-interest listservs, to contact him. These individuals approached Sean describing similarly distressing and obsessive experiences with feeling like they were meant to be disabled. They also outlined how his detailed personal experiences had resonated with them and offered solace, something which could not always be found on the other forums, which contained short messages, as opposed to long, intimate blogs.

It was this which, in 2005, led Sean to reformat his blog, turning it into a multi-authored platform. Under this new format, Sean’s growing number of followers could now submit their own blog posts for publication. The intention was to create a space for long-form accounts of living with the desire to be disabled to be

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[1] Listserv is a term used to refer to electronic mailing lists which were characteristic of early web software and popular within early internet culture. Listservs operated via one user sending an email to the list software, which would then be forwarded to all other list subscribers (Baym, 2003).

shared, intimate discussions to take place and connections to be made. With the addition of these new voices, and a cross-commenting feature which enabled forum members to respond to each other's posts, commonalities and themes began to emerge. No longer were vague desires and fascinations with disability described, instead, a clear profile surrounding the desire to be disabled and, specifically, how this related to identity developed. Largely drawing upon narratives utilised by transgender individuals, members of the forum described their desires to be disabled as arising out of a felt sense of incongruence between their inner sense of identity, as disabled, and their bodily reality, as abled. They described their internal self-images as aligning with a specific type of disability which was seen to represent the 'authentic' or 'real' self. This stood in stark contrast to current states of able embodiment, which were described as 'wrong'. Often, members of the forum had an extremely clear image of what their correct body should look like: the majority wanted to be either a paraplegic or an amputee, often specifying the precise degree or location (for example, paraplegia from the second lumbar vertebra or left below the knee limb loss). Many outlined using disability aids such as wheelchairs and crutches when in public. This was compared to transgender cross-dressing, in that it was described by members as a way in which to embody their true identities, and have these identities acknowledged by others. Although using disability aids was experienced as soothing and validating, ultimately, most of the forum members wanted to actually acquire their chosen disability insisting that, until they did, they would not feel whole or authentically themselves. Many hoped to undergo spinal cord surgery or elective amputations, and a small handful of individuals had already amputated their own limbs via various dangerous methods.

In addition to identifying and discussing common experiences relating to their desires to become disabled, conversations on the forum soon took on a political tone. Many of the forum members had approached doctors, therapists and psychiatrists for help understanding their desires to be disabled, only to be rejected, dismissed or pathologised. These shared experiences were identified as a site of collective oppression, and, in response, the members began to advocate that the desire to be disabled be recognised as a valid psychological condition to be researched, understood and treated, rather than demonised. It was at this point that Sean, who still owned and managed the multi-authored platform, coined the term ‘transabled’ and renamed the website ‘transabled.org’[2]. The term transabled, by Sean’s own descriptions, was intended to hinge on the concept of transsexualism[3]. At the time, transsexualism was mostly a lay community term used to describe the profound sense of gender-identity and sexed-body incongruence experienced by individuals with diagnoses of Gender Identity Disorder (GID). Here, the expression of sex-gender incongruence is enabled through use of the prefix ‘trans’, meaning ‘on the other side of’ (Merriam-Webster, 2020). In creating the term transabled, Sean attempted to express the similarities between transsexualism and the desire to be disabled and convey a similar sense of identity-body incongruence, albeit pertaining to a disabled-identity and abled-body. The creation of the term transabled also served the purpose of situating the desire to be disabled as a legitimate, identifiable and collectively held psychological condition.

Very quickly, transabled (adjective), and the associated noun ‘transableism’, gained resonance. Many more individuals came across transabled.org, identified with transableism and began blogging on the forum, describing this as ‘becoming a part of the transabled community’. Whilst many of the other forums dedicated to an interest in disability still existed, transabled.org soon became established as the hub and centre for a number of reasons. Firstly, it was the largest and longest running platform of its type: in total, transabled.org existed for 17 years and by the mid-2000s it had over 40 full time members, many more casual commenters and an even greater number of ‘lurkers’[4]. Related, transabled.org was also the only site which constituted an online community, both by self-description, and as fitting with broader academic definitions (Baym, 2003; Denzin, 1998; Rheingold, 1993). In accordance with academic definitions, it had a large number of full-time members, all of whom wrote under a consistent alias and identified with the collective identity of the group. Friendships and affiliations were

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[2] The name of Sean’s previous solo-authored blog is unknown.

[3] Today, the term ‘transsexual’ is rarely used in favour of ‘transgender’ and the diagnostic label of ‘Gender Identity Disorder’ has been replaced with ‘Gender Dysphoria’ (Fraser, Karasic, Meyer, & Wiley, 2010; Newman, 2002). Both of these revisions have occurred, primarily, in response to activism from within the trans community; the later terms are seem as more inclusive and less-pathologising (Baven, 2014; Valentine, 2007). At the time of Sean’s writing, however, these shifts had not yet taken place. As such, my use of the language of ‘transsexual’ and ‘Gender Identity Disorder’, both here and elsewhere within this thesis, is intentional so as to accurately reflect both the content of the blog and the historical moment within which it was written.

[4] A ‘lurker’ is the term given to a member of an online community or forum who reads content and observes interactions, but doesn’t participate (Baym, 2003). We know that there were a large number of lurkers on transabled.org as this was reported by Sean, who used Google analytics.

also developed there, and the site contained shared resources, established norms, dynamics, linguistic expressions and posting practices (Baym, 2003; Denzin, 1998). Finally, as just discussed, transabled.org was the origin of the concept of transableism, specifically as a phenomenon of identity-body incongruence, situated as a psychological disorder and containing an identifiable symptom profile. Whilst many of the other forums were targeted towards individuals who were merely curious about disability or who experimented with it for fun, transabled.org was the only site explicitly dedicated to those who 'needed' (their words) to become disabled, so as to correct an identity mismatch.

Simultaneous to the creation of the concept of transableism and growth of the transabled community, clinical interest in the desire to become disabled was increasing, ignited by the growing visibility of this phenomenon online. In 2005 a large clinical study was carried out into individuals desiring limb amputation by Michael First, psychiatrist and editor of the Diagnostic and Statistical Manual of Mental Disorders (DSM) (First, 2005). The results of First's study were significant for two reasons. Firstly, this piece of research was the largest of its kind to date (52 individuals were interviewed). Secondly, its conclusions moved away from previous clinical conceptualisations (e.g. that the desire to be disabled was a sexual or emotional disturbance) and, instead, aligned with the claims made by the members of transabled.org: First described the desire for limb amputation as arising out of a mismatch between self-identity and bodily reality. Following this, First termed it 'Body Integrity Identity Disorder' (or 'BIID', after 'Gender Identity Disorder' or 'GID') and it was proposed for entry into the DSM-V, which was to be published in 2012 (First, 2005). These recommendations were enthusiastically received by the members of transabled.org. The term 'Body Integrity Identity Disorder' (or BIID) was taken up within the community and used interchangeably with transableism. The members of transabled.org became involved in raising awareness of the term BIID, supporting its inclusion in the DSM-V and using their experiences as evidence to support the accuracy of BIID as a descriptor, and the symptom profile laid out for it. Additionally, they engaged in further communications with the medical community, initiating a follow-up study with First and facilitating recruitment on transabled.org. This incorporation of clinical definitions and involvement in advocacy served two significant purposes for the members of transabled.org. Firstly, they saw the inclusion of BIID in the DSM-V as a necessary step towards achieving their goal of recognition and access to surgical treatment. Secondly, by aligning transableism with the proposed clinical diagnosis of BIID, the members were also able to argue that their desires to be disabled represented a legitimate mental health condition and thus a 'disability like any other' (their words). This, as they hoped, would go some way towards transableism being recognised, not only by the medical community, but by the disability community also.

After obtaining this clinical description and becoming active in advocacy efforts, transableism found itself the subject of even greater research interest from a range of academic disciplines. Psychiatrists began to discuss the aetiology and symptoms of this condition (Braam, Visser, Cath & Hoogendijk, 2006; First, 2005; Elliott, 2009), neurologists debated whether it might have an organic cause (Muller, 2009; Ramachandran & McGeoch, 2007), philosophers and disability scholars considered the moral implications of the desire to be disabled (Stevens, 2011; Sullivan, 2005) and sociologists expressed interest in the online transabled.org community (Davis, 2011, 2012, 2014). Bioethicists and legal scholars also began to draw up practical and ethical guidelines for managing transableism, assuming that there would be an increase in demand for elective disability surgery, following the addition of BIID to the DSM-V (Bayne & Levy, 2000; Elliott, 2003; Travis, 2014). Alongside the academic interest it garnered, transableism was also widely debated by journalists, members of the public and disability communities. (Dyer, 2000; Stevens, 2011; Sullivan, 2005). Although, as just disscussed, the members of transabled.org attempted to situate BIID as a 'disability like any other', this was hotly debated by the disability community itself, sparking further interest in transableism (Stevens, 2011).

Thus, in entering into the 2010s, awareness of transableism was growing, it was on an upward trajectory and its formalisation as an official psychiatric condition appeared imminent. Nevertheless, despite its growing popularity, in 2013 the transabled.org community permanently closed and transableism largely disappeared, both from the internet and the cultural consciousness. Whilst in the mid-2000s, an internet search for this phenomenon would have consistently produced hundreds of hits (Elliott, 2003), by 2013 the number of mentions was in significant decline. Further to this, when the DSM-V was published in 2012, despite the recommendations, BIID was not included as a condition. Shortly thereafter, the clinical and academic interest in BIID vanished. In 2015, when this project was first conceived, the internet was completely absent of anything related to transableism, excepting articles and comment pieces published in previous years.

Thesis aim, research questions and theoretical lens

During the years of its existence, transableism was studied from a variety of academic perspectives (cited above). No research to date, however, has carried out an in-depth empirical exploration into the rapid emergence and curious disappearance of transableism. Despite the identity incongruence explanation behind transableism, alongside the desire to permanently disable the body, being situated as ‘disturbing’ (Davis, 2014), ‘bizarre’ and ‘irrational’ (Elliott, 2009), no scholar approached the question of why this apparently strange and counter-intuitive phenomenon materialised when it did, spreading into an active online community and garnering academic attention. Further to this, and despite the fact that transableism was still a relatively young and yet to be verified condition, no research entertained the possibility that it might disappear as quickly as it had arisen. To the contrary, many scholars predicted an exponential growth in individuals identifying as transabled and expressed concerns and offered guidelines regarding what this would necessitate ethically and practically (Bayne & Levy, 2000; Charland, 2004). The primary aim of this thesis is thus to fill this gap in transableism scholarship. The central research questions underpinning this project are (1) why did transableism emerge and (2) why did it disappear? Although the desire to be disabled has been sporadically noted within the clinical literature since the 1800s (Bruno, 1997), the question of transableism’s emergence here relates to its specific manifestation as a disorder of identity incongruence, which originated and grew in popularity on transabled.org, and aligned with the clinical description of BIID. Furthermore, as it is impossible to say with certainty that transableism ‘disappeared’ (in that some may still privately suffer with it), the question of transableism’s disappearance here refers to the 2013 closure of transabled.org, the decline in online visibility of transableism as a collective identity, the failure of transableism to achieve official medical certification and the dwindling academic and public interest in it.

Whilst primarily being informed by gaps in existing transableism knowledge, the aim of this thesis can also be situated within broader medical historical and medical sociological scholarship. Within these traditions, one of the uniting aims is to look at causal factors for health conditions, particularly those which are unique to certain cultural or historical moments, and are without an organic basis (Hacking, 1998; Littlewood, 2002). Within these disciplines, various explanations for the existence of specific health conditions have been put forward including labelling processes[5] (Link & Phelan, 2013), sick role theory[6] (Parsons, 1951), social functionalism[7] (Littlewood, 2002), the influence of cultural contexts and moral values[8] (Blaxter, 1978; Jutel, 2009), pharmaceutical imperatives[9] (Healy, 1997) and social inequalities[10] (Farmer, 2004; Reiss, 2013; Showalter, 1985). Whilst these explanations are informative, this thesis uses Ian Hacking's model of 'transient mental illness' (1998) to theorise the emergence and disappearance of transableism, for reasons outlined below.

The term transient mental illness doesn't refer to illnesses which affect an individual in a short-term or fluctuating way but rather to psychological conditions which are found only within a specific culture, location and historical moment (1998). These conditions appear in a particular time and place, largely affecting a group of individuals who are oppressed or socially disenfranchised in some way. They spread rapidly through this group, igniting the interests of doctors, researchers and the general public, only to disappear from the medical and cultural horizon again, years or decades later. The primary example of transient mental illness studied by Hacking is dissociative fugue. This was a condition

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[5] The labelling theory of psychological conditions posits that diagnosing particular types of mental illness stigmatises the individual, thus reinforcing and exacerbating their symptoms (Link & Phelan, 2013).

[6] The sick role is a term coined by Parsons (1951); it refers to the way in which illness is, in some way, functional in that it enables individuals a socially sanctioned withdrawal from regular social duties, alongside giving them access to privileges such as care and attention.

[7] Social functionalist explanations for psychological conditions have their origins in medical anthropology. These theories outline how particular types of culture-bound syndromes enable the expression of social tensions, whilst simultaneously reaffirming the social order (Littlewood, 2002).

[8] Social contexts and moral values can influence diagnostic categories. For example, the medicalisation of obesity is related to moral judgments placed upon fatness in certain societies (Jutel, 2009).

[9] Authors have noted how pharmaceutical companies, being driven by profit margins, work to create and construct psychological conditions, which can be alleviated by their products. Examples include depression and, latterly, Pre-Menstrual Dysphoric Disorder (PMDD) (Healy, 1997).

[10] The social inequality theory of psychological illness draws attention to the ways in which unequal power relations within societies can make some groups (e.g. women, people of colour and poor people) more prone to mental illness. This is a result of the inherent social suffering that accompanies oppression (Farmer, 2004) and the over-diagnosis of non-conformity in oppressed groups (e.g. hysteria in women (Showalter, 1985)).

which largely existed in France in the late 19th century. Dissociative fugue affected enlisted service men and manifested with them absconding from their duties to roam across the country in a trance-like state, often without knowledge of their identities, or official identity papers. This condition fit the definition of a transient mental illness in that it did not exist in neighbouring countries and had largely vanished by the start of the 20th century (1998).

There are three reasons why the model of transient mental illness was chosen to theorise transableism, as opposed to any of the other explanatory models cited above. (1) Transableism precisely conforms to the definition of a transient mental illness: it rapidly emerged in a particular time and place[11], only to disappear again just as quickly. (2) The transient mental illness model, in recognising not only the cultural but also the historical contingence of psychological conditions, has questions of emergence and disappearance at its heart. Many of the other models are designed for conditions which still currently exist and thus a historical perspective is not taken. (3) There is a tendency for the other explanatory models to offer one causal explanation for the existence of a health condition. The transient mental illness model is unique in that it seeks a broad range of intersecting and overlapping reasons.

Hacking has a term for these intersecting reasons; he notes that transient mental illnesses owe their existence to an ‘ecological niche’ (1998). This is a metaphor borrowed from evolutionary biology and, in Hacking’s adaptation of it, is used to describe the ways in which particular illness manifestations are able to flourish when a wide variety social and cultural conditions temporarily come together to form a stable home for the condition in question (1998). For instance, in returning to the example of dissociative fugue, Hacking explains the emergence of this condition by outlining how it was enabled by a number of factors, unique to its location and historical moment. These included how it was an expression of the frustration, boredom and powerlessness of working class men enlisted into military service and the ways in which their absconding was made visible via the rigorous scrutiny of their identity papers at check points across the country. Other factors included how dissociative fugue was of interest to hysteria clinicians of

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[11] Although, in Hacking’s original analysis, he situates transient mental illnesses as bound to geographical places, an argument for the internet and the online transabled community as a ‘place’ is discussed in this thesis.

the time, alongside how it expressed a tension in cultural values surrounding travel crystallised by French concerns over criminal vagrancy versus the new trend for tourism amongst the middle classes (1998). Alongside explaining a condition's emergence, the ecological niche metaphor also assists in explaining a condition's disappearance. As Hacking outlines, if one factor comprising the niche weakens or disappears, this ultimately affects the existence of the whole niche; should an ecological niche disappear, then the condition will also. Again, regarding dissociative fugue, Hacking notes how the disappearance of this condition was related to the end of vagrancy fears and associated laws in France, alongside the increasing medical scepticism regarding hysteria. Supplementing his analysis regarding the disappearance of dissociative fugue, Hacking also notes how this condition was never present in cultures such as Britain and America where there was an absence of vagrancy law and no conscript army; in other words, there was no fugue niche to begin with (1998).

When forums surrounding the desire to be disabled first appeared online, a number of philosophers suggested that this new phenomenon might be understood through reference to Hacking's ecological niche of transient mental illness theory (Charland, 2004; Elliott, 2003). Inevitably, these authors theorised that the internet might be a significant factor comprising this proposed niche. This suggestion, however, remained purely in the realm of philosophy and no empirical research was carried out to test the application of Hacking's theory to transableism. Furthermore, and, given that these philosophers were writing in the early 2000s, their ideas were not extended towards theorising the disappearance of transableism, and the ways in which this might have been related to the disappearance of its ecological niche. By applying Hacking's model of an ecological niche of transient mental illness to transableism in an in-depth empirical analysis, this thesis thus takes up from where these theoretical suggestions left off. By doing so, it opens up a new never before explored perspective on transableism, historicising it and offering novel insights into why it emerged and disappeared.

Research methods, location and scope

As discussed above, the transient mental illness model does not rely upon one causal explanation for the existence of a health condition. Instead, it seeks a broad range of intersecting and overlapping factors which can be seen to contribute towards its constituting niche. These factors can include wider cultural values and discourses, alongside social tensions, dynamics, exclusions and oppressions (Hacking, 1998). Explorations into transient mental illnesses thus take, as their starting point, the identification of these broad and diverse factors. Following this insistence upon methodological holism, this thesis takes a qualitative approach, using digital ethnography to analyse all content posted to transabled.org in its active years. Ethnographic methods were chosen because of their natural fit with methodological holism (Geertz, 1973). Transabled.org was the natural choice for the location of this research for a number of reasons. Although, as discussed previously, other listservs and forums dedicated to an interest in disability existed simultaneously, transabled.org was the largest and longest standing and it was the only site which constituted an online community (by its own description and academic definitions). It was also the origin of the concept of transableism, specifically as a phenomenon of identity-body incongruence which aligned with the clinical description BIID. Finally, by incorporating the clinical descriptor of BIID and being heavily involved in interacting with the medical community, transabled.org was, not only the central online community surrounding the desire to become disabled; it also conformed to academic descriptions of a health advocacy community (Brown et al., 2004).

Whilst, as previously discussed, when this research project was first conceived, the desire to be disabled was almost entirely absent from the internet, the cultural horizon and from academic research, over the last few years, it appears to have made a small resurgence. Since 2018, there has been activity on a sub-Reddit thread discussing the desire to be disabled. Additionally, some conversation around transableism and BIID can now be found on Twitter; whilst this later debate is, in the large part, mobilised in relation to debates over transgender rights more broadly, it occasionally redirects to the aforementioned sub-Reddit thread.

Finally, and perhaps most significantly, in May 2019, the desire to be disabled, although, having been previously dismissed by the DSM, was acknowledged in the International Classification of Diseases Volume 11 (ICD-11), under the descriptor Body Integrity Dysphoria (BID) (ICD-11, 2019); this document will take effect in 2022 as a requirement for reporting international health statistics to the

World Health organisation (WHO). The term BID is both similar to, and divergent from, transableism/BIID. It is similar in that it outlines a persistent and distressing desire to be disabled. However, in diverges in that it moves away from the identity incongruence discourse which characterized transableism and BIID and, instead, draws upon neurological explanations, research and terms, including xenomelia[12]. Michael First, the aforementioned BIID specialist and, latterly, ICD-11 consultant, explained this shift as follows:

> ‘the name was changed to remove the term “identity”—the proposal to include this condition (in the ICD-11) was a joint proposal by me and the xenomelia contingent, who rightfully objected to including the term “identity” in the name as it suggested that this condition is best thought of as an identity disturbance, which was more of a hypothetical conjecture rather than something supported by data. We now know that this condition is best thought of as a psychiatric disorder or a neurological condition…The current name (BID) as well as the current definition removes any implications about presumed causality but instead focusses exclusively on the phenomenology’ (First, 2020, private communications).

In many ways, discussions within the new online sub-Reddit community can be seen to reflect those found on transabled.org; individuals share stories of distress over wanting to be disabled, describe which disabilities they desire and outline pretending to have such disabilities. Crucially, however, they can also be seen to differ in that that language of identity incongruence and being ‘trapped in the wrong body’ is sparsely used and the concept of transableism is not applied. Instead, these conversations, in reflecting the ICD-11 reorientation, are centred around discussions of neurological abnormality and associated bodily dysphoria. Notably, this new community does not appear to be as orientated towards health advocacy and engagement with the medical community, as transabled.org so evidently was.

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[12] Xenomelia is a term coined by neurologists working in Switzerland who believe that the desire to be disabled is best considered a neurological condition. The term Xenomelia is intended to capture the proposed dysfunction in the right parietal lobe of the brain, thought to result in a lack of ownership over one or more of ones limbs (Brugger, 2013).

The above described resurgence of the desire to be disabled, alongside its slightly morphed form and aetiology is extremely significant in that it appears to reflect observations, drawn by Hacking (1998), regarding the nature of transient mental illnesses and ecological niches more broadly. As Hacking describes, sometimes transient mental illnesses seem to disappear entirely. More commonly, however, they can be seen to evolve into other conditions which, whilst retaining similar symptoms, take on different labels and explanations. These changing explanations can, as Hacking notes, be attributed to broader shifts, both within the cultural context, and within medical developments, trends and practices. Examples of this evolution from within Hacking's own work include how dissociative disorders appeared to replace symptoms previously described as 'hysteria' (1995; 1998); additionally, the changing labels applied to dissociation itself, are themselves evidence of more subtle shifts in understanding (see, for example, Hacking (1995) on how his much-studied Multiple Personality Disorder (MPD) is now termed Dissociative Identity Disorder (DID)).

The shift, described above, from transableism/BIID to BID appears to confirm Hacking's observations. Rather than disappearing entirely, the desire to be disabled has changed with time. In additional to this, its evolution appears to reflect the changing cultural and medical context in that the renaming and reconceptualization of this phenomenon can be seen to demonstrate a growing tendency to seek neurological explanations for psychological symptoms (Brugger, 2013). In other words, the resurgence of the desire to be disabled can be interpreted as evidence which supports the notion that transient mental illnesses can reappear under different manifestations, supported by slightly different niches, within various cultural and historical moments (Hacking, 1998).

Although this resurgence, and the support it offers in relation to Hacking's wider theory, is extremely intriguing, any deeper examination into it falls outside of the scope of this project. This is largely due to time constraints and the late stage in this project wherein the resurgence was identified. Nevertheless, because of the way in which this resurgence serves to usefully contextualise transableism as but one discrete episode in the ever-evolving desire to be disabled epoch, investigation into BID is strongly recommended as a project for future enquiry, as will be discussed in the concluding chapter of this thesis (**Chapter 9**). The scope of this current project is chronologically limited to 1996-2013, situationally restricted to transabled.org and theoretically limited to the study of the desire to be disabled in its manifestation as transableism: a disorder of identity incongruence which aligned with the clinical description of BIID.

Thesis findings and contributions

This research has four key findings. Findings are presented independently in each of the empirical chapters of this thesis (**Chapters 5, 6, 7 and 8**) and then, congruent with the ecological niche approach to transient mental illness, integrated in the discussion chapter (**Chapter 9**) to offer multifaceted answers for the questions of transableism's emergence and disappearance.

Individually, the findings of this thesis are: (1) contrary to how they are described within clinical literature, the members of transabled.org were not 'able-bodied' individuals, but instead suffered with what are culturally understood to be 'inauthentic' disabilities (e.g. invisible, fluctuating conditions such as depression or chronic pain) (Wendell, 1996). In conjunction, the disabilities they desired (largely paraplegia or amputation, with a focus on wheelchair use) all conformed to understandings surrounding 'authentic' disability (e.g. physical, visible, stable). (2) In addition to desiring disability, the members of transabled.org attempted to situate the diagnosis of BIID itself as an authentic 'disability like any other' (their words). These attempts were rejected by members of the disability community, who argued an essentialist, as opposed to voluntarist, ontology of disabled identity. (3) Whilst, at first appearances, transabled.org appeared to be a democratic and collaborative online community, this was deceiving. Instead, the development of a so-called collective transabled identity was significantly influenced by Sean, the community's founder, in his role as site creator, moderator, and leader of the transabled community. (4) Alongside influencing the development of transabled identity, Sean also led the health advocacy efforts of transabled.org by coordinating lay epistemologies and goals, alongside acting as spokesperson in relation to the medical community.

When integrated holistically under the ecological niche model, these findings are combined to reveal why transableism emerged and why it disappeared: as is suggested, transableism emerged because it reflected and expressed broader cultural understandings and tensions surrounding authentic versus inauthentic disability. It also offered the members of transabled.org a way to counter their experiences with inauthentic disability stigma, by allowing them to temporarily pass as authentically disabled when, as part of their transableism, they went out in public in wheelchairs. Transableism's emergence was also facilitated by the centralised model of community leadership which, for a time, successfully fostered a coherent group identity, alongside enlisting the interests of clinicians. These factors comprised a transableism ecological niche which, at the time of its existence, gave transableism resonance and enabled it to flourish and spread. On the other hand, transableism disappeared because the transableism ecological niche did: ultimately, BIID failed to conform to an acceptable authenticity politics of disabled identity and was policed accordingly. In addition, although the centralised model of community leadership initially facilitated transableism, towards the later years, this model collapsed, leading to conflict, community attrition and a failure to sustain the interests of researchers.

The above described findings, and integrated conclusion, together make 6 contributions to knowledge. (1) The first contribution is towards existing transableism scholarship. This thesis fills a gap in knowledge by historicising transableism and providing empirical explanations for its emergence and disappearance. (2) The second contribution is towards is towards broader medical sociological literatures. Whilst the usefulness and promise of Hacking's transient mental illness model has been noted within academic scholarship (Brossard, 2019; Elliott, 2003; Tsou, 2007), theorists have also drawn attention to the dearth of examples of it being used in empirical practice within medical sociological enquiries (Brossard, 2019). By providing such an example, alongside a critical commentary, on the use of the transient mental illness model in empirical practice, this thesis contributes towards removing the transient mental illness model from the realm of abstract theory, alongside offering a framework for use by future scholars.

In addition to making contributions towards existing transableism and medical sociological scholarship, this thesis makes four broader contributions to peripheral social scientific fields. For context, the reason why questions of emergence and disappearance are of such interest to Hacking is because these types of investigations not only offer access to a greater understanding of the transient mental illness itself; they also illuminate aspects of the culture more broadly (1995, 1998). By examining the cultural forces and tensions which are reflected in a phenomenon such as a transient mental illness, these cultural aspects, which might otherwise have gone unexamined, can be brought to critical enquiry. Following this, this thesis (3) contributes to the disability studies literature by drawing attention to socio-cultural understandings surrounding authentic versus inauthentic disabilities, and discussing the impacts of these on disabled individuals. (4) This thesis contributes to scholarship which explores claims to authentic identities and the limits of such claims. It also makes contributions to the literature on leadership and moderation practices- (5) within online communities in general, and (6) within health advocacy communities specifically- by revealing the role played by influential individuals in fostering these groups and movements.

Thesis structure

This thesis is divided into 3 parts. Part 1- **Chapters 2, 3 and 4**- form the background to this project. **Chapter 2** maps the academic and conceptual terrain surrounding the desire to become disabled from the 1800s to recent times. This is done primarily to historically situate and contextualise the desire to be disabled. However, this chapter also serves the purpose of highlighting gaps in the understandings surrounding transableism, which are significant when it comes to identifying factors which comprised the transableism niche. The review of the desire to be disabled literature in **Chapter 2** leads to 3 key observations. (1) Whilst the most recent clinical studies acknowledged the influence of online communities on the 'new wave' of the desire to be disabled, this has not been adequately explored, particularly in terms of lay advocacy involvement. (2) Whilst, within the sociological literature, the dynamics of online communities were addressed in significantly more depth than within the clinical literature, this analysis was also insufficient as it did not explore centralised community ownership and moderation practices. (3) Whilst the sociological studies into transableism examined broader cultural factors, in particular noting how this phenomenon drew upon modern Western concerns with authenticity and self-actualisation, these studies did not explore how authenticity intersected with understandings surrounding disability in the case of transableism. Following these observations, disability, authenticity and online health advocacy communities are highlighted as factors relevant to the ecological niche of transableism, warranting further exploration.

Chapter 3 expands upon **Chapter 2** and its 3 key observations by presenting a broad overview on the literature regarding (1) disability, (2) authenticity, and (3) online communities, including health advocacy communities. Here, I review existing research, theories and conceptual approaches within these bodies of work, in order to assess which contributions lend themselves well to theorising themes of disability, authenticity and online communities, as they relate to the ecological niche of transableism. This assessment and selection of existing contributions lays the groundwork for the empirical chapters in part 2 of this thesis, which expand up and develop existing research within the disabilities studies, authenticity and online communities' literatures. To this end, each section of **Chapter 3**, after outlining gaps in existing literature, presents a conceptual framework which underpins a subsequent empirical chapter or chapters. In the section on disability, I highlight how, as an unintended consequence of the disability rights' movement, cultural understandings developed around disability based upon a binary of authentic (e.g. visible, physical, stable) versus inauthentic (e.g. invisible, fluctuating) disabilities. This section builds a conceptual framework based upon these observations by suggesting that the binary of authentic versus inauthentic disability is a relevant 'cultural polarity' (Hacking, 1998) through which to explore transableism. In the section on authenticity, I outline how, although existential, objectivist authenticity has been discussed in relation to transableism, the social construction of authenticity, particularly regarding the members claims' that BIID itself was an authentic disability, has been overlooked. Following these observations, I suggest that a conceptual framework, based upon the social construction and negotiation of authentic identity and an associated politics of authenticity, be used to analyse transableism. Finally, in the section on online communities and health advocacy communities, I discuss the growing body of literature on online community moderators, highlighting the ways in which this literature is yet to be applied to the study of online health advocacy groups. This leads me to suggest a conceptual framework based upon power and moderation practices be used to analyse transabled.org.

Chapter 4 outlines the methodology and methods adopted for this research enquiry. In this chapter, I begin by describing the field site where this research took place. I then outline the ontological and epistemological principles which underpin the aims of this thesis, namely social constructivism and a commitment to methodological holism, interpretivism and critical reflexivity, respectively. I then move on to discussing digital ethnography, the chosen methodology for this research, as informed by these ontological and epistemological principles. I discuss the practical issues and ethical challenges I encountered through my use of digital ethnography, outlining how these were addressed. I then describe the methods that were adopted for this research, outlining the process through which data was collected and analysed. Finally, I reflect upon my research process; I discuss its limitations and the successful aspects of it, and I outline changes and adaptations I would make for future research projects.

Part 2- **Chapters 5, 6, 7 and 8**- comprise the empirical section of this thesis. **Chapter 5** explores the members of transabled.org's experiences with disability and understandings of transableism. In this chapter, the conceptual framework developed in the disability section of **Chapter 3**, based upon the 'cultural polarity' (Hacking, 1998) of authentic versus inauthentic disability, is used to situate findings. Here, I begin by describing how the members of transabled.org, contrary to how they are described within clinical literature, were not 'able-bodied' individuals, but instead suffered with 'inauthentic' disabilities (e.g. invisible, fluctuating). In conjunction with this, the disabilities they desired (largely paraplegia or amputation) all conformed to understandings surrounding 'authentic' disability (e.g. physical, visible, stable). Relatedly, I note how the members of transabled.org went out in public in wheelchairs and enjoyed the experience of temporarily passing as disabled. This, I suggest, indicated that transableism, despite the pain it caused, offered the members a 'release' (Hacking, 1998) from the struggle of being caught within the authentic versus inauthentic disability binary.

Chapter 6 explores the members of transabled.org's attempts to position the diagnosis of BIID, as a 'disability like any other' (their words), and the responses this garnered. In this chapter, the conceptual framework developed in the authenticity section of **Chapter 3**, regarding the social construction of authentic identity and a politics of authenticity, is used to situate findings. As is discussed in **Chapter 6**, the members of transabled.org attempted to align BIID with the already existing and verified condition of Gender Identity Disorder (GID), so as to index its authenticity as a legitimate mental health condition and thus ‘disability like any other’. However, alongside these attempts, the members claims’ were rejected by the disabled community, who could be seen to internally police the disabled identity category. This rejection and policing impacted the members of transabled.org, with many withdrawing from the community as a result.

Chapters 7 and 8 explore social dynamics on transabled.org. In these chapters, the conceptual framework outlined in the online community section of **Chapter 3**, regarding power, leadership and moderation practices, is used to situate findings. **Chapter 7** outlines the history and development of transabled.org as an online community. As is discussed, although, at first appearances, transabled.org appeared to be a democratic and collaborative online community, this was deceiving. Instead, the development of a so-called collective transabled identity was significantly influenced by Sean, the community’s founder, in his role as site creator, moderator, and leader of the transabled community. In the early years of transabled.org, Sean’s influence was fundamental to the development, health and growth of the transabled community. However, as I note in the latter half of this chapter, towards the later years, it created conflict, schism and community attrition.

Chapter 8 extends the analysis of power and leadership developed in **Chapter 7** towards the study of transabled.org as a health advocacy community. In this chapter, I outline how, alongside influencing the development of transabled identity, Sean also led the health advocacy efforts of transabled.org by coordinating lay epistemologies and goals, alongside acting as spokesperson in relation to the medical community. These efforts were initially successful in that they facilitated the development of health knowledges and political goals within the community, alongside enlisting the interests of researchers. As time went on, however, I note how they ran into challenges. Members of the community either resented Sean’s ideological authority or expressed ambivalence about engaging in advocacy and research.

Chapter 9 forms part 3 of this thesis, and comprises the discussion and concluding remarks. In this chapter I begin by returning to each of the findings’ chapters in turn, highlighting how they offer further contributions to knowledge. I situate these findings against existing literatures, including (1) the disabilities studies literature (2) scholarship that explores claims to authentic identities (3) the literature on leadership and moderation practices within online communities and (4) the health advocacy community literature. I then return to the overall aim and research questions at the heart of this thesis, namely to explore (1) why transableism emerged and (2) why it disappeared. Here, I use the overarching framework of an ecological niche to integrate the findings from the 4 empirical chapters. This leads me to conclude that transableism emerged not for one reason alone but because of the way in which all of the findings discussed in this thesis comprised a transableism ecological niche. I suggest that it disappeared because elements of this niche eventually weakened. I outline the contributions that these observations make to the literature on transient mental illness, suggesting that they be used in future medical sociological enquiries. I conclude this chapter by reflecting upon my research and discussing the limitations of this study. I use these reflections to outline recommendations for further enquiries into transient mental illnesses, including potential future resurgences and manifestations of the desire to be disabled.

Chapter 2

Mapping the terrain: Exploring the desire to become disabled from the 1800s to today

Introduction

Although transableism, as a disorder of identity incongruence which aligned with the clinical description of BIID came into existence in the 1990s, a pathological fascination with becoming disabled has been noted within the clinical literature since the late 1800s. Since that time, this phenomenon has evolved and resurfaced under various clinical conceptualisations and has been investigated from a range of perspectives. This chapter maps this terrain, outlining how the desire to become disabled has been understood at various historical moments, alongside detailing the literature surrounding its most recent manifestation as transableism. This is done primarily to historically situate and contextualise the desire to be disabled. It also serves the purpose of highlighting gaps in existing understandings surrounding transableism which are significant regarding the ecological niche approach to transableism as a transient mental illness. As discussed in **Chapter 1**, the ecological niche approach to transient mental illness advocates identifying and examining the broad and diverse range of cultural values and social dynamics which are reflected and expressed within the condition in question, thus constituting its niche (Hacking, 1998). As Hacking outlines, reviewing existing understandings of a condition, alongside highlighting potential gaps in knowledge and missed connections, is a fruitful starting point for identifying the elements of a condition’s niche (Hacking, 1998). Thus, by mapping the extant academic terrain surrounding transableism, this chapter begins to identify factors which might have comprised the transableism niche and paves the way for them to be explored in greater depth within subsequent chapters.

In this chapter, I begin by discussing the historical literature surrounding the desire to become disabled. I then move on to discussing the clinical studies this phenomenon attracted in the early 2000s, and the other academic enquiries generated by this interest. This leads me to my first key observation: whilst the most recent research into the desire to become disabled acknowledged the presence of online communities within the 'new wave’ of this phenomenon, the impact of these intra-community dynamics was not adequately explored.

Furthermore, whilst many of these clinical studies observed or recruited from online communities, the impact of this lay involvement on clinical understandings was not discussed. After highlighting this, I then move on to reviewing the sociological and philosophical literature surrounding transableism and transabled.org. A review of this literature leads me to a second observation: whilst, within the sociological and philosophical work, the dynamics of online communities were addressed in significantly more depth than within the clinical literature, this analysis remains insufficient regarding explorations into the emergence and disappearance of transableism. By situating transabled identity as emerging out of a process of 'collective construction', and by outlining lay involvement in medical research as similarly democratic, the influence of Sean, as leader and spokesperson of the transabled community was overlooked. Following this, I draw a third observation regarding additional aspects of the sociological and philosophical literature: whilst this body of work examined broader cultural factors informing the desire to be disabled, in particular noting how transableism drew upon modern Western notions of authenticity and self-actualisation, these studies did not explore how authenticity intersected with disability in the case of transableism. I conclude this chapter by noting that disability, authenticity and online health advocacy communities are factors relevant to the ecological niche of transableism which warrant further exploration; this paves the way for **Chapter 3** which presents a review of related literature.

Clinical understandings surrounding the desire to become disabled: Late 1800s- early 2000s

Persons either desiring to become disabled or expressing sexual attraction to the disabled bodies of others, can be traced back within the clinical literature to the late 1800s (Bruno, 1997). These accounts, however, are mostly of sporadic, individual cases and, as such, no attempt to formally classify this phenomenon appeared to exist at this time. It wasn't until the 1970s that the desire to become disabled came to be more systematically investigated within a clinical setting. In 1977 a study into 2 male patients presenting with the desire to amputate their own legs was carried out by sexologist John Money (Money, Jobaris & Furth, 1977). After interviewing the patients and noting several key characteristics including erotic fantasies surrounding the self as an amputee, sexual attraction towards amputees, other concurrent fetishes and sexual deviances (which, at the time, included homosexuality, transsexuality and bisexuality), Money concluded that the desire for self-amputation represented a paraphilia (the clinical term for a sexual perversion or deviation). He thus suggested that it be termed 'apotemnophilia' (from the Greek, meaning amputation-love)[13].

In the following two decades, a handful of other small-scale studies were carried out into the desire to become disabled, largely by clinicians observing this phenomenon in their patients (Bruno, 1997; Everaerd, 1983; Money & Simcoe, 1986; Storrs 1997). These studies reached similar conclusions regarding the paraphilic component of this phenomenon, with one small deviation. A study carried out by psychologist and post-polio specialist, Richard Bruno, suggested that sexuality motivated only a sub-section of those who desired to be disabled, with some being motivated by the need for attention, or, in a small proportion of cases, by actually wanting to become disabled. Following this, Bruno proposed an internal taxonomy of the desire to be disabled, classifying individuals as 'devotees' (those sexually aroused by disability, in self and others), 'pretenders' (those who faked disability for attention) and 'wannabes' (those who actually wanted to become disabled). Overall, Bruno categorised these sub-sections as a type of 'Factitious Disability Disorder' under the broader taxonomy of Munchausen's syndrome (Bruno, 1997).

Notably, none of the above studies attracted much attention, either within the clinical community or more broadly within academia and public interest. It wasn't until a decade later, in the early 2000s, that a larger and more varied body of research began to take place, igniting interest more broadly. This uptake appeared to be inspired by two events. Firstly, the emergence of the internet exposed relatively large listservs and forums gathered around the desire to become disabled, making these populations both more visible and more accessible (Elliott, 2003; First, 2005)[14]. Secondly, a story was widely reported in the media which detailed the case of Robert Smith, a surgeon who had performed self-requested limb amputations on two patients. Smith, in justifying these

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[13] Alongside proposing this term, Money also suggested that the associated attraction to amputees be labelled 'allo-apotemnophilia', later updated to acrotomophilia (Money & Simcoe, 1984). This later term, however, did not come to be as widely used as apotemnophilia.

[14] Around this time, some of the most popular of these types of online groups included secret-garden.com, paraamps.com, super-hosting.com/fascination, d-links.com, amp-world.com (Crawford, 2014). One listserv had, apparently, fourteen hundred subscribers in 2000 (Elliott, 2003).

procedures, stated that both patients had described feeling a ‘desperate’ need to become amputees, outlining how they felt ‘incomplete’ with all four limbs (Dyer, 2000). It was further reported that a number of other individuals had contacted Smith requesting amputations, before his hospital ethics committee intervened (Dyer, 2000).

Both of the above events challenged the presumed rarity of the desire to become disabled and drew attention to factors other than sexuality as contributing towards its occurrence. In reflecting these new insights, the studies which followed moved away from notions of paraphilia and approached the desire to become disabled from a variety of angles. First, it was briefly discussed in terms of emotional disturbance, with researchers presenting it as either an Obsessive Compulsive Disorder (Braam, Visser, Cath, & Hoogendijk, 2006) or a form of Body Dysmorphic Disorder (Braam, Visser, Cath, & Hoogendijk, 2006; Elliott, 2009). These conceptualisations, however, turned out to be fairly short-lived for a number of reasons. Firstly, the notion that individuals desiring disability were either deluded, seeking attention or, otherwise mentally unwell was challenged by philosophers whose attention had been drawn to the bioethical aspects of this phenomenon (e.g. whether it was medically acceptable for a doctor to amputate a healthy limb) (Bayne & Levy, 2005; Bridy, 2004; Tomasini, 2006). Secondly, within these new investigations, participants repeatedly indicated that their desires to become disabled were related to aspects of their ‘identity’ (Bruno, 1997; Dyer, 2000; Elliott, 2009; Smith & Furth, 2000). Whilst not given significant attention on an isolated basis, this aspect was investigated further once a pattern of claiming an inner disabled identity began to emerge.

The first academic investigation into identity and the desire to become disabled was carried out by Smith, the surgeon mentioned above, in a theoretical text co-authored by one of Smith’s patients. Smith had been due to perform an amputation on this man, Furth, before being barred from doing so (Smith & Furth, 2000). Drawing upon Smith’s clinical observations, alongside Furth’s personal experiences, this text was the first to describe the desire to become disabled as emerging from an incongruence between a disabled sense of self and an able-bodied reality. Following this, Smith and Furth concluded that this phenomenon should be considered a type of ‘identity disorder’, noting its similarities with the sex-gender incongruence experienced by those with Gender Identity Disorder.

Whilst previous studies into the desire to become disabled had acknowledged that this phenomenon could manifest as a variety of disability desires (Bruno, 1997), Smith and Furth's analysis was restricted to amputation[15]. As such, they proposed that this phenomenon be re-termed 'Amputee Identity Disorder' (AID). They suggested that this label be added to the (then forthcoming) DSM-V, and recommended diagnostic criteria directly adapted from that used in relation to Gender Identity Disorder at the time.

Whilst noteworthy, this text turned out to have little influence on broader clinical conceptualisations, most likely due to the fact that it was based on small-scale, informal observations, with the conclusions being rife with conflicting interests. Despite failing to reach a wider audience, this text ignited the interests of psychiatrist and editor of the DSM, Michael First, who went on to conduct a much larger, more systematic piece of research into the desire for limb amputation, where he carried out in-depth telephone interviews with 52 individuals who wanted to become amputees (First, 2005). First's conclusions largely echoed those drawn by Smith and Furth 5 years previously. He similarly noted that his participants were motivated towards correcting a perceived mismatch between their able bodies and their true sense of 'identity' as disabled. Again, paralleling Smith and Furth, First thus suggested that the desire to become disabled, rather than being considered a paraphilia, should be thought of as an 'identity disorder' akin to Gender Identity Disorder (GID). Although the conclusions of this study were almost identical to those drawn by Smith and Furth, First's additional recommendations deviated. Rather than labelling this phenomenon 'Amputee Identity Disorder', First instead suggested that it be termed 'Body Integrity Identity Disorder' (or BIID)[16], leaving open the possibility for non-amputee manifestations. Furthermore, and, although advocating for BIID's eventual inclusion in the DSM-V, First drew attention to the need for more research before doing so. Although, as previously mentioned, BIID never did make it into the DSM-V, First's study,

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[15] Smith and Furth's sole focus upon the need to become an amputee (as opposed to the need to acquire any other type of disability) seems, undoubtedly, to be reflective of both Smith's professional experiences and Furth's personal interests. However, it must be noted that this amputation-bias is apparent within the research more broadly (Bayne & Levy, 2005; Blom, Guglielmi & Denys, 2016; Bottini, Brugger & Sedda, 2015; Elliott, 2009; First, 2005; Kraemer, Hilti, Hanggi & Brugger, 2015; Lawrence, 2006; Muller, 2009; Ryan, 2009; van Dijk et al., 2013).

[16] This is a term First theoretically justifies in that it is based upon a hypothesised 'core developmental schema' of 'body integrity', which is akin to that of 'gender identity' and can thus become similarly disturbed (First & Fisher, 2012, pp. 4-5).

and the conclusions it reached, drew significant academic and public attention towards the desire for limb amputation.

Interest in the Body Integrity Identity Disorder (BIID) diagnosis

The predominate interest attracted by the BIID diagnosis came from bioethical theorists. These debates largely focused upon the ethics of self-demand amputation, with arguments being presented both for and against this type of surgery. Those advocating in favour supported the notion that the desire for limb amputation did indeed appear to be motivated by identity incongruence, rather than by paraphilia or delusion (Bayne & Levy, 2005; Blom et al., 2016; Tomasini, 2006). These theorists argued that the individual desiring amputation should be considered a rational agent, capable of making informed decisions about their body (Bayne & Levy, 2005; Blom et al., 2016; Tomasini, 2006). In addition, a number of authors also made appeal to the Hippocratic Oath of 'do no harm', outlining the ways in which amputation should be seen as minimising both psychological harm (by aligning identity and bodily reality) and higher levels of physical harm (which may otherwise incur through riskier self-amputation attempts) (Bayne & Levy, 2005; Blom et al., 2016). In further support of the appeal to 'do no harm', the phenomenological importance of a sense of identity-integrity in relation to the lived body was also discussed (Craimer, 2009; Slatman & Widdershoven, 2009). Contrary to this, those arguing against elective amputation practices variously claimed that it was an affront to religious sanctity to change the body (Jotkowitz & Zivotofsky, 2009), that it was economically irrational to disable the body (Elliott, 2009; Muller, 2009), or, quite simply, that elective-amputation was 'utter lunacy' (Caplan quoted in Dyer, 2000). Theorists also expressed concerns that, by institutionalising elective amputation as a psychiatric treatment, the medical community could potentially contribute towards the spread of those demanding it (Charland, 2004; Elliott, 2003; Parsell, 2008).

Alongside bioethical discussions, commentary also began to take place regarding the broader cultural, political and ideological structures which could be seen to inform the ethical and public rejection of self-demand amputation which existed at the time. As authors noted, although cosmetic surgeries and body modification practices have become normalised, self-amputation was, following its public exposure, singled out to be sanctioned and abhorred (Bridy, 2004; Jordan, 2004;

Sullivan, 2005). This seemingly paradoxical circumstance is described as arising in relation to attitudes and norms, implicitly perpetuated at all levels of society, which valorise ‘the able body’ and, by association, denigrate ‘disability’, as its constituting other (Baril, 2015; Stevens, 2011; Sullivan, 2005). As is described, amputation surgeries threatened to disrupt these standards and, for these reasons, they were prohibited under ableist legal (Travis, 2014), political (Bridy, 2004) and medical structures and regulations (Jordan, 2004; Sullivan, 2005). Further research also examined, not only the prohibition of self-demand amputation, but negative attitudes towards the desire to be disabled, as found at the time in general public, and within disability and transgender communities. For example, Stevens (2011), a disability scholar who is disabled herself, noted that ‘internalised ableism’ (the subconscious belief that disabled bodies are inferior) might have contributed towards the reluctance of disability communities to accept and value transableism. Additionally, Baril (2015), who is transgender, outlined how the rejection of transableism was likely related to cisnormativity: the belief that being born in a body congruent with one’s identity is the natural state of affairs. Baril also noted that negative attitudes towards transableism might stem from neoliberal norms regarding productivity.

Alongside attracting bioethical and broader cultural analysis, the desire for limb amputation also drew attention from neuroscientists who noted the similarities between this phenomenon and the symptoms of some neurological conditions[17]. Most frequently, parallels were drawn with Somatoparaphrenia, a syndrome that occurs following damage to the right parietal lobe of the brain and is characterised by denial of ownership of the left arm or leg (Brugger, Lenggenhager, & Giummarra, 2013; Hilti et al., 2013; McGeoch et al., 2011; Müller, 2009; Ramachandran & McGeoch, 2007). Having observed this similarity, researchers set out to investigate whether comparable neurological abnormalities might be present in those desiring limb amputation. Whilst some promising findings emerged from these studies[18], on the whole, neurological explanations were

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[17] Parallels between the desire for limb amputation and phenomenon such as phantom limb, alien hand, Poltz syndrome and ‘inner amputation’ have all been highlighted within the literature (Müller, 2009). These various syndromes, perhaps made most famous through the work of Oliver Sacks (1984), have all been identified as resulting from disturbances in areas of the brain and all manifest as the sufferer experiencing a malfunctioning relationship with one of their limbs.

[18] Following empirical research carried out which utilised MRI brain mapping technology, researchers discovered that there was a reduced cortical thickness in the right superior parietal lobule and reduced cortical surface area in the primary and secondary somatosensory cortices in

described as overly simplistic, with a further section of research within this field producing results which were insignificant (Lenggenhager et al., 2014). As such, at this time[19], proposed neurological explanations and terminologies (for example 'xenomelia' (Brugger et al., 2013; McGeoch et al., 2011)) surrounding the desire to become disabled failed to achieve prominence.

Thus, the desire to become disabled, which had previously been a sparsely studied and little understood phenomenon, became widely debated following First's study and the creation of the BIID diagnosis. However, whilst raising the profile of the desire to be disabled and contributing much towards the public discussion of this phenomenon, this body of research had one key flaw. Although many theorists acknowledged the influence of online communities on the 'new wave' of the desire to be disabled, the significance of this was not adequately explored. This body of work did not address the fact that the desire to be disabled seemed, not only to exponentially increase with the advent of the internet, but, furthermore, to be reconceptualised as a disorder of identity incongruence which went by the lay description 'transableism'. The possibility that this most recent instantiation of the desire to be disabled might have been influenced by the norms and dynamics within these communities was left unexamined. Further to this, whilst much of the clinical research discussed above actively recruited from online communities, the impact of lay involvement, particularly regarding future diagnostic and treatment proposals, was, again, left unexamined.

These oversights are significant when it comes to the ecological niche approach to transableism as a transient mental illness and the associated enquiry into transableism's emergence and disappearance. This significance lies, not merely in the fact that transabled.org was the origin of the concept of transableism, including its reconceptualization as a disorder of identity, but, furthermore, in the fact that this community was heavily involved in lay advocacy, to the extent that it substantially influenced research projects and agendas. Beyond this, these oversights have a broader academic significance. Since the advent of the internet, there has been a growing body of social scientific work which explores

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both the inferior parietal lobule and the anterior insular cortex in those desiring limb amputation, as compared to a control (Hilti et al., 2013).

[19] As discussed in the introduction to this thesis, since the outset of this project, neurological explanations regarding the desire to be disabled appear to be having a resurgence. As also outlined in the introduction, however, this resurgence is beyond the scope of this project.

online communities, situating them as meaningful spaces of culture and social interaction (Baym, 2003; Davidson, 2008; Hine, 2000; Rheingold, 1993). In conjunction with this, this body of work examines how the dynamics within these spaces can be seen to influence the collective identities which exist there, an observation which is discussed as particularly pertinent within online illness or attribute-based communities, such as transabled.org. Further to this, the oversights within the clinical literature surrounding the desire to be disabled can be seen to align with broader criticisms directed, from the social sciences, at clinical research in general. As is much discussed within disciplines such as medical anthropology, medical sociology and the sociology of diagnosis, it is common for clinical research to problematically disregard the interaction between lay communities and medical professionals. As various authors note, lay health advocacy groups can have significant influence, not only over intra-community collective illness identities, but also over supposedly top-down processes of determining formal diagnosis, research and treatment protocols; this is highlighted as particularly the case in regards to newly emerging conditions, such as transableism (Frank, 1995; Hacking, 1995, Kleinman, 1988). Following these observations, I suggest that online community dynamics and lay advocacy efforts are relevant, overlooked factors comprising the ecological niche of transableism which warrant further enquiry. In subsequent chapters I engage in this enquiry. Before this, however, I turn to a discussion of the sociological and philosophical literature which surrounded the desire to be disabled in the early 2000s.

Sociological and philosophical explorations into the desire to be disabled: Online community dynamics

Whilst online community dynamics and lay advocacy process were overlooked within much of the clinical literature and ethical and critical commentary, they were explored in significantly more depth within the sociological and philosophical literature surrounding the desire to become disabled. In particular, these aspects were examined within the work of sociologist Jenny Davis who carried out a qualitative study on transabled.org itself (Davis, 2011, 2012, 2014). Within this work, which took place between 2009 and 2012, Davis leaves aside the etiological, ethical and other issues surrounding the desire to be disabled. Instead, she focuses upon how, within the transabled.org community, 'transableism' manages to emerge as a highly distinct experience and a shared identity with which the members of the forum collectively align (2012, 2014). Davis outlines the way in which this is achieved through, what she describes, as a process of collective ‘narrative construction’. As she observes, four common themes underlie the majority of the content posted to the forum; these include (1) highlighting early childhood memories of wanting to be disabled, (2) painting a detailed picture of the ‘correct’ body, (3) grappling with ‘why’ these desires to be disabled exist, and, (4) finally accepting that they are indicative of the condition of transableism (the latter two points Davis terms ‘denial/surrender stories’) (2012, pp. 327-328). Not only do these themes work to initially describe transableism but, furthermore, once solidified, they define and delineate it by forming an implicit script towards which both older members and newcomers alike must adhere to in order to be accepted and verified as a transabled person (Davis, 2012). In other words, the members of transabled.org collectively bring their transabled identity into being through their writing, reading and re-writing of their own and others’ experiences.

In having observed the iterative and collaborative nature of this collective identity construction, Davis then pushes the analysis further by suggesting that it can be described as a type of ‘identity prosumption’ (2011). The term ‘prosumption’ is one that Davis borrows from work in other arenas (Ritzer & Jurgenson, 2010; Toffler, 1980). In its original use, prosumption refers to ‘the blurring of production and consumption’ (Davis, 2011, p. 596) that occurs under contemporary forms of capitalism. As theorists here note, the traditional distinctions upheld between these two processes can, increasingly, be thought of as false as, more and more commonly, products are produced by their consumers (Ritzer & Jurgenson, 2010; Toffler, 1980). Davis, in extending this notion, notes that, whilst the term ‘prosumption’ usefully dissolves the binary between production and consumption, to its detriment, it continues to assume that the prosumer of content and the content being prosumed are separate. As she describes, in a great deal of instances, this is not the case but, instead, ‘prosumption applies not only to things and information but to the identities signified through them’; she thus coins the notion of ‘identity prosumption’ (2011, p. 598). In applying this concept to her analysis of transableism, Davis suggests that, by producing and consuming the forum’s content, the members of transabled.org are additionally engaged in the collective prosumption of their own transabled identities as signified through that content. As Davis additionally notes, this a process which is largely made possible by the material realties of transabled.org, in that its content, as characteristic of many Web 2.0 sites, is fully user-generated (‘user-generated content’ being a quite literal description of ‘prosumption’) (2011).

A final point which Davis observes is the way in which the members of transabled.org utilise their collectively constructed identity for the purposes of lay advocacy. As she highlights, when interacting with the medical community, who at the time were still unsure of transableism, alongside the general public, who were largely condemnatory of it, the members emphasise the ‘lack of choice’ which underpins their collective experience of transableism. This notion is reinforced by the four transabled identity themes discussed above, namely early childhood memories, detailed pictures of the ‘correct’ body, and ‘denial/surrender stories’ (2012). By emphasising this lack of choice, Davis outlines how the members of transabled.org are able to position transableism as innate and presumably biologically rooted. This discourse is then mobilised to support the medicalisation of their condition, via the proposed BIID diagnosis, and its inclusion in the DSM (2014).

Although not studying transabled.org directly, a number of philosophy scholars studied the more general online forums surrounding the desire to become disabled in the late 90s and early 2000s. Similarly to Davis, these theorists were interested in the online community aspects of this phenomenon. Of particular relevance is the work of bioethicist Carl Elliott, who was interested in whether, in the early 2000s, both the growing popularity and the change in conceptualisation surrounding the desire to be disabled might be connected to the emergence of the internet and the specific dynamics of online communities (2000, 2003). As Elliott notes, groups formed around a shared illness have long existed across cultures; these communities are nothing new and have always enabled ‘stigmatised’[20] individuals to gain solidarity, provide each other with the reassurance of normality, and affirm each other’s identities (2003). He outlines the way in which online communities, whilst sharing similarities with these older groups, have two fundamental differences that can be seen to significantly

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[20] Elliottt utilises the notion of stigma as made famous by the sociologist Erving Goffman (Goffman, 1963). For Goffman a ‘stigma’ is a ‘deeply discrediting attribute’ (1963, p. 12) held by an individual, judged as such in relation to a discrepancy between societal norms of appearance and behaviour and the ‘actuality’ of one’s self (1963, pp. 12-18).

augment these original processes. Firstly, the internet, by enabling dispersed individuals to come together, allows those with particularly rare disorders to connect in ways never seen before. Alongside this, online communities, by offering anonymity, provide stigmatised individuals with the benefits of solidarity and identity affirmation, without the risk of shame or self-exposure. As Elliott remarks, prior to the internet, those wanting to be disabled might have briefly entertained these thoughts, only to have them 'wither away or take another form' (2003, p. 218). However, in the early 2000s, the specific online community processes discussed above could be seen to shape and nourish these desires, solidifying them with the individual's sense of self. As Elliott concludes, these novel processes played a fundamental role in both the increase in prevalence of the desire to be disabled in the early 2000s, alongside its redefinition as a phenomenon of incongruous identity.

Two other philosophers- Louis Charland (2003) and Mitch Parsell (2008)- also studied the more general online forums surrounding the desire to become disabled and separately reached similar conclusions to those drawn by Elliott regarding the unique role of the internet in popularising the desire to become disabled in the early 2000s. These theorists, however, offer further insight by highlighting specific technologies and social processes. To begin with, alongside remarking how the internet enabled dispersed individuals to connect, they both describe the additional role played by the types of Web 2.0 forums available at this time. As they note, these platforms were free and open for anyone to set up, thus expanding and democratising the range of possibilities for community making. Once these forums were established, Parsell additionally notes how groups gathered on them could then tightly police their boundaries by enforcing group norms, restricting membership and 'deliberately banning dissenting voices' (2008, p. 43). Further to this, as Charland describes, these groups often restricted discussion solely to the illness in question, at the expense of other more varied identity signifiers which might broaden or level the conversation. As Parsell additionally outlines, this restricted discussion could then be further aggravated by the very nature of computer mediated communication (CMC), given that, unlike 'face-to-face' communication, CMC inherently obscures indicators of individual difference, leading those interacting with one another to overemphasise their shared characteristics and sameness (2008). Charland

(2004) also highlights how the overly intimate and emotional nature of these interactions could enhance this process to an even greater extent. Consequently, both Charland and Parsell describe not only the range of community possibilities these forums allowed, but also, paradoxically, their potential to forge extremely 'narrowcast' and 'polarised' groups (Parsell, 2008, p. 44), in ways that would have been inconceivable prior to the internet. Although Charland's and Parsell's work is theoretical, both authors hypothesise on how all of the above processes might have been responsible for augmenting and solidifying narrowly delineated experiences and identities, as found within the online forums surrounding the desire to become disabled in the early 2000s. Charland draws parallels with this and similar processes as observed within online anorexia, multiple personality disorder and borderline personality disorder communities of the time.

Whilst placing the same importance as Davis upon online community processes in the development of a collective disability desire experience, and reaching similar conclusions regarding the development of collective identity within these groups, the philosophical work of Elliott, Parsell and Charland was notably more critical. As these theorists observed, collective identification could be seen to happen to such a degree within these environments that it had the potential to make the desire to become disabled a permanent feature of the self, where it might not have been under differing circumstances. As is described, this 'pernicious over-identification' (Parsell, 2008, p. 45) often came at the expense of the mental health of the individual, alongside their physical safety (given the self and elective amputation attempts recorded at the time). These three philosophers were also critical of the impacts of these collective community identities on the medical community at the time. Whilst, as previously highlighted, Davis takes a neutral, or even supportive, stance regarding the members of transabled.org's advocacy efforts, Elliott, Charland and Parsell problematize the influence of lay collective identity on medical processes. They highlight how the medicalisation of the desire to be disabled (including its formalisation into a diagnosis and symptom profile) might lead an increasing number of vulnerable individuals to identify with this phenomenon, to the detriment of their wellbeing, and society more broadly. Charland, again, draws parallels with online anorexia, multiple personality disorder and borderline personality disorder communities, highlighting how the lay advocacy efforts of these groups have, at times, enabled dangerous and harmful types of patient autonomy (2004).

Whilst the philosophical approaches differ from Davis' sociological work in their assessment of the harms of online disability desire communities, the body of work discussed in this section is united by the fact that, unlike the clinical literature outlined in the previous section, it gives due seriousness to online communities and lay advocacy efforts, situating them as central to the growth and spread of the desire to be disabled in the early 2000s. Taking this one step further, as discussed in **Chapter 1**, Elliott and Charland, when studying communities surrounding the desire to be disabled in the early 2000s, both suggested that the new wave of this phenomenon might be understood through reference to Hacking's ecological niche of transient mental illness model (Charland, 2004; Elliott, 2003). As part of this, these authors suggested that their observations regarding online communities, as outlined above, might be a significant factor comprising this proposed niche. Whilst neither Charland nor Elliott carried out empirical research to test their assertions, their observations strongly support the claims I made in the previous section regarding online community dynamics and lay advocacy efforts being relevant, overlooked factors comprising the ecological niche of transableism.

Although broadly supporting claims regarding the need to investigate online community dynamics, the body of literature discussed within this section doesn't quite go far enough and it remains insufficient regarding explorations into the emergence and disappearance of transableism for one crucial reason. Nowhere within this work is the role of influential individuals acknowledged. All of the sociological and philosophical theorists, when discussing 'collective' experiences and identities, situate the construction of such phenomenon as a collaborative process; there is an assumption that all members of the communities in question were equally and democratically involved in identity 'prosumption'. Similarly, all theorists, regardless of whether they viewed medical advocacy as neutral or harmful, appeared to assume that it was carried out equally, by 'the community' as a monolith. Any hierarchies or power dynamics which may have existed, both in terms of intra and extra-community processes, were overlooked. When it comes to Charland and Elliott, the reason for these oversights can, in all likelihood, be seen as related to the fact that neither of these theorists engaged in empirical research, as outlined above. The reasons why Davis might have overlooked the role played by influential individuals are discussed in more depth within **Chapter 4**, where they are used to justify the methods chosen for this project.

Regardless of reason, oversights regarding influential individuals are especially significant when it comes to the ecological niche approach to transableism as a transient mental illness. As discussed in **Chapter 1**, the transabled community emerged out of Sean's solo authored blog. Throughout its existence, the community remained under Sean's exclusive ownership and moderation; Sean was also widely acknowledged by the rest of the group as the leader of the transabled movement, the authority on transableism knowledge and the community's lay advocacy spokesperson. Assessments regarding the collaborative and democratic nature of online communities, including lay advocacy groups, are not uncommon within the literature and dominate much of the early research into online communities (Day and Keyes, 2008; Leibing, 2009; Malik & Coulsen, 2008; Rich, 2006). Crucially, however, there is also an emerging body of work which critiques these views, instead drawing attention to how the power vested within online community owners and moderators can significantly influence the types of identities and agendas which exist within these spaces (Coulson & Shaw, 2013; Grimmelmann, 2015; Squirrel, 2019). Following this, I suggest that, not only online community dynamics but, more specifically, the role played by influential individuals within such communities is a relevant, overlooked factor comprising the ecological niche of transableism warranting further enquiry. In subsequent chapters I engage in this enquiry. Before this, however, I critically review some additional themes developed within the sociological and philosophical literature surrounding the desire to be disabled.

Sociological and philosophical explorations into the desire to be disabled: Cultural and historical factors

In addition to exploring the online community aspects of the new wave of the desire to be disabled, the body of sociological and philosophical work outlined above also examined how this phenomenon could be seen to draw upon and reflect wider cultural discourses and values. This exploration is particularly evident within Elliott's work, which examines online forums surrounding the desire to become disabled, their increased popularity in the early 2000s and the language of selfhood and authenticity, which appeared to, increasingly, surround this phenomenon (2003). In order to understand this change in conceptualisation, Elliott situates it within the context of his larger body of work that explores the influence of cultural and market forces on medicine and health in contemporary Western society and, specifically, examines the ethics of ‘enhancement technologies’ (2003). When he talks of ‘enhancement technologies’, Elliott discusses a number of things, including anti-depressants, cosmetic surgeries, gender reassignment surgeries, Viagra, psychological therapies and diet and exercise regimes. As Elliott outlines, these practices, whilst seemingly variant can, nevertheless, be seen as crucially connected through the language of authenticity that underpins them and the promise of self-fulfilment they appear to offer. He, for example, outlines how individuals describe being ‘incomplete’ without cosmetic surgery and state that they are ‘not themselves’ when they are not on Prozac. In order to explain this, Elliott outlines in depth the particular historical and cultural context surrounding notions of authenticity and self-fulfilment, with a view towards revealing how it enables and justifies these practices.

As Elliott notes, within the late 19th century, there was a fundamental shift in society; prior to this time, one’s position in life was pre-determined by factors such as religion, family and class and, in association with this, successes and failures were measured in accordance with the expectations of these institutions (2003). However, with the advent of modernity, these institutions could be seen to break down, resulting in individuals being faced with the task of shaping their own identities and defining their own standards of accomplishment. As such, by the mid-20th century, individuals were left with a sense of meaninglessness and alienation that led to a state of great existential anxiety (2003)[21]. Elliott notes how, in order to fix these problems, the solution, within contemporary Western society, has seemingly been to turn ‘the self’ into a project, wherein finding ones authentic identity becomes both an existential goal and a moral obligation (2003). As Elliott

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[21] Elliott draws upon the work of numerous theorists to variously articulate these points regarding modernity, the break down in traditional institutions, authenticity and the pressure to shape self-identity. These theorists include Charles Taylor (1992) and Joan Jacobs-Brumburg (Brumberg, 1998). Beyond Elliott’s analysis, a number of other theorists have also discussed this shift (Beck, 1992; Castells, 1996, 1997; Giddens, 1991)). Giddens for example describes how under ‘late-modernity’, individuals are faced with an influx of choice over things such as career, family, romantic relationships, hobbies and location. This leads to an intensification in the analysis of one’s life-choices and a continual and ongoing reflexivity regarding one’s self-identity (1991).

outlines, this combination of beliefs very aptly lays the ground for the development of enhancement technologies, in that any number of apparently undesirable attributes can be labelled as incongruent to our sense of who we are and, furthermore, altering these attributes can be situated, not only as desirable, but ethically justifiable (2003). In noticing an almost identical use of the language of identity within online disability desire communities, Elliott thus situated this phenomenon upon the broader continuum of enhancement technologies, suggesting that it expressed a similarly 'ambivalent moral ideal' regarding authenticity and self-fulfilment, unique to our historical, cultural and economic moment (2003).

Davis' qualitative study of transabled.org, drew upon and agreed with many of Elliott's observations, noting how, within the last 200 years, self-discovery (knowing who you are) and self-actualisation (living out that sense of yourself) have come to occupy an almost sacred moral space within the Western world (see also Gewirth, 1998; Taylor, 1989, 1992; Trilling, 1972). In applying these observations to transabled.org, Davis describes how the members of the forum make use of these notions not only to articulate their experiences but also to position transableism as morally neutral, thus countering accusations to the contrary (2014). By articulating their desires to become disabled in terms of a refusal to accept their current state of incongruous embodiment, the members of transabled.org present transableism, not as a bizarre or perverse quirk, but, instead, as a 'noble quest for identity verification' (Davis, 2014, p. 446).

In addition to supporting Elliott's observations, Davis then takes the analysis one step further by analysing how the members transabled.org could be seen to combine the discourse of authenticity with an additional culturally and historically specific notion; namely that of transgenderism and Gender Identity Disorder (GID). Thus, in addition to situating their desire to be disabled as a need for self-actualisation, the members of transabled.org compare this experience to the quest for gender authenticity, as pursued by those with GID.

This comparison, as made by the members of transabled.org, is one that implicitly relies upon the naturalisation of transgender and GID as categories, alongside the understandings upon which these categories depend- namely that biological sex and gender identity are distinct and separate phenomenon which, as a result of their distinctness, can be incongruent within a single individual. Although Davis doesn’t explore the naturalisation of transgender and GID in depth within her work, this is done elsewhere. As numerous other theorists have examined, understandings surrounding transgender and GID are not a-cultural, a-historical ‘facts’ but, instead, are the product of a complex combination of various medical, sexological and political processes (Brubaker, 2016; Meyerowitz, 1980; Valentine, 2014).

As is noted within the body of work which deconstructs and historicises transgenderism, individuals expressing a sense of discomfort with their anatomical sex and related roles have been reported in the medical literature since the middle of the 19th century. Within this period, however, these individuals were largely understood to be suffering from a type of sexual perversion or pathology and were categorised alongside homosexuality, bisexuality and other so-called fetishisms of the time (Meyerowitz, 1980). From the late 1940s, these understandings slowly began to change. This change was heralded by Harry Benjamin, an endocrinologist and sexologist (often termed ‘the father of transsexualism’) who, following encounters with patients experiencing discomfort with their sex roles, began, in 1949, to provide hormone treatments to such individuals (Reicherzer, 2008). In 1952, Benjamin went on to provide the first sex-reassignment surgery on a patient whom he described as 'a woman kept in the body of a man', thereon coining the term transsexualism (the pre-fix trans, meaning ‘on the other side of’, thus intending to capture the phenomenon of sex role discomfort and discordance experienced within the sexed body) (Reicherzer, 2008). In 1966, Benjamin published ‘The Transsexual Phenomenon’, the first text which made a clear attempt to delineate transsexualism from homosexuality and associated sexual phenomenon (Benjamin, 1966; Reicherzer, 2008). Shortly following this, John Hopkins University, began providing surgical treatments to transsexuals in larger numbers (Reicherzer, 2008).

Lending crucial support to Benjamin’s research into transsexualism- and to the notion of sex-gender incongruence, which would soon become an accepted understanding- was the work of controversial[22] psychologist- and future researcher into apotemnophilia[23]- John Money. During his work with intersex individuals, Money theorised that we all possess a ‘gender role’, independent of our biological sex. Here, gender role refers to a phenomenon, constituted by one’s subjective sense of ‘identity’, alongside societal sex-based behavioral norms, preferences and stereotypes (Money, Hampson & Hampson, 1955). As Money outlined in his work, there are six factors which typical co-occur and can be used to identify someone’s sex (including assigned sex/sex of rearing, external genital morphology, internal reproductive structures, hormonal and secondary sex characteristics, gonadal sex, and chromosomal sex (Money, Hampson & Hampson, 1955)). However, when these factors do not all align (as is the case for intersex individuals), Money then suggested that ‘gender role’ was a useful seventh factor for determining how an infant should be raised. It was thus this notion of socially constructed and subjective gender identity, as distinct from biological sex (a notion which, prior to this time, was not conceived of), which gave final shape to our current naturalized understandings of gender-sex dysphoria, and the associated medical categories of transsexualism and GID (now termed transgenderism and Gender Dysphoria respectively) (Meyerowitz, 1980). These understandings were further solidified by 1960s feminist politics, which strategically insisted upon the distinction between sex and gender, alongside successful transgender and homosexual rights movements which grew in popularity and influence from the 1980s onwards (Brubaker, 2016a; Valentine, 2014).

Returning to Davis’ analysis, as she highlights, by comparing their quest for authenticity with transgenderism- a specific historical and cultural category which is, nonetheless, naturalised so as to emerge as an institutionally recognised ‘fact’- the members of transabled.org add further support to their claims that

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[22] Money was involved in the infamous controversy regarding the involuntary sex-reassignment of David Reimer, a natal male child who- under Money’s guidance- was raised female following a botched circumcision which irrevocably damaged his penis (Diamond & Sigmundson, 1997).

[23] Apotemnophilia- from the Greek meaning ‘amputee-love’- was the term given to individuals expressing a desire to amputate their own limbs, as studied by Money in the 1970s, and outlined in a previous section of this chapter (Money, 1977).

transableism should be medicalised via the proposed BIID diagnosis which, as previously noted, was created as a parallel to GID (2014).

Whilst both Elliott and Davis' work is insightful for the way in which, unlike the other research into the desire to be disabled, it locates this phenomenon within its cultural and historical context, their observations regarding authenticity contain one fundamental oversight. Although focusing upon how the desire to be disabled drew upon discourses of authenticity and trans-ness, both authors overlook how, within the local context, these discourses intersected with disability. This oversight is particularly pertinent when it comes to examining the emergence and disappearance of transableism for several reasons. Firstly, as discussed in the introductory chapter (**Chapter 1**), the defining characteristic of transableism was a sense that one's inner authentic identity was meant to be disabled. Further to this, not only did the members of transabled.org want to be disabled, but they did so in a highly specific way, namely by being a paraplegic or an amputee. Finally, the members of transabled.org, not only attempted to locate their need to be disabled as a medical issue to be termed BIID but, furthermore, they attempted to situate this diagnosis as a 'disability like any other' (their words). That neither Elliott nor Davis explored how, for the members of transabled.org, disability emerged as a category of authentic identity, why authentic disability was predominantly associated with paraplegia and amputation or how such claims to BIID as an authentic disability were constructed and negotiated reveals that their analysis of the connections between authenticity and transableism can be pushed significantly further. In other words, whilst Elliott and Davis' work reveals the ways in which historically specific discourses of authenticity and categories of trans-ness comprised the ecological niche of transableism, they do not explore the equally historically specific understandings of disability as a similarly constitutive part of this niche.

Elliott and Davis' oversights appear to have arisen for a number of reasons. Firstly, both authors treat disability, not as culturally and historically informed, thus demanding the same type of critical attention as authenticity, but, rather, as something natural, self-evident and thus in need of no explicit deconstruction. Further to this, both authors also appear to treat authenticity as a predominantly individual existential feeling, thus neglecting to examine the ways in which it can be socially constructed or negotiated. Whilst neither Elliott nor Davis locate understandings surrounding disability within their cultural and historical content, there is a large body of literature, from within the field of disability studies, which does. This body of work explores the history of disability, the shifting understandings surrounding it, and the ways in which recent conceptualisations revolve around notions of authenticity versus inauthenticity (Berger, 2013; Brohan, Slade, Clement, & Thornicroft, 2010; Davis, 2005; Mills, 2017; Wendell, 2011). Furthermore, and whilst neither Elliott nor Davis discusses authenticity as a constructed or negotiated phenomenon, the socially constructed nature of authenticity is broadly explored in many other arenas (Cohen, 1988; Conklin, 1997; Sissons, 2005). With this body of literature, the objective nature of authenticity, including its existential use, is problematised and, instead, authenticity is described as something which can be contingent, negotiated, emergent over time and, as a result, subject to 'authenticity politics' (Sissons, 2005). Following the above described observations, I suggest that culturally and historically specific understandings surrounding so-called authentic disability, alongside processes involving the social construction of authenticity, are both significant factors comprising the ecological niche of transableism, warranting further enquiry. Thus, alongside online health advocacy community dynamics (as drawn attention to in previous sections), the following chapter (**Chapter 3**) explores literature on disability and authenticity.

Summary

In this chapter I have mapped the terrain surrounding the desire to become disabled and have drawn three key observations. My first observation was related to the fact that whilst the most recent research surrounding the desire to become disabled acknowledged the influence of online communities on the 'new wave' of this phenomenon, the impact of this, both in terms of community dynamics and lay advocacy efforts, was not adequately explored. My second observation emerged from a review of the sociological and philosophical literature surrounding the desire to be disabled. It outlined how whilst this literature addresses the dynamics of online communities in more depth, this analysis remained insufficient in that it situated transabled identity as emerging out of a process of 'collective construction', thus ignoring the influence of Sean, as community leader and lay advocacy spokesperson. My third key observation relates to the fact that although transableism drew upon modern Western notions of authenticity and self-actualisation, the topical sociological and philosophical studies did not explore how authenticity intersected with disability in the case of transableism and BIID. In line with the ecological niche approach to transient mental illness, which advocates identifying potential gaps in knowledge in existing understandings surrounding a condition, three factors drawn from these observations- (1) disability (2) authenticity and (3) online health advocacy communities- have been identified as elements which may have contributed towards the transableism ecological niche. Before examining these elements in conjunction with the empirical material, the following chapter (**Chapter 3**) first explores the broader literature surrounding disability, authenticity and online health advocacy communities.

Chapter 3

A review of the literature surrounding disability, authenticity and online communities

Introduction

An ecological niche is a term used to describe the ways in which transient mental illnesses are able to flourish when a wide variety social and cultural factors temporarily come together to form a stable home for the condition in question (Hacking, 1998). Identification of an ecological niche is thus used to answer the question of why a transient mental illness might have emerged at a given time. Relatedly, identifying aspects of an ecological niche which disappeared or weakened can be used to explain why a condition was no longer able to flourish, subsequently disappearing (Hacking, 1998). A useful starting point for identifying the broad range of factors constitutive of a transient mental illness's niche, lies within reviewing existing understandings of the condition in question, alongside highlighting potential gaps in knowledge and missed connections (Hacking, 1998). In the previous chapter (**Chapter 2**), this was done in relation to transableism; 3 undertheorized factors relating to transableism's niche were identified which, broadly, can be categorised as (1) disability, (2) authenticity and (3) online health advocacy communities. Before exploring these three factors as they directly relate to the empirical material, this chapter presents a broad overview of the academic literatures related to each in turn. Here, I review existing research, theories and conceptual approaches relating to disability, authenticity and online health advocacy communities. This is done so as to assess which existing contributions lend themselves well to theorising themes of disability, authenticity and online health advocacy communities, specifically as they relate to the ecological niche of transableism and its related emergence and disappearance.

By assessing and selecting relevant existing contributions, this chapter lays the groundwork for the empirical chapters in part 2 of this thesis (**Chapters 5, 6, 7 and 8**). To this end, each section of this chapter, after assessing existing literature, presents a conceptual framework which underpins a subsequent empirical chapter or chapters. The section on disability builds a conceptual framework based on the ‘cultural polarity’ (Hacking, 1998) of authentic versus inauthentic disability; this is used in **Chapter 5** to analyse the members of transabled.orgs’ experiences of disability and their understandings of transableism. The section on authenticity builds a conceptual framework, based on the social construction and negotiation of authenticity and an associated ‘politics of authenticity’ (Sissons, 2005); this is used in **Chapter 6** to analyse how the members of transabled.org attempted to situate BIID as a ‘disability like any other’ (their words) and the challenges they faced in doing so. The section on online health advocacy communities builds a conceptual framework based on moderation practices within online environments; this is used in **Chapters 7 and 8** to underpin an analysis of Sean’s influence on transableism, both within transabled.org and, externally, in relation to the medical community. The structure of this thesis is such that, within the current chapter, a broad overview of the above described conceptual frameworks is presented, alongside justification for their use in subsequent empirical chapters. Then, within each of the related empirical chapters, these frameworks are discussed in greater detail, and more in-depth insights and examples related to them are used for comparison with the data from transabled.org.

Disability

Introduction

Davis, in her work on transabled.org, examined how the members utilised culturally contextual understandings surrounding authenticity to construct transabled identity and resist moral stigma (2011, 2012, 2014). Elliott explored almost identical themes in his work on the more general online communities surrounding the desire to become disabled (2003). What neither of these theorists did, however, was explore how notions of authenticity intersected with disability. In the previous chapter (**Chapter 2**), these oversights were identified as particularly pertinent regarding explorations into the ecological niche of transableism given that the defining characteristic of this condition was a sense that one’s inner authentic identity was meant to be, not only disabled, but disabled in a specific way, namely by being a paraplegic or an amputee. Following this, culturally and historically specific understandings surrounding so-called authentic disability was identified as a relevant factor comprising the transableism ecological niche, warranting further enquiry. This section engages in such an enquiry by exploring the history of disability, the shifting understandings surrounding it, the ways in which different forms of disability have come to be associated with notions of authenticity versus inauthenticity, and the relevance of these notions regarding explorations into transableism.

The medical model of disability

Although nowadays, relatively nuanced understandings of disability and disabled identity exist, this was not always the case. Historically, disability was understood through what is termed 'the medical model': a framework which defined disability in terms of essential biological and physiological characteristics, thus situating the disabled body as an issue of individual abnormality and deficiency (Bingham, Clarke, Michielsens, & Van de Meer, 2004, Marks, 2000; Palmer & Hardey, 2012). Given that, under this model, disability was conflated with deficiency, goals were targeted towards eradiation, rehabilitation and cure (Bingham, Clarke, Michielsens, & Van de Meer, 2004; Marks, 2000; Oliver, 1990). Those who did not want to be 'cured' or who resisted treatment, were interpreted as uncompliant and 'rule-flouting' (Oliver 1990) or as displaying a distorted lack of acceptance (Swain & French, 2000). In addition, under the medical model, it was the diagnosis, rather than the needs of the individual, that determined access to services and resources (Haegele & Hodge, 2016). Effects of the medical model included the association of disability with dependence (Oliver, 1990), abnormality (Morris, 1991) and personal tragedy (Swain & French, 2000). Stigma, a sociological concept first explored by Goffman, is strongly linked to medical conceptualisations of disability (1963). Within his work, Goffman described the ways in which individuals with visibly discrediting 'stigma symbols' (such as disabled bodies or disability aids) worked to conceal these signals in order to attempt to 'pass' as 'normal' (Goffman, 1963). Perhaps most significantly, by problematising and stigmatising the individual, the medical model allowed social structures, cultural attitudes and material infrastructures to remain unproblematised.

The social model of disability

In the 1980s, understandings surrounding disability underwent a stark social, political and conceptual re-orientation. This re-orientation largely arose as a result of what is now termed 'the social model of disability'; a concept formulated as a critical alternative to the medical model (Oliver, 1990). Contrary to the medical model, the social model of disability draws attention to the ways in which negative and exclusionary social and structural arrangements actually ‘disable’ bodies which are merely physically ‘impaired’ (Oliver, 1990). One of the key contributions of the social model was to distinguish between the terms ‘disability’ and ‘impairment’ in this way. This distinction was intended to highlight the idea that there is nothing inherently wrong with impairment, it being ‘nothing less than a description of the physical body’ (Oliver, 1990, p. 35). Conversely, much was wrong with disability, or ‘disablement’, in that, being exclusively the result of society, it was oppressive and discriminatory.

The social model had its origins in the disability rights movements and was devised by non-academic activists (Shakespeare, 2006). Later, however, it was taken up within academia (Barnes, Mercer & Shakespeare, 1999; Davis, 2002; Oliver, 1990); both of these applications can be seen to have had profound and far reaching effects. To begin with, by redefining disability as a societal, rather than individual, issue, the social model drew attention to the need to dismantle disabling socio-structural barriers through political reform (Haegele & Hodge, 2016). One of the most significant results of this was the introduction of the Americans with Disabilities Act (ADA) which was passed in 1990 (with comparative acts soon following in other Western countries[24]). Paralleling the Civil Rights Act of 1964, the ADA made discrimination based on disability illegal. It also mandated that employers provide accommodations for employees with disabilities and required public services to make modifications so as to ensure disabled access (ADA, 1990).

In addition to the structural adjustments brought about by the ADA, the social model of disability encouraged academic enquiry into disability and scholars began to deconstruct and challenge, not only structural arrangements, but attitudes, norms and ableist ideologies (Barnes, Mercer & Shakespeare, 1999; Oliver, 1990). A positive change in the cultural conceptualisation surrounding disability was also noted, and theorists examined the ways in which disability aids

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[24] Comparative acts to the ADA include the UK Disability Discrimination Act (DDA) passed in 1995, the Australian Disability Discrimination Act (DDA) passed in 1992 and the Canadians with Disabilities Act (CDA) passed in 1995 (United Nations, 2019).

(previously stigma symbols, as described above) became reinterpreted as liberating, enabling and, even, glamourous and high-tech (Sapey, Stuart, & Donaldson, 2005; Woods & Watson, 2004). As a cause and consequence of these shifts, physically impaired individuals began to come together to form social and political groups. In using the social model to draw attention to their shared experiences of exclusion and oppression, these groups, for the first time in history, started to redefine disability; consequently it emerged as a valid and positive minority identity, rather than an ill to be automatically denigrated or corrected (Barnes, Mercer & Shakespeare, 1999; Oliver, 1990).

Critiques of the social model

Despite the many positive outcomes of the social model of disability, a number of criticisms have been levelled at it. These criticisms have highlighted the ways in which, by completely reducing disability to a matter of social construction, the social model 'exiles' the body from critical enquiry (Hughes & Paterson, 1997), leaving a number of significant factors undertheorized. These factors include the ways in which the body can also be socially constructed, and thus how impairment can be worsened by oppressive structures (Hughes & Paterson, 1997; Morris, 1991; Swain & Cameron, 1999). To exemplify, Hughes & Paterson (1997) outline how socio-cultural meanings are placed upon physical elements of the body; this can work to situate visible signs of deformity as negative, thus excluding those who possess them from certain spheres of social life. Related to this, the social model also overlooks how disability often intersects with other embodied and socially constructed oppressions including gender (Morris, 1991, 1996; Thomas, 1999; Wendel, 1996), race (Borthwick, 1996; Morris, 1991), sexuality (Shakespeare, Gillespie-Sells, & Davis, 1996) and socio-economic status (Abberley, 1997; Charmaz, 1997) (see also Haegele & Hodge, 2016 and Marks, 1999 on the intersection of oppression). Finally, by exiling the body, the social model has been accused of leaving the phenomenological, often inherently disabling, reality of impairment significantly under-examined. Scholars have, for instance, drawn attention to how factors such as chronic pain, depression, secondary health effects, fatigue and ageing are often ignored by the social model (Charmaz, 1997; Hughes & Paterson, 1997, Wendel 1996, 2001).

In extending these criticisms, scholars have not only outlined how the social model fails to acknowledge the body and impairment; they have also described reasons for this oversight (Tichkosky, 2003; Wendell, 1996, 2001). Wendell, in particular, does this by outlining two categories of disabled person, ‘the healthy disabled’ and the ‘unhealthy disabled’. As she puts it, the healthy disabled are:

> ‘people whose physical conditions and functional limitations are relatively stable and predictable for the foreseeable future…they do not expect to die any sooner than any other healthy person their age, and they do not need or seek much more medical attention than other healthy people’ (2001, p. 19).

These individuals are economically and socially productive, and otherwise ‘able’ (see also Tichkosky, 2003). By contrast, the ‘unhealthy disabled’ are people with chronic illnesses who are ‘sick, diseased, ill…and suffering’ (Wendell, 2001, p. 18). Often these people experience inherently debilitating impairments, in ways that are unpredictable, fluctuating, severely life-limiting and without clear medical diagnosis; examples include fibromyalgia, chronic fatigue syndrome, chronic pain, multiple chemical sensitivity, rheumatoid arthritis and mental health conditions such as depression (Wendell, 2001, see also Register on ‘the interminably ill’ (1987) and Greco (2017) on medically unexplained symptoms). The unhealthy disabled are also more likely to be those who experience other embodied oppressions, most particularly socio-economic and gendered. Significantly, these individuals are often immensely limited and are commonly unable to participate in social or economic activities (Shakespeare, 2005). This is richly explicated in the work of Charmaz (1991) who describes the many social, personal and economic impacts on the lives of women- often single and working class- who experience chronic pain.

After describing the categories of healthy and unhealthy disabled, Wendell notes how the first disability activists and advocates of the social model almost exclusively fell into the category of healthy disabled; they were white, male, middle-class men with physical, highly visible, stable impairments (see also Berger, 2013; Davis, 2005; Patterson & Hughes, 1999). These individuals served to benefit from the changes demanded by the social model which focused upon physical and structural adjustments at the expense of adjustments that were more likely required by the unhealthy disabled (see for instance Patterson and Hughes and the need for a ‘critical politics of time’ to take account of the fluctuating nature of chronic illness (1999, p. 605). See also Charmaz (1997) in support of the need to consider time and illness). Furthermore, the healthy disabled could effectively convey the notion that, should structural adjustments be made, then disabled people would be just as capable as participating in society and contributing towards the economy (Tichkosky, 2003; Wendell, 1999, 2001). By contrast, the unhealthy disabled, being physically and psychologically debilitated by their impairments, stood in contradiction to the social model’s critique of the idea that disability was a deficit to be intervened upon and cured (Shakespeare, 2005; Wendell, 2001). Furthermore, they did not fit the image of disability as productive, deserving and unproblematic; on the contrary, because of the chronic nature of their disabilities, they were seen to drain resources (Tichkosky, 2003; Wendell, 1999, 2001).

Because of these factors, Wendell describes the ways in which healthy disabled activists could be seen to actively distance themselves from the unhealthy disabled in order to effectively change conceptualisations surrounding disability and achieve their accessibility goals (2001). As she writes:

> ‘there (was) a danger that acknowledging th(e) facts (of unhealthy disability) might provide support for those who prefer the individualized, medicalised picture of disability. Thus, in promoting the liberatory vision of social constructionism, it (was) safer and more comfortable for disability activism to focus on people who (were) healthy disabled’ (2001, pp. 18-19).

Unintended consequences of the social model: Authentic versus inauthentic disability

By excluding the unhealthy disabled from activism, the social model and its advocates have not only been accused of overlooking the needs of the unhealthy but, furthermore, of inadvertently creating a paradigmatic and permissible image of disability: ‘a young man in a wheelchair who is fit, never ill, and whose only need is a physically accessible environment’ (Morris, 2001, p. 9). This paradigmatic image is noted to have had profound and far reaching effects. Not only were accessibility policies structured according to this paradigm, thus making the world more accessible for the healthy disabled but, beyond this, this paradigmatic image could be seen to inform broader socio-cultural understanding surrounding what constituted ‘real’ or ‘authentic’ disability (Wendell, 2001).

For example, following structural adjustments, in 1981 the symbol of a stick person in a wheelchair was adopted as the International Symbol of Access (Stone, 1995) and was used to indicate resources for disabled persons (Ben-Mosche & Powell, 2007; Courvant, 1999; Marusek, 2005). The result of this was such that, as Marusek notes, the wheelchair (both on signs and as used by a person) became ‘the semiotic of disability’ (2005, p. 179). This reinforced the idea ‘that disability necessarily entails sitting in a wheelchair’ (Stone, 1995, p. 417) and that one is ‘not ‘really’ disabled unless the disability is visible, especially through an assistive device’ (Ben-Mosche & Powell, 2007, p. 500). This notion was further reinforced by the cultural representations of disability which began to appear at that time. As theorists note, these representations were almost exclusively based upon healthy impairments such as spinal cord injuries and amputations, and associated technologies such as wheelchairs and prosthetic limbs, thus solidifying the idea that these were the only ‘real’ types of impairments (Howe, 2011). Finally, not only were understandings surrounding authentic disability described as occurring within symbolic and cultural arenas, but also within legal and institutional settings. As described, the ADA (and similar acts) mandated that structural adjustments be made within the workplace and public sphere, so as to ensue physical accessibility. Beyond this, authors have also noted how the very notion of disability as visible is engrained within the ADA. As Marusek highlights, the ‘fundamental nature of the ADA’s definition of disability…relies on the visual representation of the wheelchair’ given that, one of its criteria for disability includes ‘*being regarded* as having an impairment’ (ADA quoted on Marusek, 2005, p. 179 emphasis my own). This association can also be found within the US medical arena, wherein access to healthcare and benefits is granted based upon a code which, in itself, requires a tangible diagnosis (Dumit, 2006). In an extension of this discussion to the UK context, Roulstone (2015) examines the ways in which assessments for Employment Support Allowance (ESA) and Personal Independent Payment (PIP) are also informed by assumptions surrounding the physicality of impairment and the semiotics of visibility.

Inevitably, this association of authentic disability with highly visible, physical impairments is described as having a detrimental effect on those with unhealthy disabilities. Not only does this association overlook these individuals but, furthermore, it posits them as inauthentic. Wendell, in describing this phenomenon, writes:

> ‘having our disabilities recognised as genuine is a major issue for many unhealthy disabled people…people wonder whether someone whose disability is not obvious is faking or exaggerating it; the trustworthiness of people who claim to be disabled but do not look disabled is always in question’ (2001, p. 29).

Doubts concerning the inauthenticity of the unhealthy disabled, including accusations of fraudulence, have been described as occurring in multiple arenas, including the workplace (Charmaz, 1997; Vickers, 2000; Young 2000) education environments (Jung, 2002) and medical settings (Dumit, 2006; Jung, 2002). Many authors also note the ways in which members of the public can now be seen to police the use of disabled resources, especially parking spaces. As Ben-Mosche and Powell note, ‘disabled people who do not use a chair…are policed when they park in accessible parking marked by the International Symbol of Access (ISA) to ensure that they are indeed ‘sufficiently’ disabled to claim the benefit’ (2007, p. 500, see also Marusek, 2005; Mills, 2017). This policing of disability has also been noted within disabled communities themselves. Deal (2003), Evans (2017) and Humphrey (2000) describe disabled communities where membership requires a ‘real’ disability, which is assumed to be ‘physical, immutable and tangible’, at the exclusion of invisible, fluctuating conditions (Humphrey, 2000, p. 69). The above concerns with inauthenticity have been variously described as related to worries over the secondary gains associated with malingering (Dumit, 2006), the desire to internally police minority group identification (Deal, 2003), a concern to restrict access to limited financial resources (Deal, 2003; Ben-Mosche & Powell, 2007; Marusek, 2005) and ‘a politics of resentment’ (where able-bodied employers and workers resent having to provide accommodations in what is perceived as positive discrimination) (Young, 2000).

What is commonly deduced from examinations into accusations of inauthenticity, is that disability stigma has changed since Goffman's descriptions of it in the 1960s (1963). Authors are now beginning to argue that, rather than declining or disappearing with the advent of the social model, disability stigma has instead shifted onto the unhealthy disabled and has evolved so that it is intertwined with notions of inauthenticity (Brohan, Slade, Clement, & Thornicroft, 2010; Davis, 2005; Mills, 2017). For example, as Hughes (2015) notes, invisible disabilities are increasingly attacked and scapegoated in media and cultural representations, where they are framed as counterfeit and fraudulent. Furthermore, this new inauthenticity stigma doesn't exist in a vacuum but, as this section has traced, it is fundamentally upheld by its polar opposite: the representation and valorisation of physical, visible disabilities as authentic. This new type of stigma has been described as hugely detrimental, not only in terms of the judgement and policing it provokes, but also for the way in which it allows those deemed inauthentically disabled to be denied access to rights, resources, community and legitimacy, all of which is acknowledged as materially, socially and psychologically harmful (Stone, 2005; Wendell, 2000).

Following this acknowledgment of harm, authors have begun to note strategies utilised by the unhealthy disabled, to manage inauthenticity stigma. A number of authors have described the ways in which individuals engage in acts of 'revealing' (Stone, 2005) or 'un/covering' (Evans, 2017). These terms refer to verbal disclosures, intended to draw attention to and seek help for a hidden disability (Davis, 2005). Additionally, authors have described the ways in which 'revealing' is done through what Siebers calls 'the disability masquerade'; this term refers to the ways in which individuals 'disguise one kind of disability with another or display their disability by exaggerating it' (2004, p. 4). Often this takes place through the strategic use of disability aids, notably wheelchairs, which are not entirely or consistently necessary (Renfrow, 2004; Siebers, 2004). Renfrow (2004) terms these acts 'aligning moves' wherein one 'explicitly displays social markers consistent with a particular identity' (2004, p. 495).

Acts of revealing, un/covering and masquerading have, in some instances, been described as useful and empowering in that they enable disabled people to communicate information, preserve energy, and engage in political action (Lindemann, 2008; Siebers, 2004). Much more frequently, however, they are described as harmful. They place a high burden of 'proof' on the disabled individual (Davis, 2005) and cause them great anxiety (Siebers, 2004; Stone, 2005; Vickers, 2000). Alongside this, Siebers notes the ways in which the masquerade, whilst making disability more visible, can also, paradoxically, make the individual (socially) invisible, given the way in which society still also denigrates those with obvious impairments. Finally, these acts have been critiqued for the ways in which they replicate ableist ideology and power, in that they require disability to be reduced to essentialist stereotypes in order to be accepted by the able-bodied majority (Lindemann, 2008; Siebers, 2004).

Authentic versus inauthentic disability: A cultural polarity

Thus far in this section I have explored the changing cultural and historical conceptualisations of disability, outlining how current understandings are structured around a binary of authentic versus inauthentic disability. Despite this shift occurring in the late 80s and early 90s, just prior to the emergence of transableism, the question of how this binary might have influenced transableism is not addressed anywhere within previous research into this condition. In the remainder of this section, I highlight how this thesis responds to this oversight by outlining a novel conceptual framework, to be used in a subsequent empirical chapter (**Chapter 5**), which combines the binary of authentic versus inauthentic disability with a concept specifically used by Hacking in his analysis of transient mental illnesses, namely the notion of a 'cultural polarity' (Hacking, 1998).

In order to theorise transient mental illnesses, Hacking notes how these phenomenon owe their existence not only to an ecological niche; more specifically, Hacking outlines how transient mental illnesses can be seen to represent core oppositional tensions or what he terms 'cultural polarities' within societies (1998). In his later work, Hacking outlines the centrality of relevant cultural polarities in constituting the ecological niche of a transient mental illness (1998). As he describes it, there are often two versions 'of the same thing' within a culture, one largely approved of and held up as 'virtuous', one disapproved of and considered a 'vice' (1998, p. 81). The particular group of people affected by a transient mental illness are united, often by markers such as class or gender but, more specifically, by the fact that they are caught between these two opposing yet intertwined values, an experience which is socially oppressive and disenfranchising. Hacking locates two factors which can be seen to give a transient mental illness its salience at a particular cultural and historical moment. The first is the way in which the illness embeds itself within a cultural polarity, expressing the unspoken tensions which exist at its intersection (1998). The second is the way in which the illness, whilst being unpleasant, nevertheless provides sufferers with a socially sanctioned way of gaining relief from the pain of being caught up in a cultural polarity; Hacking terms this 'release', a label resonant, although not identical, with the more broadly known 'sick role' (Parsons, 1951)[25]. To explicate the above by returning to the example of transient mental illness given in **Chapter 1**- namely dissociative fugue: Hacking situates the tension in cultural values surrounding travel which existed in France at the time as fugue's constituting cultural polarity. These tensions were crystallised within concerns over criminal vagrancy amongst the impoverished classes versus the new trend for tourism amongst the middle classes. Related, Hacking notes that fugue states enabled working class servicemen (who were neither vagrant criminals nor afforded the luxuries of the middle class) to access a sanctioned release from the struggles and drudgeries of military service (1998).

Given the culturally and historically specific binary of authentic versus inauthentic disability which emerged just prior to the emergence of transableism, I take this to be the cultural polarity which was vitally constitutive of the transableism ecological niche and through which explorations into the emergence and disappearance of this condition can be grounded. As noted in **Chapter 1**, the disabilities that the members of transabled.org desired (largely amputations and paraplegia with a focus on wheelchair use), conformed to the descriptions and stereotypes outlined above regarding authentic disability. The combination of the two ideas outlined in this section- the disability binary and cultural polarity- is thus

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[25] The sick role is a term coined by Parsons (1951); it refers to the way in which being ill enables individuals a socially sanctioned withdrawal from regular social duties, alongside giving them access to privileges such as care and attention. Sick role theory is strongly resonant with Hacking's notion of release. Where the terms differ, however, is that the sick role refers to the generalised catharsis experienced by withdrawing from social life via any type of illness, whereas release refers to a directly related remedy for a specific cultural tension, as manifest in the transient mental illness.

used in **Chapter 5**, as a framework through which to analyse the reasons behind and implications of the members of transabled.org's desired disabilities. Here I explore, not only the members' understandings surrounding what constituted authentic disability but also their experiences with inauthentic disability, and the ways in which both of these things expressed a broader cultural polarity and, ultimately, informed the emergence of transableism.

Authenticity

Introduction

In the previous section, I discussed how, as a result of various historical, social and political factors, specific understandings surrounding what constituted both authentic and inauthentic disability emerged in the 1980s and 90s. As outlined, these understandings were highly dependent upon institutional and cultural definitions, symbols and representations. These contextual and contingent understandings surrounding what counts as authentic are not unique to disability; indeed the socially constructed nature of authenticity is broadly explored in many other arenas, including health, illness and diagnosis (Cohen, 1988; Greco, 2012; Nettleton, 2006; Sissions, 2005). With this body of literature (which will be reviewed in this section) the objective nature of authenticity is problematised and, instead, authenticity is described as something which can be contingent, negotiated, emergent over time and, as a result, subject to 'authenticity politics' (Sissons, 2005). In the previous chapter (**Chapter 2**) I outlined how, whilst existing research into transableism centred on authenticity as an analytical concept, it exclusively studied how the desire to 'feel authentic' acted as a motivating force for the members of transabled.org. This focus on authenticity, as an existential and objectivist phenomenon, has come at the expense of exploring the ways in which understandings surrounding authenticity might be socially constructed, negotiated and subject to authenticity politics. When it comes to exploring the ecological niche of transableism, these oversights were identified as significant given that the members of transabled.org, not only described needing to be disabled, but, furthermore, attempted to construct and situate the proposed medical diagnosis of BIID as a 'disability like any other' (their words), a process which was challenged by the disability community. Following this, in **Chapter 2** processes surrounding the social construction and negotiation of authenticity - particularly in relation to health and illness- were identified as relevant factors comprising the transableism ecological niche, thus warranting further enquiry. This section carries out this enquiry by reviewing the literature on the socially constructed, negotiated and political aspects of authenticity - including authentic diagnosis- and the relevance of these notions regarding explorations into transableism.

Objectivist authenticity

Before exploring the social constructivist approach to authenticity, it is necessary to provide some context as to where this approach emerged from, namely out of a critique of existential, objectivist understandings of authenticity. Davis and Elliott are not alone in approaching authenticity as if it were an exclusively objectivist property. Indeed, as discussed in the previous chapter (**Chapter 2**) they draw their analyses from much pre-existing work within the social sciences (Berger, 1973; Giddens, 1991; Lindholm, 2008; Taylor, 1991) and Western philosophy (Heidegger, 1996; Sartre, 2003). Within these disciplines, scholars have long studied how individuals feel and act in ways they determine to be authentic (or 'true to oneself') (Vannini & Franzese, 2008). Here, the feeling of being authentic is situated as either present or absent, and is placed in a binary alongside its constituting other: feeling inauthentic (a disconcerting emotional experience of being 'untrue' to oneself) (Sartre, 2003; Vannini & Franzese, 2008). Beyond enquiries into individual experiences, these either/or understandings of authenticity and inauthenticity have also long been inherent within the study of cultural and aesthetic objects and non-Western nations, tribes and identities (Jones, 2012), alongside clinical understandings of disease and illness (Foucault, 1963). Enquiries into the authenticity of objects, groups and identities are described as rooted in modernity, where the advent of scientific reasoning led to the assumption that every object or group of people was a 'fixed and bounded entity with a unique individual character and internal essence' (Jones, 2012, p. 187). Relatedly, the question of whether a group or object 'was what it purported to be' became important (2012, p. 187) and multiple scientific practices designed to evaluate and measure the apparent authenticity of an object, artefact or non-Western group were designed. Within the realm of disease and illness, modernity and the emergence of positivist science similarly created the belief that pathologies were discrete and bounded. As such, clinical goals and medical practices were likewise oriented towards accurately discovering, labelling and classifying pathology (Greco, 2012; Foucault, 1963).

Whilst seemingly disparate, both the body of work which looks at individual existential authenticity and that which assesses the authenticity of objects, groups and pathologies views authenticity as an absolute, bounded and objectivist property, which can be truthfully determined and distinguished from inauthenticity. Although these bodies of work have been widely influential, infiltrating both academic and general understandings regarding the objectivist nature of authenticity, in the late 1980s, they began to be contested. Following what is known as the ‘crisis of representation’ (Marcus & Fischer, 1986)[26] within the social sciences, scholars began to critically examine the types of practices and ideas used to evaluate authenticity, as discussed above. Here attention was drawn to the ways in which these practices, whilst ostensibly being neutral measurements, actually worked to construct authenticity and bring it into being (Jones, 2012; Sissons, 2005). Relatedly, the contextual and contingent nature of authenticity was also highlighted. Following these observations, the social construction of authenticity itself became a subject of enquiry.

In the following section, I outline social constructivist approaches to authenticity. Although these approaches emerged in response to the objectivist categorisation practices found within museum studies - and are thus rooted in the associated fields of tourism and post-colonial studies (Sissons, 2005) – the social construction of authenticity has been implicitly applied within medical sociological and sociology of diagnosis literature (Dumit, 2006; Nettleton, 2006). As such, in the section which follows, I begin by briefly outlining the tourism and post-colonial literature where studies into the social construction of authenticity were developed; here I describe the key processes and concepts advanced in this body of work, namely the social construction and negotiation of authenticity (Cohen, 1988), indexes and semiotics of authenticity (Culler, 1990), authenticity politics, and oppressive authenticity (Sissons, 2005). After providing this

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[26] The crisis of representation refers to a broad movement in the social sciences in the 1980s wherein previously taken for granted ways of representing culture, based upon positivist theories, were contested. The crisis arose from the realisation that no theory or account could ever adequately represent reality, being that reality was subjective and socially constructed (Marcus & Fischer, 1986).

foundation and introduction to key concepts, I then place this literature alongside medical sociological literature. This is done in order to demonstrate how, within the medical sociological literature, socially constructivist approaches to authenticity (and the associated key concepts) are implicitly applied, particularly within the realm of medically unexplained, undiagnosed or contested illnesses as, at the time, BIID was (Dumit, 2006; Greco, 2012; Nettleton, 2006). By bringing these two bodies of literature together, my intention is to bring processes of authentic diagnostic negotiation into alignment with explicit social constructivist approaches to authenticity. By doing so, I pave the way for socially constructivist approaches to authenticity (including the associated concepts of authenticity semiotics, authenticity politics and oppressive authenticity) to be used, in subsequent chapters, to theorise the members' of transabled.orgs attempts to construct and negotiate diagnostic authenticity in relation to BIID.

Social constructivist approaches to authenticity: Origins and key concepts

Broadly, social constructivist theory is a critique of the assumptions inherent in objectivism which imply that a real world exists, independent of human language and activity. Instead social constructivists describe reality as emerging 'in practice' (Mol, 2002) and as dependent upon context, intersubjective setting, and networks of social and material relations (Jones, 2012; Wang 1999). Enquiries into the social construction of authenticity have their origins in the sub-discipline of tourism studies (Bruner, 1994; Cohen, 1998; Wang, 1999). Interest in authenticity within this field is described as inevitable, given that tourism inherently involves encounters with unknown objects, events and persons (Cohen, 1979). Within this field, scholars have, in line with broader social constructivist approaches (outlined above), objected to the notion that the authenticity of touristic objects and encounters can be truthfully determined; instead, they suggest that we should study the ways in which practices, contexts, settings, relationships and systems of meaning, produce and 'negotiate' authenticity so that it successfully 'emerges', within certain tourist interactions (Cohen, 1988). A number of factors have been highlighted as relevant concerning the negotiation and emergence of authenticity within tourism. These include the judgements, experiences and feelings of the tourist (Bruner, 1994; Cohen, 1988), the location or context in which a touristic object is encountered (Salamone, 1997), the web of social relations and interactions which occur there (Olsen, 2002; Wherry, 2006), and various signs or symbols of meaning which come to stand in for various aspects of a culture; Culler terms such signs ‘the semiotics of authenticity’ or ‘authenticity indexes’ (Culler, 1990).

One of the most significant contributions to come out of the field of tourism studies is that, through exploring authenticity from a social constructivist perspective, this body of work both examines the processes through which authenticity emerges and problematises them. As is commonly highlighted within this literature, what emerges as authentic is often a question of power. As Bruner (1989) notes, often ‘authenticity refers to duly authorised, certified, or legally valid’ and thus ‘the issue of authenticity merges into the notion of authority’ (1989, p. 400). Furthermore, the authority to authenticate touristic objects and events, alongside the identities of those living in tourist locations, frequently resides, not with locals, but with professionals and scholars (Bruner, 1989; Cohen & Cohen, 2012; Jones, 2010), tourist agencies and guides (Silver, 1993), certifying bodies (Cook, 2010) nation states (Hobsbawm & Ranger, 1992), and tourists themselves (Urry, 1990). This process is described as particularly problematic in relation to the cultural identities of those living in tourist locations. Here theorists describe the way in which authorising bodies (e.g. travel agencies) represent so-called authentic local identities in reductionist and stereotypical ways so as to appeal to the Western tourist’s projections, in the service of monetary gain (Silver, 1993). Given that host populations are often significantly economically dependent upon the industry of tourism, they are commonly unable to challenge or negotiate the ways in which they are depicted and often ‘have no choice but to present themselves according to romanticised imagery’ (Silver, 1993, p. 310).

Whilst, as mentioned above, socially constructivist approaches to authenticity were pioneered within tourism studies, the problematisation of power regarding the representation of cultural identity has expanded beyond this discipline, influencing associated arenas such as anthropological, post-colonial and indigenous studies. Echoing the tourism literature, this body of work has drawn critical attention to the ways in which historical colonial and national discourses worked to essentialise so-called authentic indigenous identities, often by reducing them to characteristics deemed ‘natural’ or ‘traditional’, aspects which were placed in binary opposition to understandings surrounding Western civilisation (Sissons, 2005). Within the post-colonial context, these representations are further complicated by the fact that historical understandings surrounding authentic identity are, more recently, used to inform the allocation of rights, resources and protections by non-governmental organisations (NGOs), local, and international governments (Conklin, 1997; Harris, Carlson and Poata-Smith, 2005; Sissons, 2005). The result of this is that, similarly to their discussion in the tourism literature, groups and individuals often have no choice but to 'negotiate' their authenticity by 'performing' or 'indexing' it according to essentialist understandings and imageries. Sissons (2005) calls this 'oppressive authenticity'. In providing an example of such oppressive authenticity in practice, Conklin (1997) outlines how Amazonian Indian tribes present themselves with things such as body paint and feathers (narrow Western stereotypes relating to their identities) when interacting with NGOs so as to receive official certification, thus being granted access to rights and material resources (Conklin, 1997). Similar to as is described in the tourism literature, this institutional requirement to index authenticity has resulted in a type of 'authenticity politics' emerging, wherein claims to authenticity, alongside the boundaries which determine such claims, are tightly policed by those in power in the service of gatekeeping scare resources. As an inevitable outcome of this, those who do not correctly enact a particular depiction of authentic identity are deemed inauthentic and thus denied provisions, further evidencing the oppressive effect of authenticity politics (Conklin, 1997; Sissons, 2005).

Social constructivist approaches to authenticity: Negotiating diagnoses

Whilst the above described theories regarding the construction and negotiation of authenticity might, at first, seem disconnected to the study of transableism, other disciplines, more obviously relevant to transableism, can be seen to have borrowed from the ideas developed within tourism and post-colonial studies. For example, whilst not explicitly situating it as a process of authenticity construction and negotiation, a similar process to that described in the tourism and post-colonial literature has been noted to take place in relation to medical diagnoses. This is especially the case when it comes to undiagnosed, contested or otherwise medically unexplained symptoms and syndromes (Nettleton, 2006).

To provide some context, the terms medical unexplained symptoms and/or syndromes are used to capture health phenomenon within Western medicine which have no identifiable organic basis and thus cannot by diagnosed by standard medical tests (Greco, 2012; Nettleton, 2006). Contested illness is an associated label which describes the unagreed upon and/or challenged diagnoses applied to such symptoms and syndromes. Examples of these types of phenomenon include myalgic encephalomyelitism (ME), multiple chemical sensitivity, chronic fatigue syndrome, endometriosis and irritable bowel syndrome (Greco, 2006; Nettleton, 2012). Medically unexplained and contested illnesses, whilst not having an organic basis, are characterised in terms of their, often varying and inconsistent, symptoms. As a result of the unknown variance of medically unexplained and contested illnesses, scientists and doctors fail to agree upon an aetiology and pathogenesis; this leaves such conditions lacking the status of official or 'legitimate' illness (Nettleton, 2006). The effect of this illegitimate status on individuals suffering with such illnesses is described as profound; scholars note how sufferers have to live with an ongoing sense of embodied uncertainty and liminality, alongside having to manage accusations of inauthenticity (Dumit, 2006; Nettleton, 2006). In attempts to overcome uncertainty, liminality and illegitimacy, scholars have described how, when interacting with doctors and social care providers, sufferers of medically unexplained and contested illnesses strategically perform plausible suffering and patienthood, alongside negotiating desired diagnoses and treatments (Dumit, 2006; Nettleton, 2006; Whelan, 2010). Whilst not explicitly interpreting these processes through the lens of a social constructivist approach to authenticity, within these diagnostic manoeuvres, extremely similar processes to those described within the tourism and post-colonial literature regarding the negotiation of authentic identity, can be identified.

For example, Nettleton (2006) outlines how, prior to interactions with doctors, sufferers of medically unexplained or contested illnesses often engage in considerable 'information work' to try and ascertain what is wrong with them; this involves searching through books and medical research and going online to seek advice from peers. The results of this information work are then taken to doctors in attempts to appear informed and credible, alongside being knowledgeable enough to suggest particular diagnoses be applied (Nettleton, 2006). Dumit

(2006) nicely illustrates this in his work on individuals with chronic fatigue syndrome (CFS) and multiple chemical sensitivity (MCS). As he notes, sufferers of these conditions, thoroughly research and then keep detailed logs of the elements of their illnesses which conform to existing scientific research. These logs are then presented to doctors as a means through which to demonstrate the legitimacy of what might otherwise be considered a random, disparate or exaggerated profile of symptoms (Dumit, 2006). De Graaff and Broer (2012) outline a similar process of strategic interaction between patients with electohypersensitivity (EHS) and their doctors, as does Whelan (2007) regarding endometriosis sufferers.

What makes the examples from the sociology of diagnosis literature particularly resonate with those described in tourism and post-colonial approaches regarding the negotiation of authenticity is the stakes involved. Without an official diagnosis, patients are described as unable to access treatments and material rights such as disability benefits (Dumit, 2006; Trundle, Singh & Broer, 2014), or social rights including occupation of the sick role (Nettleton, 2006; Parsons, 1951) and legitimation of identity claims (Lipson, 2004). As Nettleton (2006) outlines, sufferers of medically unexplained or contested illnesses are often dismissed with psychological explanations for their suffering; this can serve to further exacerbate stigma and heighten the sense of being ostracised from the sick role and the associated status of authentic illness sufferer.

Further to this, a lack of diagnosis- which can be interpreted as a failure of the individual to index the authenticity of the condition in question- results in accusations of inauthenticity, again, similar to those outlined within the post-colonial literatures. Accusations of inauthenticity in relation to diagnosis are described as having painful consequences. Whelan (2007), for example, notes the ways in which failure to acquire an endometriosis diagnosis can leave a woman open to accusations of psychological weakness or delusion. This is echoed in the work of both Nettleton (2006) and May (2000) who describe the shame and judgment associated with psychological or somatic explanations for, what are experienced as, physical conditions. All three theorists note how the application of psychological explanations can additionally provoke suspicions regarding malingering (see also Dumit, 2006).

Because of the severe impacts and consequences associated with a lack of diagnosis, within the medical sociological literature, authors have drawn attention to the ways in which, similarly to as discussed within the tourism and post-colonial literature, individuals often present their experiences according to narrow institutionalised representations, often at the expense of nuance. For example, Whelan (2007) describes the ways in which accounts of endometriosis which do not fit with medical definitions are excluded in patient accounts in the service of securing a diagnostic authenticity. Similarly, Werner, Isaksen and Malterud (2004) note how women with chronic back pain carefully and selectively narrativize their experiences according to normative, biomedical expectations of what illness is and how it should be performed, alongside how a 'legitimate' sufferer should present. Whilst enabling them to be treated with credibility by doctors, the processes described by Werner, Isaksen and Malterud, similarly to as Whelan outlines, work to obscure or misrepresent the reality of the illness experience.

Regardless of whether they occur in relation to cultural identity or diagnostic category, all of the above described processes regarding negotiating, indexing and aligning with the semiotics of authenticity to acquire authorisation and rights, can offer insight to the analysis of transableism. As mentioned previously, whilst existing research into transableism centred objectivist understandings of authenticity, socially constructed authenticity on transabled.org was not explored. In **Chapter 6**, I draw upon the social constructivist approaches to authenticity- which have been explicitly used in tourism and post-colonial studies and implicitly applied within the sociology of diagnosis literature- to examine the ways in which the members of transabled.org attempted to construct and negotiate the status of BIID as a legitimate mental health condition and authentic 'disability like any other' (their words).

Authenticity politics

Before proceeding with the final section of this chapter (which reviews online health advocacy community literature), one final, relevant process regarding the social construction of authenticity is examined. Whilst the majority of the tourism and post-colonial literature explores the way in which authenticity is monitored from the top-down by those in power, another body of work explores how authenticity politics are policed from the bottom-up, at the lay community level (Brubaker, 2016a, 2016b). Where this work is particularly interesting (and, indeed, relevant to transableism), is in relation to trans identity claims, wherein attempts are made, not just to enter an identity category from the margins of it but, instead, to cross a more substantial boundary. A particularly insightful examination of this phenomenon comes from Rogers Brubaker (2016a, 2016b) who studied Rachel Dolezal, a woman who made headlines in 2015 when, after presenting as African American for a number of decades, was ‘outed’ as Caucasian. In her defence, Dolezal claimed that she ‘identified as black’ and described herself as ‘transracial’ (McGreal, 2015; Sunderland, 2015). As Brubaker notes in his work, this prompted widespread outrage from the African American community who unequivocally rejected the notion of transracialism. In examining the reasons behind this rejection in more depth, Brubaker compares the treatment of Dolezal with the increasingly mainstream acceptance of transgender identity claims. As he notes, the reason Dolezal’s identity claims were rejected, whereas claims to various gender identities commonly are not, can be explained via reference to the differing culturally and historically contingent understandings surrounding gendered versus racial identities, and thus the differing types of ‘authenticity politics’ which exist for each (Brubaker, 2016a).

As Brubaker notes, gender identity is today largely understood as a subjective individual property[27]. This means that claims to a gendered identity other than that associated with biological sex are largely seen as legitimate and not subject to authenticity politics and policing[28]. On the contrary, as Brubaker goes on to outline, racial identity is understood in essentialist terms. This is due to its historical association with biogenetic and genealogical classification practices, as informed by histories of enslavement, oppression and discrimination, all of which

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[27] The product of a complex combination of various medical and political histories and discourses including sexological work which has separated sex from gender, feminist politics which has also insisted on this separation and successful trans and homosexual rights movements (Brubaker, 2016a; Valentine, 2014).

[28] Of course, some resistance to claims that gender identity is distinct from biological sex do exist, including from the conservative right, religious groups and radical feminists. Brubaker does acknowledge this; however, his argument is formulated on the basis that, within the mainstream majority, transgender identity claims are increasingly accepted (Brubaker, 2016a).

relied upon the so-called objectivity of race as a means of justification (2016a). As Brubaker describes it:

> 'racial identity is prevailingly understood as a supra-individual, social-relational phenomenon, not as a subjective individual property. (Whilst) this is compatible with a view of race as socially constructed…the prevailing mode of constructivism emphasizes the accumulated weight of others' ancestry-and phenotype-based classifications, not the constitutive significance of self-identification' (2016a, p. 435).

A result of this, and quite contrary to gender, subjectivist claims to a particular racial identity will, not only be rejected as illegitimate (subjectivity not being the grounds on which an authenticity politics of race is based) but, furthermore, they will be seen as fraudulent, threatening to those who legitimately occupy this identity and, thus, in need of policing. This was something that did, indeed, occur in the Dolezal case. When claiming to be black, Dolezal was accused by African Americans of appropriating the positive aspects of their culture for personal gain and occupying spaces and resources reserved for those with life-long experiences of marginalisation, all the while selectively ignoring the oppression and brutality associated with being African American (2016a). As Brubaker outlines, this was what lead her to be so widely discounted by the African American community who viewed her as threatening the integrity of their history and experiences, alongside their already limited rights and resources.

As discussed in **Chapter 1**, alongside constructing and negotiating the authenticity of BIID, the members of transabled.org also faced challenges to these claims from the disability community. These challenges had much in common with the bottom-up authenticity politics discussed by Brubaker regarding Rachel Dolezal and transracialism. As such, alongside exploring the members' attempts to socially construct the authenticity of BIID, the perspectives discussed within this section regarding authenticity politics are also used in **Chapter 6.** Here, I combine insights regarding the social construction of authenticity with insights regarding bottom-up authenticity politics in order to analyse, not only the members of transabled.org's attempts to position BIID as a 'disability like any other' (their words), but also the responses this elicited, and the significance of both of these things regarding the emergence and disappearance of transableism.

Online health advocacy communities

Introduction

Thus far in this chapter I have reviewed literature on disability and authenticity so as to respond to gaps in existing transableism scholarship, wherein the relevance of disability and authenticity, alongside their intersections, was not addressed. A third gap in existing transableism scholarship concerns online communities and, specifically, health advocacy communities. As discussed in the previous chapter (**Chapter 2**), extant transableism research did not examine how the clinical studies into this condition might have been influenced by online communities, neither did it explore how these communities might have been influenced by powerful individuals at the local level. Both of these elements- the significance of lay online communities and the importance of individuals within them- were, in the previous chapter (**Chapter 2**) identified as relevant factors comprising the transableism ecological niche, thus requiring further examination. This section carries out this examination by reviewing the literature on online health advocacy communities, including how this body of work has neglected an analysis of influential individuals (Day and Keyes, 2008; Leibing, 2009; Malik & Coulsen, 2008; Rich, 2006). Relatedly, more recent literature which does explore power and moderation practices within online communities, is also reviewed (Coulson & Shaw, 2013; Grimmelmann, 2015) and its relevance in relation to exploring the emergence and disappearance of transableism is discussed. Before going into depth on the online health advocacy and moderation literature, I contextualise these bodies of work by outlining the history and characteristics of online communities, and then the origins and characteristics of health advocacy communities.

Online communities: History and definition

The advent of the internet enabled the emergence of online communities. Since their existence, online communities have been a source of interest to scholars from a wide range of disciplines including social psychology (Blanchard, 2004; Putman, 2000; Turkle, 1995), information systems (Lee, Vogel, & Limayem, 2003), sociology (Baym, 2003; Rheingold, 1993) and anthropology (Boellstorff, 2008, 2012; Hine, 2000; Wilson & Peterson, 2002)). Rheingold was one of the first to study online communities from a sociological perspective and defines them as ‘webs of personal relationships in cyberspace’ (1993, p. 5). Aside from personal relationships, a number of other key characteristics of online communities have been noted. These include a uniting topic or interest, a shared space (e.g. a platform, blog or forum) and shared resources and support tools (Baym, 2003). These resources and support tools, alongside posts and messages, are permanently stored and catalogued upon the site, and there is an expectation that new community members will read these archives (Millen, 2000). These aspects are noted to contribute to the emergence of group norms, habits, routinized behaviours and a strong sense of collective identity (Baym, 2003). Community members can be ‘lurkers’ or regular contributors, they can come and go as they please or depart entirely should they wish to. Despite real names not commonly being used by regular contributors, the use of stable pseudonyms are noted to promote a comparable level of identity, reputation and accountability (Millen & Dray, 2000).

Online communities have been differentiated from social networking sites (SNS) such as Facebook, LinkedIn and Twitter (Baym, 2003, 2007; Ellison & boyd, 2013). SNSs began to grow in popularity around 2005 and, unlike online communities, their primary purpose is to create and maintain social relationships with an offline basis (Cirucci, 2017; Ellison & boyd, 2013). Unlike online communities, SNSs do not operate around a single shared environment or topic, they are non-anonymous and usually do not allow pseudonyms or digital personas, instead favouring ‘radical transparency’ (Mark Zuckerberg, chief executive officer of Facebook, quoted in Kirkpatrick, 2010, p. 209). All of these features mean that SNSs do not contain the strong group norms and collective identity so fundamental to online communities (Cirucci, 2017; Baym, 2007; Dugay, 2016).

As discussed in **Chapter 1**, transabled.org very much conformed to notions of online community, both by its own self-description and the above described academic definitions. Within the literature, however, online communities are further differentiating according to the shared topic, need or interest which constitutes them (Baym, 2003). One much studied example, relevant to transabled.org, is online health advocacy communities where individuals united by a common medical condition or illness experience, come together to form allegiances, share advice, and develop tools and resources for political and medical advocacy (Akrich, 2010; Leibing, 2009; Whelan, 2007).

Health advocacy communities: Origins and characteristics

Communities formed around a shared health condition have long been identified across history and culture (Turner, 1968). In the West in the 1990s, however, they could be seen to proliferate and take on a new characteristic, namely the emphasis placed, not only on a shared health condition, but a sense of collective identity based upon this. The development of this characteristic has been linked to the emergence of genetic technologies which, as Rabinow (1996) describes, brought about transformations in knowledge and new ways of collectively identifying based upon biological criteria.

A further attribute which has been associated with this new wave of health communities is the way in which they are characterised by political activism and an ability to intervene upon medical knowledge, which includes reformulating diagnostic boundaries, advocating for better cures and treatments and resisting stigma and pathologization (Brown et al., 2004; Leibing, 2009). Crucially, this process is described as enabled by the emerging collective identities within these communities. These collective identities facilitate the exchange of experiential and embodied knowledges (Whelan, 2007), which are then be used to shift epistemological authority from the realm of medicine to that of lay expertise (Leibing, 2009). Further to this, the existence of a collective identity is described as highlighting a sense of shared marginalisation, which further enhances the means of contesting medical authority. In describing this, Brown et al. write that collective and 'oppositional' health identity is formed around 'a common experience with government, medical and scientific institutions' wherein groups of individuals 'experience their conditions in ways that contradict scientific and medical explanations, and these contradictions are identified as a source of inequality' and a basis for political action (2004, p. 61). Various terminology has been used to describe these new communities and their bottom-up processes including, 'embodied health movements' (Brown et al., 2004), 'emergent concerned groups' (Callon & Rabeharisoa, 2008) and 'epistemological communities' (Akrich, 2010; Leibing, 2009; Whelan, 2007). For clarity, I refer to them as health advocacy communities.

Although health advocacy communities did exist prior to the internet, after its inception, they increased in even greater number and were 'supercharged' through the application of digital technologies, which enabled ever more dispersed populations to connect (Hagen, 2012). Since this recongition, a growing body of work has focused on exploring digital media and health advocacy communities, highlighting the ways in which the application of new technology can offer novel ways of connecting and sharing health and illness knowledge (Foster, 2016; Maslen & Lupton 2020; Phillips & Rees, 2017). Alongside health advocacy communities growing in number, the internet has also been described as contributing to an even greater sense of collective illness identity within them, further facilitating the community's ability to intervene upon scientific discourse and contest medical authority. Indeed, as Peterson, Schermuly and Anderson (2019) note, the application of digital technologies has profoundly altered the characteristics and goals of health advocacy communities, in that they are now closely aligned and mutually interactive with doctors, clinicians and pharmaceutical companies, in ways never seen before.

The greater sense of collective identity and closer alignment with doctors now found within online health advocacy communities has been attributed to many of the unique features of online communities, including the ways in which computer mediated communication enables individuals to obscure indicators of difference leading those interacting with one another, not only to overemphasise their shared characteristics but to build these into a coherent and credible experiential epistemology for use in advocacy (Whelan, 2007). As Schermuly, Peterson and Anderson (2020) additionally note, the unspoken, yet nevertheless extremely powerful, priority placed upon close, supportive relationships within online health communities, not only enables individuals to obscure differences, but indeed actively encourages and requires them to do so.

This process is further enhanced by online community practices such as restricting membership only to those with specific diagnoses, as well as silencing or banning dissenting accounts, lest these narratives dilute the group's emerging experiential epistemology. For example, Adler & Adler (2008), Giles (2006) and Whelan (2007) note the restricting of membership to those with relevant behaviours or diagnoses in communities surrounding self-harm, eating disorders and endometriosis, respectively; Giles (2006) and Charland (2005) note the banning of dissenting voices in eating disorder communities.

Structural features of online health communities, including archives of illness narratives, bibliographies (including links to medical research), fact sheets, frequently asked question (FAQ) pages and logs of key posts and concepts, are also described as enhancing the collective identification process whilst simultaneously enabling a bank of evidence to accumulate around a specific issue, which can then be brought to the attention of experts (Akrich, 2010; Leibing, 2009; Whelan, 2007). Akrich (2010), for example, describes this later process occurring in relation to episiotomy (the surgical incision of the perineum and conjoining vaginal wall) in online childbirth communities.

As discussed in **Chapter 1**, not only did transabled.org fit the definition of an online community but, due to its involvement in raising awareness of BIID and interacting with the medical community, it could also be categorised as a health advocacy community. In the following sections, I examine how online health advocacy communities have been studied within extant literature. Although this review does reference some of the newer health advocacy communities hosted on SNSs (e.g. post the 2005 growth and popularity of SNSs (Ellison & boyd, 2013)), it prioritises reviewing research into early Web 2.0 communities, more comparable (in structure, characteristics and ownership model) to transabled.org. In the following review of online health advocacy communities, I critique digital utopia approaches and introduce literature which examines power and moderation practices, thus being more relevant to studying the organisational structure on transabled.org.

Online communities as digital utopias

Since their emergence, online health advocacy communities, and indeed online communities in general, have been a source of much academic interest, particularly in the social sciences (Leibing, 2009; Powell, Daver & Gray, 2003; Walther & Boyd, 2002). In the beginning theorists could be seen to take rather a utopic view of online communities, seeing them as egalitarian spaces of creative and political possibility (Beer & Burrows, 2007; Benkler & Nissenbaum, 2006; O’Reilly, 2005). Scholars drew attention to the fact that the internet is a distributed network comprised of autonomous individuals, meaning that its organisational structure is intrinsically anti-bureaucratic and non-hierarchical, with democratically distributed relations of power (Castells, 2012; Dowding, Dunleavy, King & Margetts, 2016). Under this type of structure, individuals in online communities were said to voluntary 'gift' their participation for altruistic reasons (Benkler & Nissenbaum, 2006; Lampell & Bhalla, 2007; Wasko & Faraj, 2000). These equal, altruistic exchanges were said to give way to a new type of 'participatory culture' (Jenkins, 2006) within which users were involved in the collaborative creation of content and knowledge (sometimes termed 'peer-production' (Benkler & Nissenbaum, 2006)). This content and knowledge was not only described as socially embedded and collectively owned, but as a creative and subversive reaction to dominant norms and institutions (Beer & Burrows, 2007; Kollock, 1999; Wasko & Faraj, 2000). This view on collective knowledge production was extended to the area of identity, with the collective identities existing within online communities being similarly described as democratically produced and owned (Charland, 2005; Day & Keyes, 2008; Parsell, 2008; Rich, 2006). These collective identities were also situated as subversive in that they were said to challenge traditional forms of expertise, which includes the specific challenge to medical expertise. For example, Rich (2006) outlines how, within online anorexia communities, young women contest the pathologization and medicalisation of their illness, instead situating it as a type of adaptive social identity. Similarly, Davidson (2008) notes how, within online autism communities, the deficit model of autistic communication is contested and, instead, situated as a unique cultural variant.

As outlined in **Chapter 2**, it was this utopic view of online communities that was applied to the analysis of transabled.org in previous sociological research (Davis, 2011, 2012, 2014). However, as was also discussed in **Chapter 2**, the application of this utopic view crucially overlooked the role played by Sean as transabled.org founder, moderator and spokesperson to the medical community. Fortunately, there is a more recent body of work which has begun to critique the digital utopia view of online communities. This will be more useful for analysis of transabled.org and thus I turn to it now.

Power and moderation practices within online communities

Whilst being a popular and influential rhetoric (Beer & Burrows, 2007), the notion that online communities were digital utopias has, nevertheless, been critiqued (Schneider, 2021; Wilson & Peterson 2002; Zuboff, 2019). Critics contest the notion that online communities are democratic environments and draw attention to the power relations present within these environments which can be seen to shape and direct the knowledges and identities that exist there. The types of power relations discussed are varied. To begin with, theorists have highlighted how online communities often replicate or magnify hierarchies found offline (Smith & Kollock, 1999; Wilson & Peterson, 2002). The result of this is that, rather than participants engaging in egalitarian production and exchange, these processes are shaped by systemic inequalities and oppressive social categories, such as race or gender (Circucci, 2017; Lundmark & Normark, 2014). Power has also been examined as arising from inter-community dynamics themselves. Most commonly, attention has been drawn to how group norms and collective identities, rather than being subversive and collectively constructed, can instead be restrictive and oppressive (Watson, Peng & Lewis, 2019). Group norms can often work implicitly to discourage individuals from articulating experiences which run counter to agreed-upon community narratives. Furthermore, collective identities are noted to enable members to strictly police and sanction each others' behaviours and self-expressions (Adler & Adler, 2008; Charland, 2004; Giles, 2006; Parsell, 2008). For example Giles (2006) notes how, within online eating disorder communities, 'real' anorexic behaviour and identity is sharply distinguished from 'fake' attempts, with individuals who fall into the latter category facing community exclusion and ostracization (see also Boero & Pascoe, 2012 on a similar process regarding 'wannarexics').

In addition to these social factors, attention has also been drawn to the ways in which material and technological attributes can enact power in online environments. Building on disciplines such as science and technology studies (STS) and actor network theory (ANT), which situate agency as inherent to non-human actors within offline environments (Latour, 1996; Law, 1992), online theorists have similarly highlighted the agency contained in attributes such as algorithms and search engines (Ballatore, Graham, & Sen, 2017; Lash, 2006; Nettleton, Burrows & O'Malley, 2005), and the structure or features of webpages themselves (Davis, 2010; Ruppert, Law, & Savage, 2013). These authors have noted how the architecture of online communities encourages particular types of interactions, identifications and self-presentations, whilst disallowing others (Circucci, 2017; Davis, 2010; Duguay, 2016; Lundmark & Normark, 2014; Papacharissi, 2009). Papacharissi (2009) for example, describes how Facebook architecture encourages the sharing of personal information in a colloquial way; this is compared to the architectural affordances of LinkedIn, which offer much less opportunity for personal disclosure. Relatedly, Schneider (2021) describes the limited and unnegotiable architectures present on platforms such as Facebook and Reddit as

Whilst the above described literature largely situates power as an unintentional effect of particular social, structural or material arrangements, theorists have also examined the more intentional modes of control which exist in online communities. Of particular relevance to transabled.org, attention has been paid to the role of individual community moderators (Busch, 2011; Coulson & Shaw, 2013; Grimmelmann, 2015; Thompson & Round, 2016). Whilst moderation in online space can be external, commercial, algorithmic, or otherwise top-down (Gillespie, 2019; Roberts, 2019), in online communities (particularly smaller ones), it is commonly carried out from the bottom-up by specific community members, who are often also the owners of the sites in question (see Busch, 2011 for examples of this in online Buddhist communities, see Thompson & Round, 2016 for examples within an online book group).

Within this body of work, the role played by these individuals is commonly outlined as positive; moderators are described as vital to ensuring a welcoming community dynamic, to the extent that they foster cooperation and encourage participation between members (Coulson & Shaw, 2013; Grimmelmann, 2015). Moderation is also described as key to the success and longevity of the community, in that it protects against issues such as underuse, congestion, cacophony (too much of the same content) and abuse (e.g. harassment, spamming or trolling) (Grimmelmann, 2015). All of this is described as key to enabling a pleasant environment, within which coherent discourse can take place (Akrich & Meadel, 2012; Grimmelmann, 2015; Squirrel, 2019). The motives of online community moderators have also been described in positive terms and include being driven by a need to educate, connect with and give back to others

(Coulson & Shaw, 2013). As Seering and Wang note, moderators 'feel a strong commitment to their communities, deriving personal meaning from guiding them and helping them grow' (2019, p. 2). As is commonly described, the most successful moderation takes place when moderators hold these collectively focused goals, and thus respond to the needs and views of all the community's members. Squirrel (2019) terms the productive balance struck between maintaining coherence and responding to the needs of members the 'platform dialectic'.

In addition to these positive functions and motivations, online community moderation has also been discussed less favourably. The high degree of power possessed by moderators has been highlighted, with the view to emphasise how this power can be used to shape and direct the narratives of the community in question (Busch, 2011; Grimmelmann, 2015; Thomas & Round, 2016). Several theorists have described moderators as driven by their own ideological or political views, which can result in them manipulating content so as to push these agendas (Grimmelmann, 2015; Squirrel, 2019). In many instances, this exercise of power is described as extremely successful given that, as Grimmlemann notes, moderators 'influence what is seen, what is valued, what is said' (2015, p 45). As is also noted, this power and influence is further heightened if the moderator in question is also the owner of the website and platform (Grimmelmann, 2015).

The power and influence associated with online community moderation has been described as arising informally, through the social authority and status associated with being a moderator, and through more formal means, via the moderator's direct control over and management of the webpage's content, rules and infrastructure (Busch, 2011; Grimmelmann, 2015). These formal modes of control are enacted through various mechanisms, including exclusion (banning or withholding membership or deleting posts), organisation (categorisation, editing, filtering or annotating content towards a particular goal) and official norm-setting (through the use of tools such as FAQs, codes of conduct or 'new and noteworthy posts') (Grimmelmann, 2015). These mechanisms can be utilised both prior to social action taking place and after it; as Grimmelmann puts it 'moderators can act ex ante- using their power over the infrastructure to allow some actions and prohibit others- or they can act ex post- using their powers to punish evil doers and set right that which has gone wrong' (2015, p. 67). Whilst the general power and agency of online architecture was discussed above, within the moderation literature, this power is more explicitly connected to that of an individual. This is because, within smaller online communities, infrastructure is commonly designed and manged by a single moderator, who is often also the owner of the site in question (Grimmelmann, 2015). Schneider (2021) terms this top-down mode of social and architectural control, as found within online communities, 'implicit feudalism'. This term is intended to capture how online communities are, through their very technological design, intrinsically autocratic and hierarchical. For example, the templates available to set up online communities, rather than offering blank text fields for collective rule-making (as sites such as Wikipedia do), instead insist upon the use of structured rule-making interfaces, which are predetermined and singularly managed by a community leader. As Schneider notes, this arrangement results online communities becoming 'subject to a power structure that is absolute and unalterable by those who lack power' (2021, p. 3), 'power' here referring to the ability to change architectures and the rules and norms expressed through them.

A good example of the combined use of the above described moderation tactics can be found in the work of Busch (2011), who studied the online Buddhist community, E-Sangha. In her work Busch describes how moderators of the E-Sangha community use their positions to situate themselves as ideologically authoritative with regards to the Buddhist faith. This enables them to determine standards of 'correct' Buddhist practice and orthodoxy, which they then enshrine into official and unofficial community rules and norms. Through this, the boundaries of online Buddhist community membership and collective Buddhist identity are also determined.

Because of their high degree of power and status, online community moderators are often seen to be treated with deference, admiration and respect by other community members (Akrich & Meadel, 2012; Thompson & Round, 2016). This, however, is not always the case. Moderation has been described as a source of conflict, particularly when moderators are seen to be overly 'autocratic' or 'power-grabbing', or when their work becomes contradictory to the needs of the community (Busch, 2011; Squirrell, 2019; Thompson & Round, 2016). Returning to the example of E-Sangha, Busch notes how members of this community began to describe moderators as 'control freaks', criticising them for their 'lack of transparency' and for their running the community 'as a dictatorship' (2011, p. 68). Following this, as a number of theorists have highlighted, when conflicts over moderation occur, they can be hugely detrimental to the community; its common narrative can become incoherent, members may leave and, at times, the community fails entirely (Busch, 2011; Grimmelmann, 2015; Thompson & Round, 2016; Wanner, 2005). As Squirrel notes, 'moderators are subject to the risk that if they push their desires too hard then alienated users will go elsewhere' (2019, p. 14).

Although, increasingly, authors have drawn attention to the importance of studying individual moderators, with the view to challenging the assumption that online spaces are non-hierarchical, this is still noted to be an underdeveloped area of study in need of greater critical examination (Akrich & Meadel, 2012; McGillicuddy, Bernard, & Cranefield, 2016; Thompson & Round, 2016). This is particularly the case within online health advocacy communities, where there is a near absence of this examination (see Akrich & Meadel, 2012; Coulson & Shaw, 2013 for an examination of moderation practices in an online health support group, without a clear advocacy basis). This absence is doubly marked as, not only does it neglect to explore how online health advocacy community moderators might be influential in shaping collective illness identities, experiential epistemologies and communications with medical parties; it is also significant because the role of influential individuals is highlighted as important within some older offline health advocacy community scholarship. Within this body of work, attention has been drawn to the ways in which individual leaders or organisers can be seen to impact the success of the health advocacy group to the extent that they can demonstrate epistemological credibility, proficiency with scientific language and knowledge of existing medical research. In other words, leaders must be able to understand and fluidly move between the two social worlds of science vs experience, if they are to credibly challenge the former epistemology with the later (Brown, et al., 2004). Success of offline health advocacy communities has also been associated with the leader's ability to demonstrate social and cultural credibility so as to assist them in positioning themselves as meaningful representatives of the community at large, 'enrol(ing) supporters behind their claims (and) legitimating their arguments as authoritative when engaging with external parties' (Epstein, 1995, p. 411, when discussing the leaders of HIV and AIDS activist communities who were largely young, able-bodied, white, middle class, educated men, many of whom were doctors and lawyers. See also Scott, 1990 on a similar phenomenon amongst veterans advocating for the recognition of Post-Traumatic Stress Disorder (PTSD)).

Given, as I have been highlighting, the position of transabled.org as an online health advocacy community, alongside the overlooked role of Sean within this community in extant transableism literature, the above described insights regarding the significance of online community moderators have much to offer in relation to the aims of this thesis. As such, the conceptual framework- which highlights the significance of power dynamics within moderation practices- is used in **Chapters 7 and 8**. Here, the lens of moderation practices is used to underpin an analysis of Sean's influence on transableism (both within transabled.org and, externally, in relation to the medical community) including the ways in which this influence contributed towards the emergence and disappearance of transableism.

Summary

This chapter has built upon the previous chapter (**Chapter 2**) by reviewing literature related to gaps identified in extant transableism scholarship, focusing upon three areas (1) disability, (2) authenticity, and (3) online health advocacy communities. This chapter has presented a broad overview of these literatures in turn. This was done with the purpose of assessing which existing perspectives lend themselves well to theorising themes of disability, authenticity and online health advocacy communities, specifically as they relate to the ecological niche of transableism and its related emergence and disappearance. Three key frameworks were presented- (1) the cultural polarity (Hacking, 1998) of authentic versus inauthentic disability, (2) the social construction and negotiation of authenticity and an associated politics of authenticity (Sissons, 2005) and (3) moderation practices within online environments. These frameworks will be used to underpin analysis of empirical findings in **Chapters 5, 6, 7 and 8**, respectively. Before proceeding with the empirical chapters, however, the following chapter of this thesis (**Chapter 4**) outlines the methodology and methods adopted for this research enquiry.

Chapter 4

Digital ethnography: Methodology and methods

Introduction

Methodology is the philosophy and theoretical analysis of research methods. Methods are the tools used to conduct research (Schwandt, 2007). This chapter outlines the methodology and methods adopted for this research enquiry. The aim of this research was to explore the emergence and disappearance of transableism via application of Hacking's ecological niche of transient mental illness model (1998). In order to explore this aim and, congruent with this theoretical approach, this research took the form of digital ethnography on transabled.org.

In this chapter, I begin by describing the field site where this research took place, namely transabled.org, alongside outlining the means through which it was accessed via The Internet Archive and The Wayback Machine. I then outline the ontological and epistemological principles which underpinned this research, namely social constructivism and a commitment to methodological holism, interpretivism and critical reflexivity, respectively. I then discuss digital ethnography, the chosen methodology for this research, as informed by these principles. In justifying this choice, I critically assess alternative methodologies adopted by previous studies of online communities, outlining why I rejected these in favour of digital ethnography. In the subsequent section I discuss the practical issues encountered through my use of digital ethnography including (1) the challenge of adapting traditional ethnographic methods to the online context, (2) virtual placemaking, (3) authenticity online and (4) whether to combine my study with offline or follow-up research. I outline how I addressed these issues, drawing on debates within the online community literature to support my choices. I then discuss the ethical challenges I was faced with during the course of my research, including (1) privacy and informed consent, (2) the ethics of archival research and (3) anonymity online; I describe how I approached these ethical issues using existing recommendations for conducting research online. The penultimate section of this chapter describes the methods adopted for this research enquiry and outlines the process through which data was collected and analysed. Finally, I reflect upon my research process, discuss its merits and limitations and consider changes and adaptations I would make for future research projects.

Background to the field site: transabled.org, The Internet Archive and The Wayback Machine

The research for this thesis took place on transabled.org, an online community for sufferers of transableism, which existed between 1996 and 2013. As discussed in **Chapter 1**, in 1996 the site was set up by a man using the alias 'Sean', and it was originally his solo-authored blog (the name of which is unknown). Here Sean wrote about his fascination with disability and his growing desire to experience it. Blog updates were infrequent, averaging at 2 per year. Sean's blog was structurally similar to other blogs which existed at this time, in that it was hosted on a lengthy, 'static' webpage, a format characteristic of Web 1.0 and very early blog culture (Mead, 2000; O'Reilly, 2007). In 2005 Sean then re-formatted his solo-authored blog into a multi-authored platform and named it transabled.org. This new instantiation was hosted on a 'dynamic' web page. Dynamic webpages differ from static sites in that they store their content in an external database under a content management system (or CMS). The CMS enables the owner or provider to edit, delete and update a variety of different types of content (text, images etc.) which can then be viewed and interacted with through more complex hyper-linked architectures (e.g. homepage, sub-pages and further categories), accessed through a series of interfaces (Blood, 2000). Alongside creating this new structure, Sean also recruited other contributors to write for transabled.org; these were mostly individuals who had been following Sean's blog or whom he had met elsewhere on the web and identified as having similar desires regarding disability. The change in format and arrival of new members meant that transabled.org now met the definition of an 'online community' in that it had its own vocabulary, newcomers, established participants, norms, acceptable and unacceptable topics, and standard posting practices (Baym, 2003; Denzin, 1998).

From 2005 to 2013 there were 20 to 40 full-time members of transabled.org (e.g. members who posted regularly under a consistent pseudonym). There were many more casual commenters (those who commented on blog posts, without writing their own) and an even greater number of 'lurkers' (those who did not blog or comment, yet visited the site, as determined by web analytics and remarked upon by Sean). At this time, a new, full-length blog post appeared as frequently as once a day. Blog posts were roughly 300-400 words in length and received, on average, 5-6 comments; more popular posts received nearly 100 comments. Transabled.org's popularity peaked between 2007 and 2010, both in terms of site traffic and frequency of blogs and comments. Following 2010, the site's popularity slowly declined and, in 2013, transabled.org permanently closed and disappeared from the web. In all the years which transabled.org was active, Sean remained its exclusive owner and moderator. This meant that he made all decisions on site design, architecture and layout. He also decided who could become a permanent transabled.org member, as well as pre-moderating all blog posts and retrospectively moderating (and, at times, deleting) comments. Following its closure in 2013, a web search for transabled.org would bring up a '404 server not found' message or a domain squatter's advert. Nevertheless, despite disappearing from the live web, the content of transabled.org was not lost. Throughout its life course, the site had been regularly archived by The Internet Archive, meaning that almost its entire content was, and still is, accessible through The Wayback Machine.

The Internet Archive is a non-profit, digital library based in San Francisco. It was founded in May 1996 by computer engineer Brewster Kahle. Kahle's motivation for founding The Internet Archive was to save the ever growing but, until then, ephemeral medium of the internet, creating a resource and making it freely available to 'researchers, historians, the print disabled, and the general public'. He writes that 'our mission is to provide Universal Access to All Knowledge' (Kahle, 2019). The main bulk of The Internet Archive data is collected automatically by web crawlers: 'bots' which systematically browse the entirety of the public[29] web at intervals set by an algorithm, capturing, preserving and indexing snapshots of it. This archived web content is saved in a database which, since 2001, has been available for access by the general public via The Wayback Machine.

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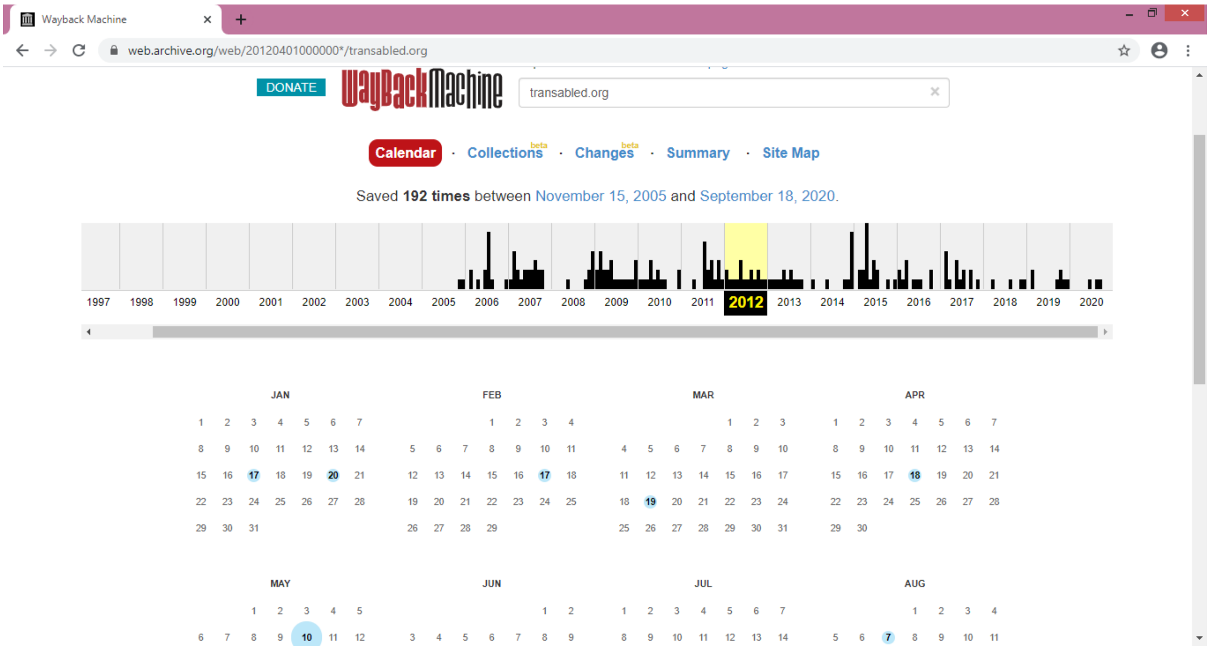
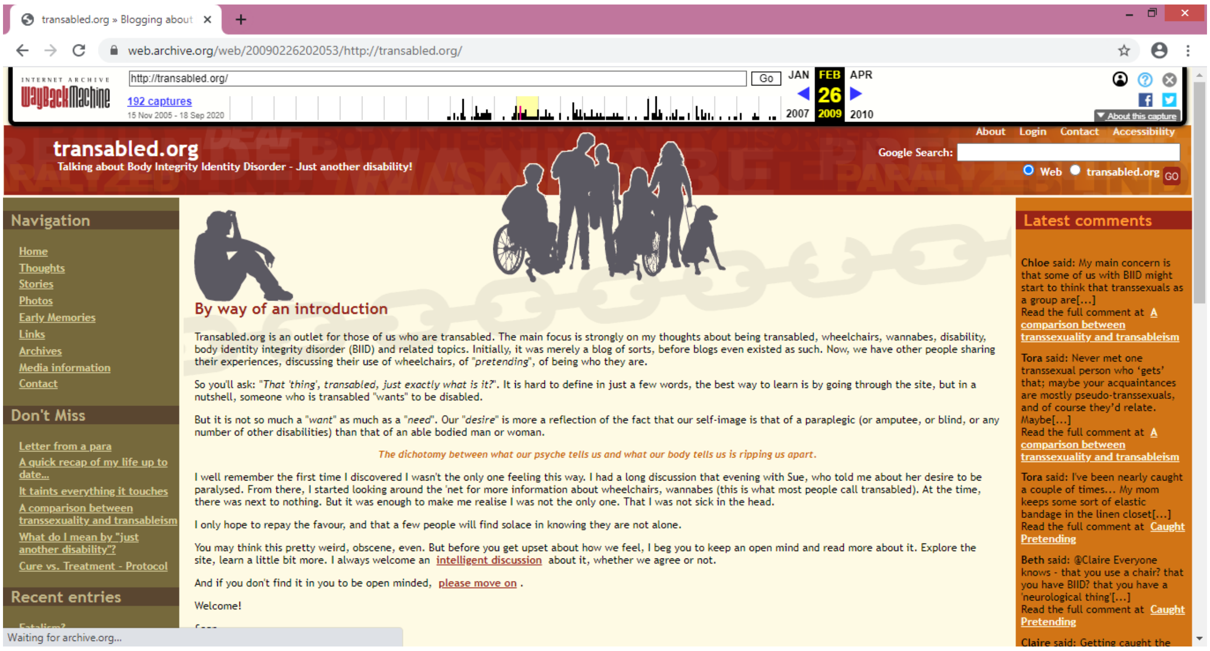
[29] The Internet Archive does not archive 'pages that require a password to access, pages that are only accessible when a person types into and sends a form, or pages on secure servers. Pages may not be archived due to robots exclusions and some sites are excluded by direct site owner request' (Internet Archive Help Centre, 2019).

Put simply, The Wayback Machine is a tool- a type of retrieval mechanism- through which all of The Internet Archive's captured content can be navigated and accessed. One cannot type key words or phrases into The Wayback Machine and expect to be met with results. Instead, in order to access an archived copy of a web site, the exact Uniform Resource Locator (URL) needs to be entered; in this sense The Wayback Machine has much more in common with a digital library or an archive than a search engine. Once a URL is entered into The Wayback Machine, the user is taken to a calendar view page which displays (with blue dots) the dates on which that particular page was captured by The Internet Archive (see **Figure 1** for example). From there, the user clicks on one of these blue, date-stamped dots and is taken to the webpage in question, as it existed on that given date (see **Figure 2** for an example of transabled.org on 26th February 2009, date chosen at random). From there, the rest of the site can be navigated as normal, as if it still existed. During the years of its existence transabled.org was captured 122 times. The most recent capture (prior to the forum's closure) was on 26th August 2013. That particular time stamp thus provides access to almost the entire internal archive of transabled.org. Earlier time stamps allow one to view how the webpage looked in previous months and years. This entire archive of transabled.org- including every available blog post, and the website, as viewed from different points in time- was what constituted the field site for this research.



Saved **192 times** between November 15, 2005 and September 18, 2020.

Figure 1: The Wayback Machine calendar view of transabled.org (The Internet Archive, 2020)



transabled.org
Talking about Body Integrity Identity Disorder - Just another disability!

By way of an introduction

Transabled.org is an outlet for those of us who are transabled. The main focus is strongly on my thoughts about being transabled, wheelchairs, wannabes, disability, body identity integrity disorder (BIID) and related topics. Initially, it was merely a blog of sorts, before blogs even existed as such. Now, we have other people sharing their experiences, discussing their use of wheelchairs, of "*pretending*", of being who they are.

So you'll ask: "*That 'thing', transabled, just exactly what is it?*". It is hard to define in just a few words, the best way to learn is by going through the site, but in a nutshell, someone who is transabled "wants" to be disabled.

But it is not so much a "*want*" as much as a "*need*". Our "*desire*" is more a reflection of the fact that our self-image is that of a paraplegic (or amputee, or blind, or any number of other disabilities) than that of an able bodied man or woman.

The dichotomy between what our psyche tells us and what our body tells us is ripping us apart.

I well remember the first time I discovered I wasn't the only one feeling this way. I had a long discussion that evening with Sue, who told me about her desire to be paralysed. From there, I started looking around the 'net for more information about wheelchairs, wannabes (this is what most people call transabled). At the time, there was next to nothing. But it was enough to make me realise I was not the only one. That I was not sick in the head.

I only hope to repay the favour, and that a few people will find solace in knowing they are not alone.

You may think this pretty weird, obscene, even. But before you get upset about how we feel, I beg you to keep an open mind and read more about it. Explore the site, learn a little bit more. I always welcome an intelligent discussion about it, whether we agree or not.

And if you don't find it in you to be open minded, please move on .

Welcome!

Chloe said: My main concern is that some of us with BIID might start to think that transsexuals as a group are[...]
Read the full comment at **A comparison between transsexuality and transableism**

Tora said: Never met one transsexual person who 'gets' that; maybe your acquaintances are mostly pseudo-transsexuals, and of course they'd relate. Maybe[...]
Read the full comment at **A comparison between transsexuality and transableism**

Tora said: I've been nearly caught a couple of times... My mom keeps some sort of elastic bandage in the linen closet[...]
Read the full comment at **Caught Pretending**

Beth said: @Claire Everyone knows - that you use a chair? that you have BIID? that you have a 'neurological thing'[...]
Read the full comment at **Caught Pretending**

Figure 2: Example of transabled.org homepage as captured by The Internet Archive (The Internet Archive, 2009)

Ontological and epistemological principles; the choice of digital ethnography

The aim of this research was to explore the emergence and disappearance of transableism on transabled.org via use of Hacking's model of an ecological niche of transient mental illness (1998). Historizing and culturally contextualising social phenomena as a means through which to understand their existence and transience, as bound to a particular time and place, is a well-developed practice within the social sciences (Wang, 1999). Enquiries of this nature are fundamentally orientated against 'objectivism': the idea that reality exists independently of human social action. Instead, the ontological understandings which underpin these projects are grounded in 'social constructivism' which posits that social phenomena emerge 'in practice' (Mol, 2002), as dependent upon complex networks of social and material relations (Jones, 2010; Latour, 1996; Wang 1999), power dynamics, knowledges, 'discourses' (Foucault, 1969; Hacking 2002), labels and systems of meaning. Following this, the epistemological principles of those exploring transient social phenomena dictate that knowledge is to be accessed by locating and studying the multiplicity of attributes which variously contribute towards their contextual emergence and disappearance (Geertz, 1973; Hacking, 1998; Jones, 2010; Mol, 2002).

This type of ‘methodological holism’ is situated within the interpretivist, as opposed to positivist, tradition (Beck, Bryman & Liao, 2004; Geertz, 1973). Practitioners working within this tradition are not orientated towards seeking the ‘objective’ truth of a situation; instead they recognise that any knowledge produced will be one particular interpretation of any given topic. This acknowledgement comes with the additional caveat that the researcher’s own values and beliefs will, inevitably, inform her interpretations. Following this, critical reflexivity- the requirement that the researcher continually reflect upon and scrutinise her own processes and analyses- lies at the heart of holistic, interpretive research practices (Goodly & Smailes, 2011; Mauthner & Doucet, 2003; Saukko, 2003).

The above described social constructivist ontology, and its associated epistemological commitment to methodological holism, interpretivism and critical reflexivity is what informed the methodological choice for this research, namely ethnography, which centres these practices. In theorising transableism through the ecological niche of transient mental illness, my aim was to explore the ways in which it was constituted, not by one singular factor, but by a web of intersecting elements; ethnography is grounded in the study of ‘total social worlds’ (Geertz, 1973) and, for this reason, I saw it as an ideal fit for my research aim. Whilst originating in offline contexts, since the advent of the internet, ethnography has been variously adapted for the study of online environments (Baym, 2003; Hine, 2000, 2012; Wilson & Perterson, 2002). The application of ethnographic methods to online contexts can be closely linked to shifting ontological understandings regarding the internet itself. Whilst, in the early years of internet research, many scholars viewed online worlds as somehow inferior or less ‘real’ than their offline counterparts (Calhoun, 1991; Putnam, 2000; Turkle, 1995), at the end of the 1990s, the internet was acknowledged as an important cultural context in its own right (Hine 2005). In conjunction with this, spaces such as multi-user-domains (MUDs) (Smith & Kollack, 1999), virtual worlds (Bollestoff, 2008) and online communities began to be similarly viewed as ‘total social worlds’, warranting the same holistic, ethnographic explorations as offline cultures (see Baym, 2003 and Rheingold, 1993 who were essential in establishing ethnographic approaches within online communities).

My understanding of transabled.org was that it was likewise a 'total social world' warranting serious enquiry. This position was informed by elements discussed in **Chapter 1**, namely that transabled.org was the largest and longest standing forum dedicated to the desire to be disabled, that it constituted an online community (by its own description and academic definitions) and that it was the origin of the concept of transableism. Because of this ontological position regarding the nature of transabled.org, my ethnography took place entirely on this site. Many terms have been applied to different types of ethnography carried out online (Garcia, Standlee, Bechkoff & Cui, 2009, Kozinets, 2010), with one of the most common being 'virtual ethnography' (Hine, 2000). This term, however, refers to a method which emphasises the need to blend online and offline research, seeing the former as partial and incomplete (Hine, 2000, see also Horst & Miller, 2012). Research conducted entirely online, such as mine was, is usually referred to by the term 'digital ethnography' (Murthy, 2008). This term advocates the study of distinct online worlds, as separate from offline environments and as meaningful in and of themselves (Boellstorff, Nardi, Pearce, & Taylor, 2012; Kozinets, 2010; Murthy, 2008). As such, 'digital ethnography' is my term of choice for this research. Before discussing digital ethnography in more depth, I describe a further method commonly used within online community research, without an additional offline basis, and explain my reason for not choosing it (my justifications for not choosing to blend with offline research methods are discussed in depth in a later section of this chapter).

One of the most commonly used methods in online community research, without an additional offline basis, is a type of 'microanalysis' (Subrahamanyam, Greenfield & Tynes, 2004, also termed 'a snapshot approach' or 'restricted sampling' (Hine, 2000)). This approach involves sampling a cross-section of data (posts, comments etc.) from the community for thematic or content analysis (Rosen, Woelfel, Krikorian, & Barnett, 2003). Sampling varies but has, in previous studies, included discussions which focus on a specific topic (Giles, 2006), a relevant time of year (e.g. Christmas time on a pro-anorexia website Noris, Boydell, Pinhas & Katzman, 2006) or a pre-determined time frame (Lasker, Sogolow & Sharim, 2005; Subrahamanyam, Greenfield & Tynes, 2004). Davis (2011, 2012), who previously undertook research on transabled.org sampled the community members' introduction statements (the first entry a member writes, introducing themselves to the community). Whilst the microanalysis method is noted to have many benefits, in that it allows systematic analysis of a particular topic or faster analysis of a large community (Hine, 2000), a number of critiques have been levelled at it. As theorists have noted, this method privileges language over context, detaches data from its discursive, social and material context (Androutsopoulos, 2008), and can lead to overgeneralisations about the community as a whole (Lindlof & Shatzer, 1998). As Hine notes, 'the selectivity of these approaches goes against the ethnographic ethos…of a holistic attention to all practices as constitutive of a distinct culture' (2000, p. 21). Much of my critique of Davis, as developed in **Chapter 2**, focused on her failure to adequately identify and explore the numerous internal and external factors which influenced the development of transableism on transabled.org. A large part of this oversight can be intrinsically connected to her use of micro-sampling. Given that this thesis aims to build upon Davis' oversights by exploring transableism holistically, I rejected the micro-sampling method in favour of digital ethnography.

Practical issues encountered

Digital ethnography is still a new and exciting frontier for social scientists, and many have embraced the possibilities afforded with in-depth research online. Nevertheless, some practical issues have been identified regarding the use of ethnography in online contexts (Campbell, 2006; Garcia, Standlee, Bechkoff & Cui, 2009). During my research I encountered a number of these issues myself, the most pertinent being (1) the challenge of adapting traditional ethnographic methods to the online context, (2) virtual placemaking, (3) authenticity online and (4) whether or not to combine with offline or follow-up research. In this section I discuss the specific ways in which these issues emerged in relation to my research and how I overcame them by drawing on debates and suggestions within the online community literature.

Adapting traditional ethnographic methods

Traditionally, the primary method for carrying out ethnography offline was participant observation. This describes the practice wherein the researcher immerses themselves in a particular field site for a sustained period of time, 'participating' in social life and 'observing' unfolding interactions and evolving environments (Geertz, 1973; Hammersley & Atkinson, 2007). This was not possible for my research: due to the nature of my field site, I was dealing with historical, textual content, as opposed to live embodied interactions which I could ‘observe’ in real time, much less ‘participate’ in. Consequently my digital ethnography of transabled.org was comprised of a number of adapted methods, namely studying (a) the ‘traces’ (Webb, Campbell, Schwartz & Sechrest, 1996) left behind by community members in the form of blogs and comments, (b) the ways in which these traces were organised and catalogued in the archive of transabled.org, and (c) the internal environment of transabled.org. These methods have been advocated within the digital ethnographic and online community literature as necessary responses to a rapidly changing discipline (Garcia, Standlee, Bechkoff & Cui, 2009; Kozinets, 2010; Ugoretz, 2017). The adapted use of these methods ensures that, whilst not precisely resembling older instantiations, newer forms of digital ethnography can still be classified as ethnographic (Kozinets, 2010; Murthy, 2008).

Regarding (a) studying the ‘traces’ left behind by members in the form of blog and comments (details of which were described in the opening section of this chapter), my decision to do this was informed by my interest in exploring the broader cultural factors which may have influenced the emergence and disappearance of transableism. I saw the examination of blogs and comments as a way into the investigation of how these broader themes and discourses might be incorporated into collective narratives and systems of meaning on transabled.org. This decision was also informed by my interest in exploring the internal social dynamics influencing transableism, as I wanted to examine how these dynamics operated at the level of textual interaction. In line with my commitment to methodological holism, I analysed all blogs and comments left on transabled.org.

The study of ‘traces’ left behind by humans has its origins in the development of ‘unobtrusive’ offline research methods which were designed to allow the researcher to conduct enquiry without disturbing or biasing her participants (as was identified to be the case with ‘reactive’ methods) (Webb, Campbell, Schwartz & Sechrest, 1996). Although initial discussions of unobtrusive methods were restricted to offline applications, and mostly involved studying physical marks (e.g. scuffs, wear and tear, graffiti), the unobtrusive study of user-generated traces in the form of posts and comments has, in more recent years, been seen as an ideal method for use in ethnography online (Harvey, Crawford, Macfarlane & McPherson, 2007; Ugoretz, 2017). Here, online researchers have drawn attention to the wealth of 'digital traces' left behind as individuals navigate the internet (Beer & Burrows, 2007; Hine, 2011, 2015). Researchers note how this data provides important insights into the aspects my research aimed to investigate, namely how members form collective and culturally informed narratives, alongside the ways in which they constitute relationships and social dynamics (Baym, 2010; Hine, 2011; Soukup, 2000).

Regarding (b) studying the ways in which these traces were organised and catalogued in the archive of transabled.org, the decision to investigate this element was primarily informed by the need to study the internal social dynamics and, in particular, the power relations on transabled.org. Given that Sean was the exclusive owner and moderator of transabled.org (in other words, the site's 'archivist'), this involved paying close attention to his moderation practices, including how he determined what would appear in website archive itself (e.g. via membership selection, pre-moderating of blogs and deleting of comments), how he represented that content (e.g. via the webpage's structure, including categories, subcategories and promoted content), and the narrative which emerged as a result of these processes.

This need to study both archival documents and the processes through which they are selected and organised has its origins in the works of Michel Foucault (1969) and Jacques Derrida (1996). Both of these theorists drew attention to the ways in which archives, rather than being neutral depositories, are intrinsically bound up with relations of power (whether individual, cultural or institutional), to the degree that they can be seen to constitute fundamental structures of thought, knowledge and memory (Derrida, 1996; Foucault, 1969). Following these observations, theorists from a range of disciplines[30] began to study the role power and authority plays in determining what becomes the archival record to begin with (via process of appraisal and selection) and, following this, how that record is represented (via organisation and cataloguing), so as to prioritize particular narratives, whilst subjugating others (Bowker & Star, 2002; Featherstone, 2006).

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[30] Disciplines include archival science (Hedstrom, 2002; Wagner, 2017; Yakel, 2003), digital humanities (Dalziell & Genoni, 2015; Hedstrom, 2002; Manovich, 1999), anthropology and post-colonial studies (Featherstone, 2006) and science and technology studies (Bowker & Star, 2002).

Within online community research such as mine, this critical reading of the archive is increasingly being recognised as important regarding the study of power manifest in online moderation and archival practices (Harvey, Crawford, Macfarlane & McPherson, 2007; Hetland & Morch, 2016; Ugoretz, 2017). This recongition reinforced my choice to critically analyse the archival organisation on transabled.org.

My final adapted ethnographic method involved (c) studying the internal environment of transabled.org. I did this by immersing myself in the webpage, interacting with its features and navigating through its architectures. This decision was firstly practical- it was a way in which to explore both the content and the layout of the transabled.org archive. It was also informed by my commitment to methodological holism and need to explore all the factors and dynamics that would have been relevant to the members of transabled.org themselves. As I saw it, immersing myself in the digital environment of transabled.org would enable me, as much as possible, to get a feel for what it would have been like to be a community member, and to get an idea of the common themes, narratives and dynamics they would have encountered by means of being present on transabled.org. Within online community research, this interactive practice has been advocated by a number of researchers. Those with similar research aims to mine have outlined how logging on to a community, immersing oneself in it and navigating through its various pages can be a way to offer the researcher subjective insight into the experience and issues of relevance facing community members (Beaulieu, 2004; Davis, 2010; Hine, 2000). This technique has commonly been termed ‘the walkthrough method’ and, whilst it is often used in communities which are still live, it is seen as equally effective for the purposes of immersion in relation to historic communities such as transabled.org (Light, Burgess & Duguay 2018; Moller & Robards 2019). I found the use of this method on transabled.org to be extremely effective. Whilst I wouldn’t go so far as to say it made me completely understand the desire to be disabled, it enabled me to empathise with the members’ experiences and struggles, in that I became immersed in their lives and saw their stories evolve over time. It also allowed me to understand the appeal of being a regular member of transabled.org, in that I found the content fascinating, was compelled to return to the site and began to develop genuine affection for many of the members.

Virtual placemaking

The second issue which I encountered in my digital ethnography was that of placemaking - of figuring out where my field site should be and then determining and justifying the boundaries of that choice. In traditional ethnography, this process is presented as relatively (albeit deceptively) simple in that the researcher physically travels to a separate village, town or nation and goes ‘into the field’ (Clifford, 1997; Lyman & Wakeford, 1999). In my case, neither physical locations, nor the need for travel, existed, and thus placemaking became more problematic (for discussions of this in relation to digital ethnography in general see Lyman & Wakeford, 1999; Ruhleder, 2000; Rutter & Smith, 2005). Whilst I knew that I wanted to study the transabled community, I was faced with the question of why I had chosen transabled.org as the place to do so. Given transabled.org wasn’t a physically demarcated space, what justification did I have for the decision to centre my research there? When addressing this question, it was useful to shift from thinking about field sites as physical spaces and, instead view them as defined by social significance. This is a practice both explicitly advocated (Guimaraes, 2005) and implicitly used within online community research (Baym, 2003). As previously discussed, whilst other forums surrounding the desire to be disabled existed in the late 90s and early 2000s, transabled.org was the first and largest of its type, it was the place where the notion of transableism was coined, it was the most active in medical advocacy, the members themselves defined it as the hub of their community and Sean was widely acknowledged as the leader of the transabled movement. Evidently, transabled.org was the key site of social significance for the members and, with this fact in mind, I felt justified in using it as my central field location.

Having demarcated transabled.org as my central field site I then encountered other placemaking issues. Although, in the majority, the members kept their interactions to the transabled.org forum, they would occasionally post hyperlinks to external sources. These were mostly links to the blogs of disability activists sharing their views on transableism, which the members would then discuss at length. This led me to question whether I should include these blogs in my analysis, despite them not being hosted on transabled.org. Ultimately, I chose to extend the boundaries of my field site to include these sources (analysis of which features in **Chapter 6**). As I saw it, these sites had been posted to transabled.org because, alongside the central forum itself, the members deemed them to have social significance. Including externally located sources within ethnography of online communities is a method which has been advocated by other researchers who highlight how this technique offers a more flexible way of conceptualising online communities, in that it views them not as bounded by a single webpage (Dodge & Kitchen, 2001; Hine, 2000; Schneider & Foot, 2005). Schneider and Foot describe these more flexible field sites as 'web spheres': 'a set of dynamically defined digital resources spanning multiple websites deemed relevant or related to a central event, concept or theme, and often connected by hyperlinks' (2000, p. 158).

Authenticity online

A third issue to consider when carrying out my digital ethnography was related to authenticity online. In the initial stages of my research, when discussing or presenting my project, I would often be asked how I would know whether the members of transabled.org were 'who they said they were' or whether the claims they were making were 'true'. At first, these types of questions came as a surprise to me as I had not even considered the authenticity of the members of transabled.org to be an issue. In reflecting upon this, I realised that I had been implicitly adopting a dramaturgical stance in relation to identity, as made famous through the work of Erving Goffman (1959). Goffman drew attention to the way in which *all* social identities are, to some degree, 'personas' which we 'perform' and noted that the task for the social scientist was to discard attempts to access the 'backstage' or so-called 'authentic' person, and instead analyse the richness, and contextual authenticity of the performance itself.

Although Goffman's dramaturgical stance was one which I had been implicitly holding, most likely informed by my ontological and epistemological assumptions, following the questions I faced regarding authenticity, I began to research this position as it applied to online communities. I found that, within the online community literature, some theorists viewed online identities as potentially inauthentic and outlined a need to validate identity claims and research findings by meeting participants in person (Cherny, 1999; Mann & Stewart, 2000; Turkle, 1995). Many others, however, supported Goffman's position, both explicitly and implicitly, thus advocating that researchers abandon attempts to validate online personas by seeking out individuals offline (Baym, 2003; Campbell, 2006; Guimaraes, 2005; Hine, 2000). As Taylor puts it:

> ‘the idea that verifiability can be achieved offline is…embedded in a larger epistemological claim…that via the offline interview, one can confront the true authentic other to get past persona in some way…we are always creating and recreating selves (therefore) the assumption that somehow offline interview space is located in a way that allows for more authentic conversation is a bit problematic’ (1999, p. 443).

This additional context enabled me to feel justified in my choice not to question the validity of the identities or claims of the members of transabled.org and, instead, take their online personas at face value and study the richness of them in context.

Combining with offline or follow-up research

A final issue encountered during the course of my research concerned the question of whether or not to combine my ethnography with offline or follow-up research (such as interviews). Again, when presenting my work, I would often be asked whether or not I was going to attempt to find the members of transabled.org and conduct follow-up interviews with them. Early on in my research, I made the decision not to do this. My reason for this choice was primarily connected to the ontological issue just discussed, namely authenticity online; those insisting on supplementary offline research (both within the literature and in my anecdotal experience) were usually of the opinion that this was a necessary way of validating online identities and data gathered (Hine, 2000; Turkle, 1995). Given my dramaturgical stance, I already interpreted online personas as legitimate in their own right and thus did not see a need to further validate them.

In addition to being informed by my ontology of online identity, the decision not to combine with offline research was also a practical one. Even if I had felt the need to validate the members’ claims, or ask follow-up questions, I would not have been able to do so. During the course of my research I occasionally, out of curiosity, tried to identify some of the members of transabled.org via Google searches. Given that the members all wrote under pseudonyms this was, inevitably, a fruitless enquiry. I was never able to connect any of the members’ pseudonyms to a reliable offline identity, thus removing even the possibility of combining my ethnography with supplementary research (there are additional ethical issues associated with such attempts to identify, which I discuss in a later section of this chapter).

A final factor which contributed towards my decision not to combine my digital ethnography with offline research was related to the aim of this thesis, namely to explore the factors involved in the emergence and disappearance of transableism, specifically on transabled.org between 1996 and 2013. As I saw it, any data gathered outside of the context of transabled.org, or up to seven years after transableism's disappearance, would be divergent from this aim. For example, even if I had been able to locate the members for interview, their retrospective reflections on transableism might have been divergent from the action which took place on transabled.org in its active years. As is commonly noted regarding retrospective interviews, participants often unwittingly rewrite their histories according to current perceptions and self-images, or provide biased responses based on what they think they researcher wants to know (Garcia et al., 2009). My decision not to include follow up interviews on the basis of my research aim is supported by much of the literature. As many practitioners carrying out digital ethnography within online communities have noted, supplementing online research should only be done where the context makes it necessary (e.g. if an online community also holds offline meetings, crucial to the topic). It should not be pursued when online field sites are 'complete social worlds' in and of themselves, as transabled.org was, or were the research aims do not require it, as mine did not. Indeed, as theorists have noted, unnecessarily supplementing online research can even run the risk of biasing data, or forcing connections and insights which do not exist (Garcia et al., 2009); as outlined above, this was my worry. Further supporting my choice, there have been multiple successful studies carried out on online communities based purely on online research, where supplementation was deemed unnecessary (Baym, 2003; Nelson & Otnes, 2005; Walstrom, 2000).

There was one exception I made regarding the decision not to carry out research supplementary to my digital ethnography. I did communicate with Dr Michael First (psychiatrist and expert on Body Integrity Identity Disorder) over email and interviewed him once over Skype. My reasons for doing this related to the fact that First had coined the term Body Integrity Identity Disorder (BIID) in 2005 and, in 2007, was conducting follow-up research into this condition. This follow-up research had been initiated by a conversation between Sean and First (posted to the forum) and First was recruiting participants from transabled.org, with Sean acting as a mediator. The results of this research were never published. Whilst this process was discussed at length on transabled.org, this discussion was inevitably somewhat one-sided in that the members had no knowledge regarding the workings of this study, why it was never published and why, ultimately, BIID failed to enter the DSM. Given that the aim of this thesis was to explore factors contributing to transableism's disappearance, I thought it important to seek clarity on what happened with this study and the DSM, where possible. This is why I chose to contact First and my questions to him consisted mostly of fact checking information regarding this study and the failure of BIID to enter the DSM. This practice of interviewing experts as a complimentary addition to situated ethnography has been discussed within the literature, with theorists noting how it can be a useful way to fulfil aims such as mine; namely clarifying or fact-checking technical details or results of processes (Bogner, Littig & Menz, 2009). When conducting the interview with First, I followed suggestions outlined within this literature, which largely involved orienting my questions, not around First's clinical expertise, but around my specific research aims (Bogner, Littig & Menz, 2009). The findings of this interview are discussed in **Chapter 8**.

Ethical issues associated with the use of digital ethnography

So far in this chapter, I have discussed the practical issues I encountered through my use of digital ethnography. In this section, I outline 3 key ethical issues that I had to consider during the course of my research. These were (1) privacy and informed consent, (2) the ethics of archival research and (3) anonymity online. The importance of ethical practice in social scientific research has long been acknowledged and formally codified by professional organisations (e.g. The British Sociological Association (BSA), The Social Research Association (SRA) and The Association of Social Anthropologists (ASA)). Although the internet has presented social scientists with exciting new opportunities for research, challenges have emerged regarding the effective adaptation of offline ethical guidance for online contexts (Ackland, 2013; Singiura, Wiles & Pope, 2017). In response, attempts have been made to update offline guidelines, new, internet specific, guidelines have also been introduced (The Association of Internet

Researchers (AoIR), 2012, 2020) and individual researchers have offered their own contextually adapted frameworks (Kozinets, 2010; Langer & Beckman, 2005). During the course of my research, when considering my three key ethical issues, I drew upon all of these sources to create an ethical framework best suited to my particular field site and needs. This ethical framework was supported by the University of Exeter's Ethics Approval Board. Given the nature of my field site and project, I did not have to consider ethical issues associated with the use of big data, the analysis of social media data, the legality of social media data usage[31] and General Data Protection Regulations (GDPR)[32] , thus these debates are not addressed here.

Privacy and informed consent

The first ethical issue to consider in relation to my research was whether or not to seek informed consent from the members of transabled.org. Informed consent refers to the responsibility of the researcher to explain to her participants the nature and scope of the research, ensuring willing and knowledgeable participation in the process (The British Sociological Association (BSA), 2017). Although securing informed consent is now an essential ethical requirement in offline research with human subjects, within online community research the guidelines are less clear. Ultimately, I made the decision not to attempt to seek informed consent from the members of transabled.org, after careful consideration of the discussion around this issue within similar contexts, which I discuss below.

Much of the debate within online community contexts centres around the question of whether the data found here should be considered public or private. Although it is almost universally accepted that password protected communities are private (Mann & Stuart, 2000), researchers are divided when it comes to openly accessible sites such as transabled.org. Depending upon what position is held, different views exist regarding whether informed consent should be sought from community members. On one side of the debate, some theorists insist that *all* online community data (not just that which password protected), should be

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[31] Often data held on social media sites is owned by the platform in question and thus the use of it for research purposes, without site permission, has the potential to breach copyright laws. This was not the case for my project, as data held on The Internet Archive is open access use.

[32] General Data Protection Regulations (GDPR), which came into effect in 2018, outline guidance for research involving 'personal data' (Data Protection Act, 2018). These did not apply to my project as none of the data held on transabled.org meets the definition of personal data.

treated as private. As is highlighted by these researchers, even on open, public forums, there may be a ‘perception of privacy’, which should be respected (Eysenbach & Till, 2001; Hudson & Bruckman, 2004). Following this, these researchers insist upon always disclosing their presence and intentions to online community members and, crucially, seeking full informed consent to use messages and observe interactions (King, 1996; Kozinets, 2010).

On the other hand, this overly cautious approach has been criticised by researchers who argue that data openly accessible online (e.g. not password protected) is part of the public domain, and therefore should not be subject to requirements regarding informed consent (Langer & Beckman, 2005; Mann & Stewart, 2000; Sanders, 2005). Theorists have also noted the ways in which members of open forums often explicitly assume they are being observed and researched. As Sanders (2005), who carried out ethnographic work with an online sex worker community, writes ‘the web is a public domain and those who post information realise that it is not private in the traditional sense of the personal conversation but accessible for anyone to read’ (2005, pp. 71-72) (notably, this is a view that is backed by the Association of Internet Researchers (AoIR), 2012). An additional element of the argument regarding the public nature of online community data highlights how viewing these sources as private, and thus insisting upon informed consent, can, not only be unnecessary, but annoying and damaging (Langer & Beckman, 2005; Sanders, 2005). The presence of a researcher may cause a community to fracture or, alternatively, being contacted after a community has closed may be intrusive; both possibilities are situated as arguably more unethical than the alternative. Following these observations, theorists have advocated the use of ‘unobtrusive methods’, as discussed in a previous section of this chapter (Ugoretz, 2017; Webb, Campbell, Schwartz & Sechrest, 1996). Within the ethical context, these methods are situated, not only as a practical solution to carrying out ethnography online, but also a way of protecting individuals from harm by preserving the integrity of the community and minimising personal intrusion (Sanders, 2005).

Whilst my decision not to seek informed consent was largely practical (see above for a discussion of the impossibility of tracing the members of transabled.org), I further justified my decision by reference to the later aspect of the public versus private debate. As saw it, the transabled community was very much in the public domain, due to the openly accessible nature of both transabled.org (when it existed) and The Internet Archive. Similar assessments have been made in research by Sanders (2005) regarding online sex worker communities and Giles (2006) regarding online pro-anorexia communities; these communities were comparable to transabled.org, both in terms of depth of discussion, controversial topic matter, access and availability. My assessment of the public nature of transabled.org was further supported by comments made on the forum, wherein members acknowledged the visibility of transabled.org. It was also supported by the members' willing acceptance of previous social scientific research undertaken within the community, notably by Davis (2011, 2012, 2014), whose research they were aware of, and supported. The argument regarding the unethical nature of disrupting individuals to seek informed consent also informed this stance. Even if I had been able to track down the individual members of transabled.org to seek their consent, I feel this would have been very disruptive, given that this research took place up to 7 years after the community closed. By this point in time, the members might have recovered from transableism or otherwise moved on with their lives; a reminder of their past struggles would, potentially, have been upsetting. Furthermore, an awareness that their identities could be discerned from pseudonyms might have been unnerving. As discussed in the previous section, I did choose to contact First for a follow-up interview. This choice was justified by the fact that he did not write pseudonymously (indeed, he published academic papers on his findings). Furthermore, due to his position as a researcher as opposed to transableism sufferer, I did not feel that First would be emotionally disturbed by my contacting him.

The ethics of archival research

Within the debates just outlined, regarding the public versus private nature of online community data and the need for informed consent, there is little discussion of how these considerations might relate to historical or archived data. However, due to the relatively unique situation of my field site (an online community which was, firstly, internally archived by Sean the owner, and, secondly, externally archived by The Internet Archive), I saw this as an issue requiring extra consideration. Given the dearth of discussion on this matter within the online community literature, I looked to literature within archival studies for this extra ethical guidance.

Historically, there has been relatively little consideration of the ethics of conducting archival research. More recently, however, this has begun to change; practitioners can now be seen to routinely engage with the fact that their objects of study are, not merely documents, but representations of individuals and communities (Tesar 2015; Kirsch & Rohan 2008; Ramsey, Sharer, L'Eplattenier & Mastrangelo 2010). This acknowledgment has led practitioners to outline a number of aspects which the researcher wanting to undertake ethical archival work should consider, including considering whether an individual represented in an archive would view their material as public and whether they would have consented for it to be archived. For example, Cameron (2001), in addressing these considerations, notes how researching archived psychiatric notes would be wholly unethical, given that neither of the above requirements are met. Further aspects highlighted for consideration include the passage of time, whether the archive is open access, whether individuals have the option of requesting their information to be removed from the archive, the ethical justifications for archiving in the first place and whether individuals are represented in negative ways, against their will (Cameron, 2001; McKee & Porter, 2012; Moore, 2010). What emerges from these recommendations is the need for a sensitive, bottom-up approach wherein the researcher assesses the ethicality of individual archives, collections and documents on a case by case basis.

During the course of my research, I used the above guidelines when addressing both the internal archive of transabled.org and the fact it was externally archived by The Internet Archive, ultimately deeming both to be ethically acceptable. In terms of the internal archive of transabled.org, although, as previously discussed, blogs and comments were reviewed, selected and moderated by Sean, the members were fully aware of the public nature of transabled.org. Furthermore, they had willingly written content in their own words and had, not only consented, but actively wanted it to appear on the website for others to read. There was one exception to my treating the content in the internal archive of transabled.org as ethically acceptable. This related to one member who, after a few years of posting, asked Sean to delete all of his content from transabled.org, fearing that he would be identified in real life. Although Sean removed a portion of this member’s content, some remained; I felt it was ethically important to respect this member's wishes and, as such, his remaining content is excluded from my analysis.

When assessing the fact that transabled.org had been externally archived by The Internet Archive, there were a number of factors which lead me to conclude that the use of such data was ethically acceptable. Firstly, I was encouraged by the fact that The Internet Archive has a policy of removing content if website owners request it (evidently, Sean had not made this request) (The Internet Archive, 2020). Secondly, I deemed The Internet Archive's justifications for archiving content (i.e. to provide individuals, including researchers, access to knowledge and cultural resources (Kahle, 2019)), to be altruistic and benign. Finally, discussions on the forum made apparent that the members of transabled.org were aware of The Internet Archive; many expressed enthusiasms over the fact that transabled.org was being preserved and none expressed concern or resistance.

Anonymity online

A final ethical question I was faced with during my research concerned whether or not I should anonymise my data. Debates regarding anonymisation originate in offline research practices. Here changing individual names and obscuring other features (e.g. age, race, location, narratives) has long been common practice as it is seen as a way to protect research subjects from any harm that may arise as a result of being identifiable. Applying this guidance to research within online communities has been somewhat complicated by the fact that, on many of these forums, pseudonyms are used by members. Whilst some online community researchers insist that there is no need to alter pseudonyms, given that they already ostensibly protect the privacy of the individual, there are others who disagree with this view. Anonymising pseudonyms can be used as a way to provide additional justification and ethical assurance regarding the use of 'unobtrusive online methods' (as previously discussed) (AoIR, 2012; Sugiura, Wiles & Pope, 2017; Rutter & Smith, 2005). Moreover, many online researchers drawn attention to the importance of online personas (as discussed in the previous section on authenticity online), thus highlighting the need to protect these pseudonymous identities from harm (Sugiura, Wiles & Pope, 2017; Rutter & Smith, 2005).

Based on the above discussions, I decided to anonymise the pseudonyms used by the members of transabled.org, altering them to different names of the same gender. If the reader of this thesis wanted to find a particular participant on transabled.org by pseudonym, they would, very easily, be able to, given that sections of the archive are categorised thus (e.g. 'Jacob's story'). These categories contain all of the blog posts ever written by that individual member. Whilst, as I saw it, a handful of quotes by a given member did not threaten their online identity or offline privacy, when viewed within the larger context of all their blog posts, this potential might have existed. Thus, the decision to anonymise pseudonyms was made so as to, as much as possible, protect the importance of online aliases and safeguard against any chance of the real-life individual being identified via their pseudonym. Relatedly, the names of the disability bloggers' sites (as discussed in the section on placemaking) are also omitted or anonymised.

Whilst a great deal of the social scientific literature advocates anonymising names and identifiable details, some exceptions do exist. Firstly, as authors have noted, it is often critical to the inquiry to know details such as the name of an organisation being researched or the location of a project (Corti, Day & Backhouse, 2000). Anonymising this type of data is often not possible without introducing an unacceptable distortion (Corti, Day & Backhouse, 2000). Secondly, the anonymisation of the names of public figures is also seen to carry this risk. This type of anonymisation is additionally described as ineffective, given that readers can quickly piece together details. Theorists have justified their decision not to anonymise the names of public figures by outlining how the researcher is unlikely to pose harm to that individual over and above any risk they place on themselves by means of their position (Corti, Day & Backhouse, 2000).

Although I made the decision to anonymise the majority of my data, following the above two caveats, there were two exceptions to this rule. Firstly, I did not alter the website's name: transabled.org. Given the aim of this project (to situate and explore transableism as a transient mental illness), I felt it would have been, not only an unacceptable distortion to do so, but wholly impractical. Secondly, I did not anonymise the pseudonym of transabled.org's owner: Sean. This decision was informed by the fact that, being the owner of transabled.org, Sean fell into the category of an easily identifiable public figure. Knowing that Sean was an obvious alias that could not be traced to any real-life individual (as I made sure to check), enabled me to feel comfortable with this decision.

A final issue discussed in relation to the anonymisation of online community data relates to whether or not to alter or obscure verbatim quotes. Whilst some theorists state there is no need to change this data if pseudonyms have been changed (Bruckman, 2004; Hookway, 2008), there are others who advocate a more cautious approach. They suggest that direct quotes from community forums be Googled prior to write up so as to ensure that they are not traceable back to the original user, altering them if they are (Day & Keyes, 2008). When writing up my findings, I did not deem it necessary to alter or obscure verbatim quotes as, unlike with live online forums, textual content stored within The Internet Archive does not come up on Google, neither can it be searched internally via The Wayback Machine. The quotes used in the ethnographic sections of this thesis are thus mostly verbatim, although some have been edited for length or grammatical clarity.

Methods for data collection and analysis

Thus far in this chapter I have discussed the field site where this research took place, the ontological and epistemological principles underpinning this research, my chosen methodology of digital ethnography and the practical and ethical issues associated with this. This final section describes how my research was carried out, by outlining the methods I used for data collection and analysis.

My first stage of data collection and analysis took the form of an initial scoping. I immersed myself in the transabled.org website, exploring and navigating through the website’s structure, all the while making extensive field notes. My notes at this stage focused, firstly, on the material environment of the site, its layout, look, feel, design, change over time, the structure of the archive, categories and subcategories, hyperlinks to other sites and any notable absences. I also recorded my observations on the social structures and dynamics within the community, implicit rules, hierarchies and relationships, relevant site and relationship history, individual character profiles and, finally, my own impressions and emotional reactions.

My second stage of collection and analysis focused on the written content on the site, i.e. the blogs and comments. Although moving away from a broad overview of social and material structure, as explored in stage 1, I held these insights in my mind when approaching the written content, and continuously referred back to my initial fieldnotes. In order to manage my data at this stage, I copied and pasted all of the archived written content of transabled.org into a word document, totalling over 4000 pages of A4, which I printed out. My primary reason for doing this was that I found myself getting lost or confused when attempting to systematically navigate through the archive; the disorientating nature of post-modern spaces such as hyperlinked and layered websites, and thus the need to re-orientate oneself, has been described by other theorists working within similar environments (Clarke, 2006; Harvey, 1990; Jameson, 1999). Printing out the archive had a further benefit in that it enabled me to manually analyse it by underlining, annotating, and highlighting key words; what is termed the ‘scribble and doodle’ approach (Bazeley, 2013). It also enabled me to analyse and file this content alongside my field notes, as compiled in stage 1 (Hine, 2000). Whilst I knew that ultimately I would analyse my data using data analysis software, during this initial stage, the manual approach was essential in enabling me to immerse myself in and become familiar with such a large volume of data.

As is often the case with qualitative data, these initial processes of analysis provided rich and detailed, albeit very messy, descriptions. This mess, alongside the sheer mass of data, was overwhelming. As such, I disengaged with my data and field site for a while to allow for reflection, followed by a subsequent, much more productive, re-engagement and third stage of data analysis (see Hine, 2000 on the use of this practice in virtual ethnography). This third stage was more structured than the first 2 and took the form of thematic analysis: ‘a method for identifying, analysing, and reporting patterns (themes) within data’ (Braun & Clarke, 2006, p. 6). I went through my notes and annotations, highlighting and colour coding persistently emerging topics and ‘themes’ (Braun & Clarke, 2006). I assigned ‘codes’ to these themes, which I kept track of in a table; at this stage there were around 40 codes. After identifying and coding these themes, I then returned to the transabled.org website, alongside my field notes and print-out, to verify my emerging observations. Here, I worked through my data, grouping together content according to identified themes, coding it again in an attempt to draw out the defining aspects of these themes and refine my codes.

Following extraction of the above topics and themes, there was, evidently, still a lot more analytical organisation to do. A significant turning point occurred when I organised my many observations into visual representations (or 'mind maps' (Braun & Clarke, 2006)), making clusters of sub-themes around 4 key larger themes. These larger themes were (1) disability, (2) authenticity of BIID, (3) online community moderation (4) health advocacy efforts (see **Figures 3, 4, 5 and 6** for a representation of these four themes and associated sub-themes).

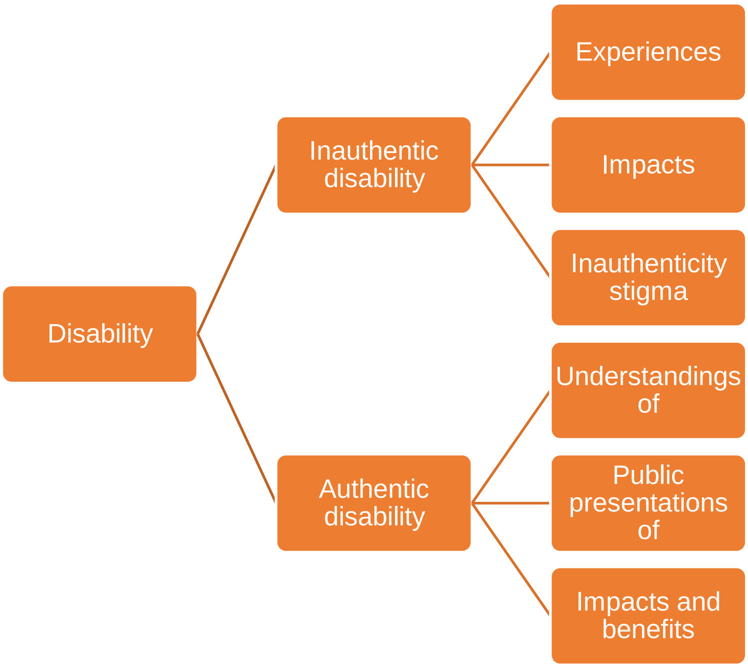

Figure 3: Visual representation of theme 'disability'

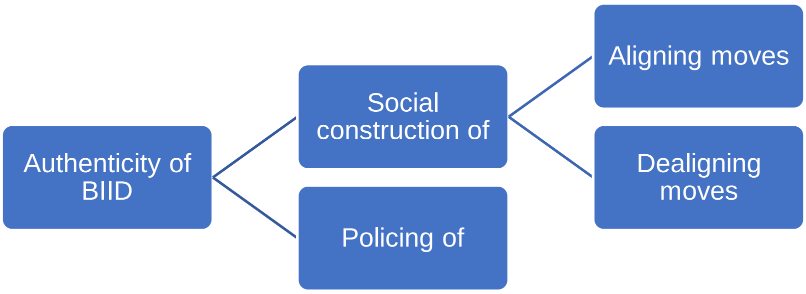

Figure 4: Visual representation of the theme 'authenticity of BIID'

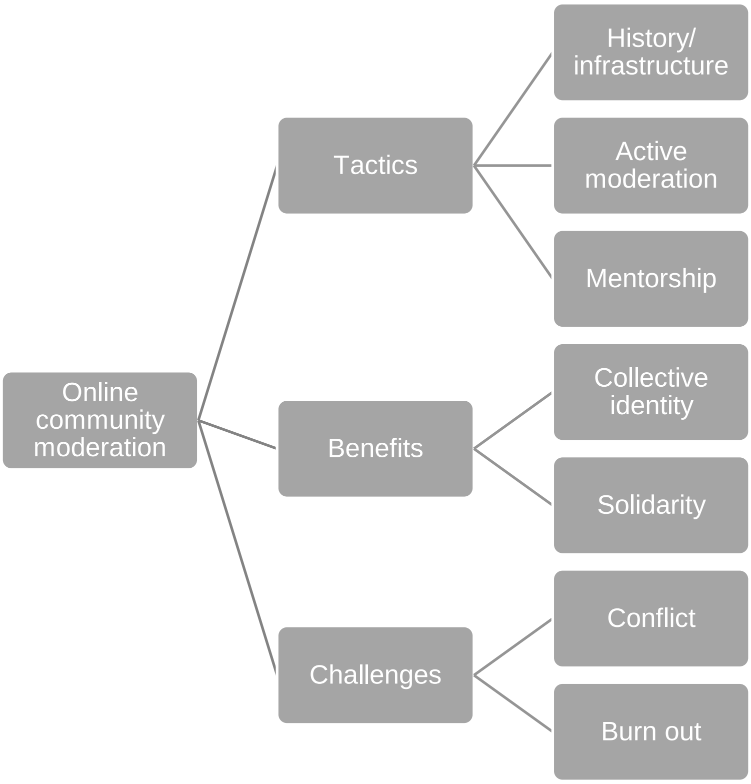

Figure 5: Visual representation of the theme 'online community moderation'

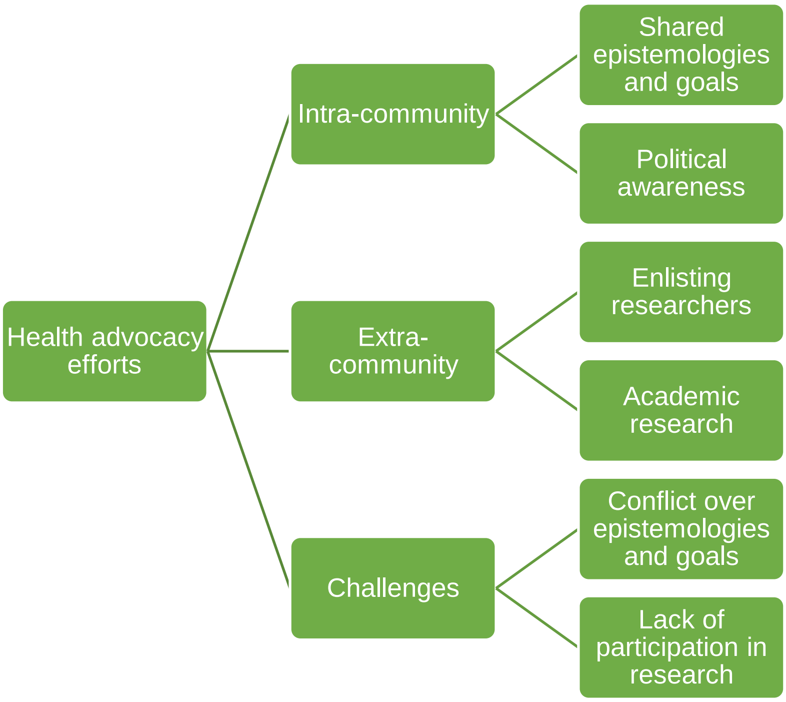

Figure 6: Visual representation of the theme 'health advocacy efforts'

After identifying these four key themes, the final stage of my data analysis began. At this stage, I saw a need to once again visit my data so as to verify my overarching themes, make sure they were reflective of the total social world of transableism, double check I had reached ‘theoretical saturation’ (Strauss & Corbin, 1998), and ensure there wasn’t anything relevant I had missed. There was, however, still an overwhelming amount of data, the totality of which it would have been impossible to carry out this final iterative process on. As such, I decided to sample 1 month of blogs and comments from each year of the transabled.org archive, which, alongside my fieldnotes, I put into NVivo data analysis software (Bazeley & Jackson, 2013). As I saw it, this would enable me to verify my overarching analytical framework against a chronologically representative portion of data and reflections on the overarching material and social structure of my field site. On this data, I carried out a much more focused round of coding, largely comprised of refining and solidifying my 4 key themes and associated sub-themes.

Throughout my research I adopted an abductive approach to data analysis (Tavory & Timmermans, 2014), which involved integrating theory with empirical data in an iterative, interpretive exploration (Reed, 2011). What this meant for my project was that, as I began collecting data, I continued to constantly engage with relevant literature, moving back and forth between observation and theorising (Tavory & Timmerman, 2014). My reasons for choosing an abductive, as opposed to a purely inductive, approach (as is also frequently chosen in qualitative research (Strauss & Corbin, 1998)), relate to the topic and objectives of this thesis. Given the historical nature of transableism, I wanted my exploration to be grounded in research into transableism which had proceeded mine, in particular the gaps identified there. Furthermore, given that one of the aims of this thesis was to historicise transableism, I needed my exploration to be informed by theory on relevant historical contexts and cultural phenomenon surrounding this condition. As discussed in **Chapter 3**, using existing research and cultural contexts to inform the analysis of data is a tactic further recommended in the ecological niche approach to a transient mental illness (Hacking, 1998).

Alongside moving back and forth between observing and theorising, my stages of data collection and analysis were also carried out iteratively (Strauss & Corbin, 1998). This process is variously described as a 'sequential analysis' (Becker, 1970) or a 'spiral approach' (O'Reilly, 2009). What this meant in practice was that, as I worked through the content on transabled.org (blogs, comments, layouts etc.), I explored whether my emerging ideas were reflected in subsequent content. I went back and forth between data as more ideas developed. This enabled me to see individual pieces of content in their own right, alongside contextualising them as part of a whole.

My final analytical framework, as discussed, is comprised of the 4 key themes: (1) disability, (2) authenticity of BIID, (3) online community moderation and (4) health advocacy community efforts. The following 4 ethnographic chapters (**Chapters 5, 6, 7 and 8**), comprise the second part of this thesis and are organised according to these themes, respectively. Although, in these chapters, I have mostly presented data from across the transabled.org archive, as grouped together under a theme, in **Chapter 7** 1 section of data is presented in a more chronological way. **Chapter 7** explores online community moderation and, in order to examine this theme, it was essential to paint a picture of the history of transabled.org and how it developed over the years, including the role Sean played in this process. Although this data is presented in a chronological narrative form, it still all falls under the broader theme of online community moderation.

Whilst building upon both the literature discussed in **Chapter 3** and the conceptual frameworks developed there, the empirical chapters are primarily findings-based; throughout, I provide direct quotations and observations from my field notes to support the themes discussed. Whilst these chapters have emerged from lengthy, abductive and iterative processes of data collection and analysis (as described above), I acknowledge that the accounts they present will also have been informed by my individual subjectivity as a researcher, alongside decisions I made during the data collection process regarding 'which sources of information to visit, and which connections to follow' (Hine, 2000, p. 80). Thus, as with all ethnography, the findings presented here, will, inevitably, be 'partial', 'incomplete' and unique to setting and author (Hine, 2000).

Reflections on my methodology and methods

Having described my choice of methodology and methods, in this section I look back on my use of them in practice, discuss their limitations, outline changes and adaptations I would make for future research projects and discuss the most successful elements of my chosen methods. This reflection is purely on the use of methods with this research project; a broader discussion of the theoretical and conceptual limitations of this project is undertaken in **Chapter 9**.

One limitation I encountered during the course of my research concerned The Internet Archive. As discussed in an earlier section of this chapter, the main bulk of The Internet Archive data is collected automatically by web crawlers. This archived web content is saved in a database which is then made available for access by the general public via The Wayback Machine. Whilst, in general, I found The Internet Archive easy to use, it seemed as if only about 90 percent of the content of transabled.org had been crawled and captured, meaning that the remaining 10 percent was not available for me to analyse. When attempting to navigate to one of these pages, I would be met with a message informing me that it had not been captured and archived. These pockets of missing content have been noted by scholars of The Internet Archive and are mostly described as a random result of the algorithmic archiving (Leetaru, 2015, 2016). Nevertheless, these absences were frustrating, even more so if the page had an especially interesting title (which I could see from the previous page). Further to this, I worried that these absences compromised my commitment to methodological holism. Whilst I reassured myself that absences have long been a source of frustration and mystery for archival researchers and are seen as intrinsic to historical enquiry, I was also aware that had I carried out my research on a live online community, I would have been less likely to come up against this limitation.

In hindsight, the key change I would make to my method concerns my ethnographic process. I fully stand behind my decision to carry out digital ethnography on transabled.org, rather than only analysing a cross-section of its content (see previous section for a discussion and critique of this method, known as ‘microanalysis’ (Subrahamanyam, Greenfield & Tynes, 2004)). I feel that the use of ethnography enabled me to identify changes in the community over time, alongside the power relationships on transabled.org, in ways that would not have been possible through microanalysis. Nevertheless, during the early stages of my research, I became overwhelmed at the sheer scale of data I had to analyse. Upon reflection, I spent far too long conducting an initial scoping of the website and reading through the printout of blogs and comments; I took extensive fieldnotes during these stages, writing a note for almost every paragraph of transabled content I read. For further digital ethnographic projects, I would either carry out my research within a much smaller community or, if this wasn't possible, take less detailed notes at the outset. This, I anticipate, would reduce the feeling of overwhelm, and free up time for a more complex analysis to take place in later stages, once a general feel for the community was established.

An aspect of my research which I found particularly fruitful was my use of mind maps. Being a visual person, these helped me to organise my data, picture important connections and clarify my thoughts. In future projects, I would make use of this tool right from the outset, potentially replacing the process of lengthy note-taking described above. A further aspect which I found both useful and essential to my analysis were the printed records of the archive of transabled.org. Whilst I did have concerns over the environmental impact of this and found it time-consuming, having a hard copy of transabled.org played a vital role in enabling me to make sense of all the data, make links between multiple parts of the forum content, and situate individual blogs and comments as part of a whole. This was done via flicking back and forth through the text, using place markers to link up content, and cross-referring between multiple pages as I read. Although this method isn't widely advocated within the digital ethnography literature, it is one I would wholly recommend to other practitioners.

Summary

In this chapter, I have described the field site where this research took place. I then reiterated the aims and objectives of this thesis, alongside the ontological and epistemological principles which underpin these, namely social constructivism and a commitment to methodological holism, interpretivism and critical reflexivity, respectively. I then discussed digital ethnography, the chosen methodology for this research. As part of this discussion, I outlined practical and ethical issues which I encountered during my research and described how I dealt with these. I then discussed the methods that were adopted for this research, outlining the process through which data was collected and analysed. Finally, I offered reflections on my research process, including limitations, suggestions for change and a discussion of what was successful. The next 4 chapters of this thesis (**Chapters 5, 6, 7 and 8**) comprise the ethnographic section, organised around the 4 key themes as outlined above. The analysis begins with **Chapter 5**, which presents the findings on the theme of disability.

Chapter 5

‘My wheelchair is part of my paraplegic identity’: Binary understandings of authentic versus inauthentic disability amongst the members of transabled.org

Introduction

During the years in which transableism was active, it attracted much attention from social scientists and philosophers (Davis, 2011, 2012, 2014; Elliott, 2003). This research, unlike the clinical research into the desire to be disabled, made attempts to situate this phenomenon within its cultural and historical context by noting the way in which it could be seen to reflect modern Western concerns with authenticity. These explorations could, however, be seen as insufficient, largely because they did not devote similar attention to the way in which transableism was influenced by disability, including the intersection of discourses surrounding disability with those of authenticity. Following this, in **Chapter 2**, I suggested that disability represented a relevant, overlooked factor comprising the transableism ecological niche. In **Chapter 3**, in an attempt to address the oversight regarding this element of the transableism niche, I presented a review of the literature on disability, focusing upon the changing cultural and historical understandings surrounding it. This review led me to observe that, just prior to the emergence of transableism, as an unintended consequence of the disability rights movement, cultural, public and institutional conceptualisations of disability were split into a binary. On the one side of this binary was so-called authentic disability (physical, ‘healthy’ (Wendell, 2001), visible and stable e.g. paraplegia), on the other side were disabilities deemed to be inauthentic (invisible, ‘unhealthy’ (Wendell, 2001) and fluctuating e.g. depression or chronic pain). I then suggested that, as a way to understand transableism, this historically specific binary be combined with a concept utilised more broadly within social constructivist approaches to psychological conditions, namely the ‘cultural polarity’ (Hacking 1998) of a transient mental illness. This concept is used as a way in which to explore how a transient mental illness can be seen to emerge and gain salience, firstly by lodging itself between two oppositional tensions within a society (the ‘cultural polarity’) and, secondly, through the way in which it offers individuals caught within these tensions a culturally sanctioned ‘release’ from their distress (Hacking, 1998). I suggested that these two notions- the binary of authentic versus inauthentic disability and the cultural polarity of a transient mental illness- be combined into a novel conceptual framework through which explorations into the emergence and disappearance of transableism could be grounded.

In this chapter, this suggestion is put to use in empirical analysis; here data coded under the broad theme of ‘disability’, and its various subthemes, is presented to support this analysis (see **Chapter 4** for details of the development of this theme and **Figure 3** for a visualisation of it). In the first section of this chapter, I reintroduce the history, origins and key characteristics of the disability binary. Then, in using empirical evidence from transabled.org, I discuss the ways in which the members’ experiences of disability and understandings of transableism could be seen to map onto this binary. As I outline, contrary to how they are described in much of the existing literature, the members of transabled.org were not ‘able-bodied’ individuals who wanted to be disabled but, instead, they all already suffered with inauthentic disabilities. The disabilities they desired (largely paraplegia or amputation) all conformed to understandings of authentic disability. I present and discuss this data via the framework of cultural polarity, suggesting that this approach offers a way to answer one of the key questions of this thesis, namely why did transableism emerge when it did. In the final section of this chapter, I turn to the second part of Hacking’s theory, namely how a transient mental illness gains further salience via the way in which it offers a ‘release’ to individuals caught within a cultural polarity. Using my empirical data, I outline how, despite the pain it caused, transableism also offered the members of transabled.org a ‘release’, by enabling them to temporarily ‘pass’ as authentically disabled, an experience which went some way towards countering their previous experiences of inauthentic disability stigma. I conclude this chapter by summarising how this notion of release offers further insight into the question of why transableism emerged.

The disability binary

Prior to the disability rights movement, disability was understood as a medical issue and deficit of the, much stigmatised, individual body. However, following political action and advocacy, disability, or ‘disablement’, became reconceptualised as the product of oppressive and exclusionary social and structural arrangements via what is known as the ‘social model’ of disability (Oliver 1990). Whilst largely positive, an unexpected and detrimental consequence of this movement and model could be seen to occur, namely the division created regarding two different types of disability. On the one hand, there were those with physical disabilities that were largely consistent, stable and without serious health complications. The paradigmatic image of this sort of disability is a man in a wheelchair with a condition which is not likely to get any better or worse, for example paraplegia. These individuals were also economically and socially productive, or otherwise ‘able’, and are thus described, by Wendell, as ‘the healthy disabled’ (2001 p. 19, see also Tichkosky 2003). As is noted in the literature, the early disability activists and advocates of the social model almost exclusively fell into the category of the healthy disabled and they served to benefit from the changes demanded by the social model which focused upon physical and structural adjustments (Wendell 2001). On the other hand, there were those with invisible, fluctuating and chronic conditions, which were also often inherently debilitating, severely life-limiting and without clear medical diagnosis. Examples include chronic pain or fatigue conditions and mental health issues such as depression. These individuals relied, to a much greater degree, on long-term socio-economic support, they had much worse long-term outcomes and are thus described by Wendell as ‘the unhealthy disabled’ (2001, p. 18, see also Charmaz, 1991; Hughes & Paterson, 1997; Register, 1987). Wendell describes the ways in which healthy disabled activists could be seen to actively distance themselves from the unhealthy disabled in order to effectively change conceptualisations surrounding disability and achieve their accessibility goals; and they were largely successful in doing so (2001).

As a further result of this internal division, those with healthy disabilities came to stand in as the paradigmatic image of disability, given their publicity and the ensuing ways in which their impairments and needs were reflected in policies, structural adjustments, public symbols of disability (e.g. the wheelchair symbol) and cultural attitudes. A further binary classification thus emerged from this wherein the healthy disabled, being the dominant paradigmatic image of disability, became associated with ‘authentic disability’, and, in conjunction, the unhealthy disabled were deemed ‘inauthentic’ (Mills, 2017; Wendell, 2001). This binary could be seen to infiltrate cultural attitudes and institutional arrangements, alongside impacting the designation of material resources such as welfare benefits and workplace adjustments. The categorisation of types of disability into authentic versus inauthentic thus came to dominate understandings surrounding what did and did not constitute disability across multiple arenas. As will be discussed below, these binary conceptualisations were also reflected within the members of transabled.org's experiences of disability and their understandings of transableism. The empirical data presented in this chapter was, during data analysis, coded under the broad theme of 'disability'. Two sub-themes- inauthentic disability and authentic disability- fell under this broad theme (see **Chapter 4** and **Figure 3** for more details). I begin by discussing the sub-theme of inauthentic disability, as was reflected in the members of transabled.org's experiences.

Inauthentic disability

In much of the existing research into transableism and BIID, sufferers of this condition were described as able-bodied individuals who want to become disabled (First, 2005). Research was also devoted to exploring why an apparently healthy individual would want to voluntarily disable themselves, with many theorists expressing confusion, outrage and a strong ethical objection towards harming the able-body (Bayne & Levy, 2005). Studying the material on transabled.org, a different story emerged. Contrary to what the literature described, the members of transabled.org were not able-bodied individuals who wanted to become disabled. Quite the opposite, nearly all of them had conditions which would fall into the category of unhealthy disability. As discussed above, this category incorporates invisible, fluctuating and chronic conditions. Often these conditions are without a clear medical diagnosis, and they include psychological conditions or, at the very least, have psychological effects. The unhealthy disabilities that the members of transabled.org suffered with were varied, but, nevertheless, conformed to these descriptions. Back problems, fibromyalgia and chronic pain issues were common alongside depression, anxiety, bipolar disorder and autism. Often, a member would have multiple conditions which intersected with and exacerbated each other, a phenomenon which is also noted in the literature (Charmaz, 1991; Register, 1987; Wendell, 1996). Karen for example described having:

> ‘congenital moderate reverse slope hearing loss, fibromyalgia since 1986, and accidental category D spinal cord injury (SCI) in 2006 (as well as) selective mutism as a child, all made worse by social anxiety disorder, OCD and being a hermaphrodite (and probably being on the autistic spectrum!)’

What has been described as particularly characteristic of unhealthy disabilities, and, indeed, as contributing towards their severity, is their chronic nature, alongside the way in which they are inherently physically disabling (Charmaz, 1991; Hughes & Paterson 1997; Wendel 1996, 2001). This was reflected across the board in the members of transabled.org’s experiences; they described their conditions as lifelong, having been present since childhood and showing little sign of improving. They also highlighted the delimiting physical symptoms associated with their conditions, including pain and fatigue. Lucy for example, who suffered from back pain, orthopaedic issues, depression, celiac disease and undiagnosed hand tremors, wrote:

> ‘I’ve been through a lot of pain in my short life. I constantly burn myself with my shaky hands condition. On some days I can’t stand for longer than ten minutes before my feet start getting excruciatingly painful…I almost died when I was a toddler (because of my celiac disease) ...When I was seven, my best friend was a hot water bottle. It helped ease the pain in my gut…these health problems are things that I have learned to live with’.

The stark contrast Lucy describes, between relentless, high levels of pain, combined with a sense of resignation to it, resonates with the experiences of chronic illness sufferers. In addition to the pain itself, the lack of predictability and control around such experiences has also been noted within descriptions of unhealthy disability (Charmaz, 1991; Hughes & Paterson, 1997; Wendel 1996, 2001). Such fluctuating pain and energy levels can pose challenges for managing daily life and future planning (Charmaz, 1991) and this was reflected in the members of transabled.org’s experiences. Charlie, for example, wrote:

> ‘I have fibromyalgia. I have a lot of pain and fatigue. Some days are worse than others. Sometimes I have to do more than others…Other times, I am just well enough to walk…I rarely know which sort of day it

> will be which makes organising anything for more than a week away nearly impossible'.

Alongside being physically debilitating, and often being accompanied by diagnoses of clinical depression, unhealthy disabilities are also noted to cause additional severe social and psychological effects. Charmaz (1991) in particular, describes the detrimental impact that chronic illness can have on a sufferer's self-esteem, self-concepts and sense of their position in the world. These struggles deeply resonated with many of the members of transabled.org. Lisa, for example, in outlining the accumulating effects of living with chronic pain, fatigue and clinical depression, wrote:

> 'When I was young, I was intelligent and knew it. Everything came easy, I had no problems learning anything new. I had kids and stayed home to raise them…then I became ill for the first time…my husband had to make all the important decisions because I was too tired... My brain turned to jello. But even worse is, I've been on long-term medication whose side-effect is to impair concentration and memory. I've been very afraid of losing the gifts I had… It took a huge toll on my self-esteem. I started to feel stupid and relied on everyone around me to remember things or make decisions. People talked about situations that happened and I couldn't follow the conversation because I didn't get it. I just nodded like I understood. It's a horrible feeling. Not only do you feel stupid, you feel left out. Unable to pursue your friendships because you don't get what they're saying. Isolated, and very alone, and scared about what the future holds'.

What Lisa describes is a slow spiral into an ever-greater loss of identity, confidence and connection, initially triggered by her illness, but then made worse by its treatments and symptoms. This was echoed in the experiences of other members who, after becoming ill with an unhealthy disability, described losing friends, suffering blows to self-esteem, and having to give up careers and hobbies.

Although unhealthy disabilities cause pain and suffering for all the reasons described above, what is often described as one of the worst things about them is the way in which they have come to be culturally and institutionally associated with inauthenticity. As a number of authors have noted, since healthy disabilities (e.g. physical, visible and stable conditions) came to represent the paradigmatic image of disability, thus becoming exclusively associated with authenticity, disability stigma has shifted onto the unhealthy disabled (Wendell, 2001). Whilst, prior to the disability rights movement, disability stigma was directed towards bodies deemed deficient or abnormal, now authors describe the way in which it has evolved so as to be intertwined with notions of inauthenticity (Berger, 2013; Mills, 2017). This stigma has been described as hugely detrimental in that, those deemed inauthentically disabled, have become subject to doubt, scrutiny and accusations of fraudulence (Berger, 2013; Mills, 2017; Wendel, 1996). As is noted, this can occur across multiple arenas, including within friendship and family groups, education environments (Jung 2002), the workplace (Ben-Mosche & Powell 2007; Crow, 1996; Young 2000) and even within disability community groups themselves (Deal, 2003). Being the target of a wide range of inauthenticity stigma was reflected within many of the members of transabled.org's experiences. Lucy detailed this by outlining how she was bullied at school because of her disabilities, noting how her school principle refused to intervene because he could not see evidence of her conditions. She also described how she was denied the privilege of moderating an online community for people with disabilities because the other members did not feel her conditions were real. Finally, she described being accused of malingering and avoiding work:

> 'I seem to constantly feel the need to explain myself, justify myself, and at times convince others that I'm not a pathetic loser who sits at home all day…(however) people seem to think it's okay to tell me I'm a drama queen, or that I over exaggerate my physical problems. Part of me wonders "Do they want to see a medical certificate proving it isn't just all in my head?" But then I know that even that would be pointless. A friend pointed out to me today that people do that because I give them permission to judge my life as they see it.
>
> Well I'll say this now: it is NOT ok to tell me I need to get a job in a supermarket because you don't think my problem with my feet is real…If I want your opinion I'll ask for it, otherwise just be supportive or shut up'.

As Lucy's descriptions make apparent, inauthenticity stigma and accusations of fraudulence were extremely frustrating. Many other members of transabled.org shared similar experiences and expressed comparable frustrations. Karen, who was also accused of faking her various unhealthy disabilities, vented her frustrations over this:

> 'I am NOT able bodied. I state EXACTLY the physical impairments I have, no more, no less. My physician has NEVER lied about me on any documents whatsoever. She says that I have fibromyalgia (if you think this is not a disability, then please get educated about disabilities)…It particularly irks me when people don't take one's invisible disabilities seriously.'

Alongside the frustration they feel, what is particularly evident in Lucy and Karen's accounts, are the ways in which they feel like they have to defend, 'explain' and 'justify' themselves and their conditions. This strongly echoes with discussion about the high burden of proof commonly placed on those with unhealthy disabilities (Davis, 2005) and the anxiety this causes (Mills, 2017; Stone, 2005; Vickers, 2000).

Another point which emerges from Karen's observations is her recognition of the fact that she is the target of inauthenticity stigma because of the 'invisible' nature of her conditions. When she states that it irks her when people don't take invisible disabilities seriously, she demonstrates an awareness of, and is critical towards, the priority given to visibility when it comes to judging the validity of disability. These critiques are reflective of what is noted in much of the literature, wherein authors have critiqued the ways in which 'real' disabilities have become inexplicably associated with physical, visible markers, most notably assistive devices such as the wheelchair (Ben-Mosche & Powell, 2007; Marusek, 2005). Awareness of the priority given to visible markers of disability, and the stigma associated with invisibility, was reflected to an even greater degree in the experiences of members with mental health issues. Cassandra, for instance, wrote:

> 'I don't look disabled when I wear long sleeves (to cover self-harm scars)- but my mental illnesses are still disabling. I don't sound disabled when I speak, but I still have trouble doing so (because of

> social anxiety) So just because disability doesn't show doesn't mean it's not there. So why do people have to make a big deal and wonder if it is real- just because they can't point out a disability by looking?'.

In describing similar experiences Jay wrote:

> 'I've had people say "You don't *seem* depressed"…I don't know if that's supposed to be a compliment- but (it's) aggravating…just because you can't see it doesn't mean it's not real'.

As is apparent from both of these accounts, Cassandra and Jay intrinsically associated their experiences of being dismissed or disbelieved with the fact that their disabilities were not visible and thus not available to be 'seen', 'shown', or 'looked at'.

In addition to provoking doubt and accusations of fraudulence from friends, family, employees and members of the public, what is highlighted as particularly harmful about inauthenticity stigma is the way in which it results in individuals being denied access to rights and resources (Dumit, 2006; Mills, 2017; Roulstone; 2015). Again, this was evident on the transabled.org forum, wherein many of the members highlighted the lack of support for their unhealthy disabilities, arising out of doubts concerning legitimacy. Amy faced these challenges over a long period of time and in relation to multiple services and institutions:

> 'I've been on disability since the end of July. Haven't been to work for 9 months now. I am definitely encountering the attitude of 'it's not real, since it's just a mental condition.' How do you support the claim that it's real, and that it really is incapacitating me, especially when in other areas of my life, I look very normal? I received a letter from my disability insurance just the other day, stating that they've decided I'm not really disabled, so are not going to authorize any further claims'.
>
> I'd already decided that I was doing somewhat better and was ready to try returning to work. I was scheduled to go back on the first of May, but HR contacted me yesterday, asking me not to come in until they let me know. Said they need to figure out if they can make use of me still with the modifications and ramp up my doctor has suggested. I'm

> scared this means ‘we don’t think your disability is real enough to put the effort into working with it’…I have to wonder, if I was using a chair instead, if the response would be the same’.

As this description makes evident, Amy is conscious that the termination of her disability benefit, alongside the resistance of her employer to making workplace adjustments, are both related to her condition being ‘just mental’, and thus judged to be ‘not real’. Whilst a lack of material support due to concerns over authenticity took many different forms (such as being denied disability benefits and work place adjustments, as discussed above) it was particularly common for members to outline it in relation to parking placards: official badges prescribed by medical professionals which enable individuals to park in specially designated areas, designed to accommodate wheelchair use. Harriet described how, despite often having to use a wheelchair for a fluctuating chronic pain condition, she had been denied this resource:

> ‘Because I don’t have a *proper* condition, I don’t have the parking placard, I haven’t been written one…so I don’t use the accessible parking, even though my chair might be in my trunk’.

James, in replying to this post, described an almost identical experience, going on to further outline the impact this had on his life:

> ‘I’m in the same position with my parking placard. I haven’t been written one because my condition doesn’t need it 100% of the time and there is no way of proving that on the days I do need it, I really do. I guess they think I’m faking those days or I’d need it all the time…it seems you have to be full time in a wheelchair to get any help with this. And the rest of us, well we just have to stay at home’.

The frequent discussions on the forum surrounding parking plaques are notable, given that this particular resource is also commonly discussed within the literature. As theorists here note, this interest arises out of the fact that parking occupies a paradoxical position, being both an individual resource and a very public space. The result of this is that disabled access to parking is policed, not only by officials in charge of delegating resources, but also by members of the public (Ben-Mosche & Powell, 2007; Marusek, 2005). This threat of public policing was reflected in the members of transabled.org’s experiences. Without possessing parking placards, the members described being scared to use accessible parking spaces in case they received retribution and punishment from the public, including further accusations of inauthenticity. Monica, in outlining this, wrote:

> ‘Even though I need to I wouldn’t just go ahead and use the space anyway. Besides from the ethical side of it, I would be too scared of what would happen. There are a lot of people out there who love sticking their noses and saying ‘you are a faker’...There is a website caughtya.org where people can submit photos of illegally parked cars…I don’t want to end up on that’.

As this description makes apparent, inauthenticity stigma and the associated denial of resources affected the members of transabled.org, not only by making their lives more difficult, but also by instilling fear of public humiliation and encouraging them to police their own behaviour. Whilst the above described manifestations of inauthenticity stigma impacted the members of transabled.org, taking on this burden of fear and self-policing could be seen to result in internalising the inauthenticity stigma and doubting their own legitimacy and entitlements, an experience also represented in academic accounts (Wendell, 1996). Karen, for example, who *had* been granted a parking placard for her partial paralysis and fibromyalgia described the conflict she faced when it came to using it:

> ‘It’s one thing to get the comfort and validation of the placard in full view as one drives. The next question is whether one is really going to use the parking spaces to which one is now legally entitled. It is a problem that has been vexing me for quite a while…Is one morally entitled?
>
> …what if I took a parking spot that was needed by someone else? If their need was greater than mine, I would be greatly bothered by my action. It’s not that I consider my need to be zero…I have a genuine physical disability which limits the distances I can walk. BUT, I don’t have a physical need to wheel. Maybe there are people with a placard who have less need of the parking spot than myself, but for sure there are people with more need’.

After voicing this conflict, Karen then outlined in depth a day spent driving to different appointments and, at each, debating whether her use of the accessible parking space would disadvantage those whose need for it might be ‘greater’:

> ‘(When I got to my second appointment)…there were plenty of nice accessible parking spots, and nobody was parked in any of them. So I took one. It seemed very reasonable. I wasn’t depriving anybody of anything…
>
> (Then) I headed to work…All of the (accessible parking) spots are often taken…Seemed like a regular parking spot would be the most reasonable option here.
>
> On the way home I needed to stop at the grocery store.…Another complexity of the grocery store was that a big storm had moved in and it was pouring with rain. There seemed a reasonable probability that others would be needing the accessible spots. I parked in a regular spot…When I came out of the store. I got soaked putting all the groceries into the car with one hand’.

Despite possessing a parking placard, having a clear need for accessible parking, alongside vocally critiquing the minimisation of invisible disability (as discussed above), Karen’s account evidences the self-attribution of inauthenticity stigma. She appears to have internalised the notion that there were others more authentically disabled then herself, and thus more entitled to resources and she responded accordingly by only using accessible parking spaces when they weren’t otherwise needed, often to her own detriment.

Authentic disability

The cultural category of unhealthy disability, and the associated inauthenticity stigma, did not emerge in isolation but, crucially, in relation to its constituting other, namely ‘healthy’ disability (e.g. physical, visible and stable conditions) (Wendel, 1996). As discussed above, those with healthy disabilities were the key activists of the disability rights movement, and thus their impairments became associated with paradigmatic or ‘authentic’ disability. Authentic disability became additionally associated with wheelchair use, given that structural adjustments were mandated in relation to physical needs and public symbols reflected this (e.g. the symbol of a stick person in a wheelchair was adopted as the International

Symbol of Access in 1981 (Stone, 1995)). As Marusek notes, following these adjustments, the wheelchair (both on signs and as used by a person) became 'the semiotic of disability' (2005, p. 179), reinforcing the idea 'that disability necessarily entails sitting in a wheelchair' (Stone 1995, p. 417).

In much of the existing literature, the members of transabled.org are described as having an intense desire to be disabled. This desire is theorised through the lens of individual, existential authenticity, with authors focusing upon how the members describe their desired disabilities as representing their 'true selves', using phrases like 'this is who I am supposed to be' (Davis, 2012; Elliott, 2003). Whilst insightful, these explorations do not account for the specific *types* of disabilities desired by the members. This oversight is significant as, in addition to the binary of authentic versus inauthentic disability being reflective of the members of transabled.org's experiences, it could also be seen to inform the disabilities they desired and thus their expressions of transableism. In addition to the sub-theme of inauthentic disability describing many of the members of transabled.orgs's experiences, the sub-theme of authentic disability was also present of the forum. Specifically, the actual disabilities that the members of transabled.org desired conformed to socio-cultural notions surrounding authentic disability. In other words, they nearly all desired physical, visible, healthy disabilities that, crucially, would necessitate the use of a wheelchair.

To exemplify: amongst the 38 permanent members of transabled.org, 1 wanted to be blind and 2 wanted to be deaf. 1 wanted to become quadriplegic and 13 wanted to become paraplegic. 9 members wanted an unspecified but nevertheless visible disability that would necessitate the use of a wheelchair. The remaining 12 members wanted an amputation. Of these 12, 6 wanted a single limb amputation whereas the other 6 wanted a double leg amputation, again, specifically so as to necessitate the use of a wheelchair. In total, 29 of the 38 members of transabled.org wanted a disability that required the use of a wheelchair; for only 9 of the members was this not deemed important or was not explicitly outlined (**Figures 7 and 8** display these breakdowns in frequency tables). Significantly, none of the members of transabled.org desired a disability of the unhealthy, inauthentic type: none of them desired, for example, clinical depression or fibromyalgia. As such, and, despite, as outlined in the previous section, the members of transabled.org already experiencing significant disabilities, their understandings surrounding what constituted a ‘real’ disability could be seen as heavily informed by broader conceptualisations regarding visibility, physicality and wheelchair use.

Disability desired (type)	**Frequency**
Blindness	1
Deafness	2
Quadriplegia	1
Paraplegia	13
Unspecified disability	9
Single limb amputation	6
Double leg amputation	6
TOTAL	38

Figure 7: Frequency of disability desired by type

Disability desired (wheelchair requirement)	**Frequency**
Necessitating use of wheelchair	29
Wheelchair use not important/ not outlined	9
TOTAL	38

Figure 8: Frequency of disability desired by wheelchair requirement

Nowhere was this internalisation of broader conceptualisations surrounding authentic disability more apparent than within the members’ descriptions of the disabilities they desired, where wheelchair use was the defining and most important characteristic. For example, those who wanted to be paraplegic, rather than discussing the physicality or phenomenology of this, instead made statements such as ‘My wheelchair is part of my paraplegic identity’ (Lisa) and ‘I cannot separate my wheelchair from who I am inside (a T12 paraplegic)...it’s an intrinsic part of this identity’ (Lucy). In addition to these statements being made by members whose desired disabilities would make the use of a wheelchair a practical necessity (e.g. paraplegia), members who desired either amputations or unspecified disabilities also emphasised, to a similar extent, the importance of wheelchair use in relation to these identities. Flora, for example, wrote:

> ‘I too want to be paralysed, T12 would work for me and I don’t care if complete or incomplete so long as it requires use of a wheelchair…I need to need a wheelchair for mobility…the specific disability is not as important’.

Similarly Margaret wrote:

> ‘(I) need to have legs that don’t work very well, so that I have to use a wheelchair if I want to move more than a few steps. I imagine this would mean a fairly low-level spinal cord injury, perhaps incomplete…whatever means I will have to use a wheelchair to walk’.

It is apparent here that the desired disabilities were fundamentally structured around the use of a wheelchair, with any details surrounding the actual physical disability seeming to hold secondary importance, or, indeed, to be little understood. Thus, reflecting findings in the academic literature (Ben-Mosche & Powell, 2007; Marusek, 2005; Stone, 1995), authentic disability was associated with wheelchair use above any other factor. To some degree, this association could be seen as foreshadowed in the members’ experiences of unhealthy disability, where they were aware that their unhealthy disabilities were deemed inauthentic due to their lack of visible markers, with many speculating that they were disbelieved and denied access to resources as a result of them not needing to use a wheelchair on a permanent basis. This foreshadowing is further evidence of the way in which members had internalised and been influenced by the broader cultural binary which associates authentic disability with wheelchair use and inauthentic disability with its absence.

Understandings surrounding what constitutes authentic versus inauthentic disability, not only emerged out of changes to institutions and policies, but were also reinforced by public understandings and judgments (Marusek, 2005; Roulstone, 2015). Just as public judgements (or, at least, the threat of them) reinforced the members’ experiences of inauthentic disability (e.g. they were too scared to use accessible parking for fear of being judged as inauthentic, a judgement that became internalised), public assessments could also be seen to inform the members’ experiences of authentic disability. This was evident in discussions of wheelchair use within social interactions. For context, many of the members of transabled.org owned wheelchairs and went out in them in public. Whilst this was often situated as a therapeutic treatment for identity incongruence, public wheelchair use was also valorised for the ways in which it afforded the members a sense of social recognition. Within public interactions, what appeared to be especially significant for the members of transabled.org was when they 'passed' (Goffman, 1963) as 'genuinely' disabled. In other words, when they were read by members of the public as having an authentic disability. Lisa exemplifies this within her description of an interaction she had with a strange man who saw her transferring from her wheelchair to her car:

> 'he (said) "My wife is handicapped too…" If his wife is handicapped "too" then I must be the other handicapped person! That gave me a little thrill of pleasure, regardless of how politically correct the expression is'.

Similarly, Monica, in describing entering a supermarket in her wheelchair, wrote:

> 'The server at the door saw me and straight away said "If you need any assistance today Miss then let us know". Whilst I felt like saying to him, it's Ms not Miss, I was ecstatic that he assumed I was disabled and wasn't about to correct him on that!'

Other members, in adding to these conversations, outlined the reason why passing was experienced as so pleasurable. As Benjamin put it: 'Yes! External validation, or acceptance from other people that I am a wheeler, is a big reason to go out in my chair'. Reinforcing this, and as further evidence of external validation as a motivation for wheelchair use, many of the members of transabled.org did not use their wheelchairs when alone at home. As Lisa described it, 'wheeling alone in the house is a pretty poor substitute for being seen in public'. Whilst public judgements of inauthenticity were internalised, causing the members pain and leading them to doubt themselves, public judgements of authenticity had the opposite effect; they brought 'ecstasy' and 'pleasure', alongside 'validation', or the internalisation of authenticity. This resonates with descriptions in the literature, which outline how the recognition, belief and validation of disability can be hugely beneficial, not just in terms of the material resources it enables, but also in terms of social and psychological wellbeing (Charmaz, 1991; Dumit, 2006; Wendell, 1996).

As discussed, for the members of transabled.org, authentic disability was associated with wheelchair use, above any other factor, demonstrating their internalisation of broader cultural understandings. The fact that passing as authentically disabled was always a direct result of the members of transabled.org using their wheelchairs, served to further reinforce this association. Members themselves acknowledged that their wheelchairs played this communicative role. Luke, for example, wrote:

> ‘Most people who see a wheelchair user will automatically assume that person is permanently disabled and often paralysis is the reason for the device…that’s the reason that (most with BIID) use a wheelchair’.

Karen offered a particularly interesting perspective on this issue. Often Karen, who was intersex, would discuss her experiences of gender passing on the transabled.org forum. She described the various types of ‘gender cues’ she had explicitly enhanced or concealed throughout her life so as to have her authentically felt gender identity (female) socially recognised. She spoke of removing her facial hair, enhancing her breasts and wearing feminine clothing and makeup. She directly compared her public use of the wheelchair and passing as paraplegic to this process. She wrote:

> ‘We all present an ensemble of gender cues. The most potent male gender cue is facial hair. The most potent female gender cue is breasts. Likewise, we present an ensemble of disability cues. The most potent of which being a wheelchair’.

Thus, the members of transabled.org demonstrated an awareness of the culturally specific ‘semiotic load’ carried by the wheelchair, and its role in communicating authentic disability (Ben-Mosche & Powell, 2007; Courvant, 1999). Nevertheless, the fact that they still used wheelchairs (and primarily associated authentic disability with doing so) is evidence that this critical awareness was not enough to overcome their internalisation of the broader, cultural disability binary, thus demonstrating its strength. This paradox reflects discussions within the literature, wherein sufferers of unhealthy, fluctuating disabilities are critical of the authenticity they are granted when using wheelchairs and other aids, yet persist in doing so within particular contexts that require the verification of disability (e.g. workplaces, educational establishments, social services and sporting arenas) (Renfrow, 2004; Siebers, 2004).

Authentic versus inauthentic disability as a cultural polarity

As I have been discussing thus far in this chapter, the members of transabled.org were not able-bodied individuals who want to be disabled but, instead, they all already suffered with inauthentic disabilities. Relatedly, the disabilities they desired conformed to understandings of authentic disability. These experiences and expressions were not, I argue, arbitrary but, instead, could be seen to reflect a broader 'cultural polarity' (Hacking, 1998) regarding authentic versus inauthentic disability. As discussed in **Chapter 3**, when theorizing transient mental illnesses, Hacking notes how these phenomenon owe their existence not only to an ecological niche but, more specifically, to the way in which such conditions can be seen to represent core oppositional tensions or what he terms cultural polarities within societies (1998). The term cultural polarity refers to the way in which there are often two versions 'of the same thing' within a culture, one largely approved of and held up as 'virtuous', one disapproved of and considered an, often criminal, 'vice' (Hacking 1998, pp 48-49). As Hacking outlines, a transient mental illness gains its salience largely by embedding itself between the two values of a cultural polarity, drawing upon the economy of images and social roles which constitute them, and expressing the core tensions which exist at their intersection (Hacking, 1998 see also Brossard, 2019). In this sense a cultural polarity is often a fundamentally constitutive part of an ecological niche of transient mental illness and thus, identifying such a polarity aids in understanding why the condition in question emerged when it did.

Following this, I suggest that authentic and inauthentic disability were the two, respectively, virtuous and vicious poles comprising the cultural polarity which enabled the emergence of transableism. Not only were these two poles culturally and historically specific to the emergence of transableism (being solidified in the early 90s following the disability rights movement); but they were also widely conceived of as virtuous- authentic disability being legitimated and incorporated into policies and institutions- and vicious- inauthentic disability being subject to stigma and accusations of fraudulence. These judgements regarding the virtuous versus vicious nature of authentic versus inauthentic disability, respectively, were strongly evidenced in the members of transabled.org's experiences, as discussed above. These experiences did not emerge in a vacuum but were reflective of the broader concerns surrounding the vicious, or even criminal, nature of inauthentic disability and the simultaneous prioritization and legitimation of authentic disability. Thus, transableism, manifesting as the desire to move from being inauthentically to authentically disabled, was firmly embedded between these two opposing cultural understandings and concerns, and I suggest it is this which enabled it to emerge and gain salience when it did.

As outlined in **Chapter 3**, in addition to Hacking describing how a transient mental illness lodges itself within a cultural polarity, he also discusses a second, interconnected, factor which gives a transient mental illness its salience. As he notes, the illness in question, whilst being unpleasant, nevertheless provides sufferers with a socially sanctioned way of gaining 'release' from the pain of being caught up in a cultural polarity (1998). In relation to this notion of release, there is one final point to be made about the members of transabled.org's manifestations of transableism, in particular, their prolific use of wheelchairs. As described above, although wheelchair use was situated as a therapeutic treatment for transableism, it also brought the members pleasure, joy and, crucially, a sense of validation and recognition in passing as authentically disabled. Further to this, at times, the members of transabled.org even explicitly linked their wheelchair use and associated passing to their experiences with inauthentic disability, as discussed in the previous section. In outlining this, Monica wrote:

> 'I have spent my whole life being told that my pain is all in my head so when I am seen in my wheelchair it is like I am finally being recognised and taken seriously…It is such a relief. It almost makes all that that's gone before shrink and go away'.

While Monica does not explicitly situate her transableism as caused by her previous experiences with inauthenticity stigma, it is, nevertheless, evident that passing as authentically disabled is an emotionally corrective experience. In other words, it offers a fitting remedy- or release- from a lifetime of disability invalidation. It is for this second, interconnected, reason that I suggest transableism emerged when it did; the members of transabled.org were united by their experiences of inauthentic disability, and transableism- including the associated wheelchair use and social passing- offered them a release from this collectively held pain. In some ways, this experience of release can be seen to resonate with accounts detailed within the academic literature. As is noted here, a number of strategies are often utilised by the inauthentically disabled, to manage inauthenticity stigma. A number of authors have described the ways in which individuals engage in acts of ‘revealing’ (Stone, 2005) or ‘un/covering’ (Evans, 2017) invisible disabilities through, what Siebers calls ‘the disability masquerade’ (2004). This term refers to the ways in which individuals ‘disguise one kind of disability with another or display their disability by exaggerating it’ (2004, p. 4). Often this takes place through the strategic use of disability aids, notably wheelchairs, which are not entirely or consistently necessary (Renfrow, 2004; Siebers, 2004). This enables inauthentically disabled individuals to secure both the social validity and the material support they need (Siebers, 2004; Stone. 2005). Whilst these academic examples do differ from transableism, in that use of the wheelchair is here self-consciously strategic, the release offered to the members of transabled.org via their use of wheelchairs can, nevertheless, be thought of as representing a crystallised microcosm of the more widespread behaviours related to the disability binary, albeit taken to their most extreme conclusion.

Summary

This chapter has combined two notions- the binary of authentic versus inauthentic disability and the cultural polarity of a transient mental illness- into a novel conceptual framework, through which empirical data from transabled.org has been explored. As highlighted, the members of transabled.org’s experiences of disability and their understandings of transableism could be seen to precisely map onto the authentic versus inauthentic disability binary. The members were not able-bodied individuals who wanted to be disabled; they all already suffered with inauthentic disabilities. Simultaneously, the disabilities they desired all conformed to understandings of authentic disability. Given that these experiences and understandings were reflective of the broader issues associated with the cultural polarity of authentic versus inauthentic disability, these observations offer an explanation for why transableism emerged when it did: transableism emerged out of this cultural polarity, it drew upon its central understandings and discourses, and it was a microcosm of its core tensions. What this thus tells us is that, rather than transableism representing a desire to be disabled per se., it was expressive of a desire to be authentically disabled, as broadly culturally understood.

The later section of this chapter illustrated how transableism offered benefits to the members of transabled.org by enabling them to temporarily pass as authentically disabled, an experience which was validating and went some way towards countering their previous experiences of inauthentic disability stigma. This observation offered a second, associated, explanation for why transableism emerged when it did, also connected to the theory of cultural polarity. Despite the pain it caused, transableism provided the members of transabled.org a release from the specific experience of being caught within, and oppressed by, the cultural polarity of authentic versus inauthentic disability. The social exclusion that resulted from inauthenticity stigma left the members of transabled.org in a liminal space- they had lived, often painful, experience of disability, yet they were denied recongition and legitimation. By identifying as transabled and taking part in transabled rituals and expressions (namely public wheelchair use), the members of transabled.org were able to temporarily exit the liminal space they found themselves in, when they might not otherwise have been able to. Many individuals deemed inauthentically disabled, who do not have transableism, are unable to escape this liminality, despite wanting to. The emergence of transableism can thus be seen as inexplicably intertwined with a more broadly held need for those with inauthentic disabilities to be recognised as authentic and granted legitimacy, in that it precisely reflected and enacted this need. In **Chapter 9**, I return to these findings, integrating them with findings from subsequent empirical chapters, alongside discussing their broader significance, particularly in relation to the field of disability studies. Before that, however, I discuss the second theme to emerge from the data on transabled.org, namely authentic BIID.

Chapter 6

‘BIID is a disability like any other’: The social construction and negotiation of BIID as an authentic disability

Introduction

Whilst previous research into transableism used authenticity as an analytical concept, it exclusively studied how the desire to ‘feel authentic’ acted as a motivating force for the members of transabled.org (Davis, 2011, 2012, 2014; Elliott, 2003). This focus on authenticity, as an existential and objective phenomenon, came at the expense of exploring authenticity through a social constructivist lens. When it comes to understanding the ecological niche of transableism, this oversight is significant given that the members of transabled.org, not only described needing to be disabled, but attempted to construct and situate Body Integrity Identity Disorder (BIID), a newly emerging and yet to be verified psychological condition, as a ‘disability like any other’ (their words). In **Chapter 3**, in an attempt to address the oversight regarding social constructivist theories of authenticity, I presented a review of this literature. As was outlined here, rather than viewing it as an entirely objective property, many theorists have advocated that we study the ways in which authenticity comes into being via various practices, symbols, settings and relationships so as to successfully emerge within certain encounters and contexts (Cohen, 1988; Jones, 2010; Wang, 1999). Intrinsic to this understanding is the observation that, being subject to social construction and negotiation, authenticity exists in relation to power and authority (Bruner, 1989; Silver 1993; Sissons, 2005). Whilst being explicitly developed in the fields of tourism and post-colonial studies, the social construction and negotiation of authenticity has also been implicitly applied in medical sociological studies regarding processes of diagnosis negotiation. Following this, in **Chapter 3** I suggested that a conceptual framework based on the social construction and negotiation of authenticity and an associated ‘politics of authenticity’ (Brubaker, 2016a, 2016b; Sissons, 2005) be used to analyse how the members of transabled.org attempted to negotiate the diagnosis of BIID and situate it as a ‘disability like any other’.

In this chapter, this framework is put to use in empirical analysis; here data coded under the broad theme of 'authenticity of BIID', and its various subthemes, is presented to support this analysis (see **Chapter 4** for details of the development of this theme and **Figure 4** for a visualisation of it). In the first section of this chapter, I expand upon the literature regarding the social construction of authenticity. Using empirical evidence from transabled.org, I then discuss the ways in which the members attempted to construct and negotiate the authenticity of BIID. I argue that this this was done, firstly, via their attempts to align it with the already established and authenticated diagnostic category of Gender Identity Disorder (GID): when articulating BIID, the members borrowed key narratives, symbols and themes from GID so as to index the authenticity of BIID. It was also done via members attempting to delineate what transableism was *not*, namely 'devoteeism' (a sexual fetish) or 'pretending'. These negotiations were all carried out with the ultimate goal of having BIID officially authorised via its inclusion in the DSM-V. In the second part of this chapter I analyse the 'politics of authenticity' (Brubaker, 2016a, 2016b; Sissons, 2005) that surrounded BIID and were enacted on transabled.org. As I describe, members of the disability community denied the status of BIID as a 'disability like any other', attempted to police the members of transabled.org's behaviour and protect the boundaries of their own identity category. In the final part of this chapter, I suggest that these observations can be used to answer one of the central questions of this thesis, namely, why did transableism disappear. I contend that, although the members of transabled.org made strong attempts to negotiate the authenticity of BIID as a 'disability like any other', the fact that it did not conform to an acceptable politics of authenticity, and was policed accordingly, played a role in its disappearance.

The social construction and negotiation of authenticity

Broadly, social constructivist theory is a critique of the assumptions inherent in objectivism that argues for the existence of a 'real world', independent of human language and activity (Jones, 2010; Wang, 1999). Instead, social constructivists describe reality as emerging 'in practice' (Mol, 2002) and dependent upon context, intersubjective settings, and networks of social and material relations (Cohen, 1988; Jones, 2010; Wang, 1999). In relation to the study of authenticity, scholars have critiqued the notion that this is a property which can be truthfully determined, instead suggesting that we should study the ways in which certain practices, contexts, settings, relationships and systems of meaning, work to produce and construct authenticity. As these theorists have been keen to clarify, this view of authenticity, despite what is implied in the term ‘construction’, does not always indicate intention or agency, hence the existence of words such as ‘emergence’ (Mol, 2002). Nevertheless, particularly when it comes to authentic identity, certain authors have highlighted how agency, intention or ‘negotiation’ *are* often present (Conklin, 1997; Sissons, 2005).

For context, those studying the social construction of authenticity in relation to identity, have noted how what counts as so-called authentic identity is commonly determined by those with power and authority, and officiated in relation to certification processes and bodies (Bruner, 1989). This point is observed within theoretical critiques of identity politics (Appiah, 1994; Fraser, 1997) and, as discussed in **Chapter 3**, within empirical explorations in tourism and post-colonial studies (Conklin, 1997; Silver, 1993; Sissons, 2005). As the tourism and post-colonial literature notes, given the unequal relationships of power and histories of oppression, native populations heavily rely upon Western tourists or colonisers for their economic livelihoods, alongside access to rights and resources. The allocation of such resources is often determined by stereotypical, essentialist and historical understandings surrounding so-called authentic identity (Conklin, 1997; Harris, Carlson and Poata-Smith, 2005; Sissons, 2005). What this then means is that, within these touristic and post-colonial contexts, those in positions of lesser power, whilst not being able to delineate authentic identity on their own terms, can be seen to negotiate it for strategic gain. This is done via minority identity groups indexing their authenticity via the semiotics that surround it, as determined by those in power and their authorising bodies. Such semiotics of authenticity include traditional dress and bodily decorations (Conklin, 1997), emphasis on ancestral lineage and connection to nature (Harris, Carlson & Poata-Smith, 2005) alongside the performance of shamanic rituals (Rogers, 1996).

Whilst not explicitly situating it as a process of authenticity negotiation, a similar phenomenon to that described in the tourism and post-colonial literature can be seen to take place in relation to medical diagnoses, particularly regarding emerging or contested illnesses, such as BIID (Dumit, 2006; Trundle, Singh & Broer, 2014; Whelan, 2010). As outlined in diagnosis literature, when interacting with doctors and social care providers, illness sufferers often strategically index authenticity in relation to desired diagnoses, which can include narrativising experiences in alignment with formal diagnostic categories. In these instances, this is likewise carried out with the aim of acquiring official certification and associated rights and treatments (see **Chapter 3** for discussion Dumit, 2006; Trundle, Singh & Broer, 2014). This process of negotiating, indexing and aligning with the semiotics of authenticity to acquire authorisation and rights, was found to be present on transabled.org regarding the members' claims that BIID was a legitimate mental health condition and thus a 'disability like any other'. The empirical data presented in this chapter was, during data analysis, coded under the broad theme of 'authenticity of BIID'. Two sub-themes fell under this broad theme (see **Chapter 4** and **Figure 4** for more details). The first of these sub-themes was the social construction of BIID. As I will now discuss, this sub-theme covered attempts made, and strategies used, by the members of transabled.org to position BIID as an authentic diagnosis and 'disability like any other'.

Negotiating the authenticity of BIID

The insistence that BIID was 'a disability like any other' was common parlance on transabled.org; it was written in the homepage introduction and was frequently used elsewhere on the forum. The rationale behind this claim was that BIID was a psychological condition and that, according to the Americans with Disabilities Act (ADA), psychological conditions were considered disabilities as much as physical conditions were. Despite members reiterating these points, in the years that transabled.org was active, the status of BIID as a psychological disorder was not official. Although it had been proposed for entry into the, then forthcoming, DSM-V, BIID was still a contested and emergent condition (unlike, for example, bipolar disorder or schizophrenia). As such, it was necessary for the members of transabled.org to negotiate and index the authenticity of BIID, as a psychological disorder, in order to support their claims that it was 'a disability like any other'. This was done in a number of ways, all of which can be seen as comparable to those outlined within the literature discussed above.

The primary authentication tactic used by members was the way in which they supported the comparison and alignment of BIID with GID. For context, when, in 2005, BIID was proposed as a new psychological disorder, researchers described it as akin to the already existing condition of GID (First, 2005). BIID was described as being similarly caused by a sense of identity incongruence and as sharing associated symptoms and characteristics with GID. As such, researchers recommended that it should likewise be categorised under the ‘identity disorder’ family (First, 2005). On the forum, the members directly advocated this clinical comparison. Laura, for example, wrote:

> ‘Michael First was right to draw the parallel between Gender Identity Disorder and BIID. He’s right that this is a fundamental question of identity and not a lifestyle choice’.

In addition to explicitly supporting the broad alignment with GID, in order to further back this up, members compared their experiences of BIID to the full range of already established symptoms and narratives surrounding GID. Firstly, they compared the sense of identity incongruence that characterised both conditions. Whilst all the members of transabled.org drew this comparison, it held particular weight when it was made by those with experiences of both GID and BIID. Sophia, for example, wrote:

> ‘I am a transsexual. I had GRS (genital reassignment surgery) in October 2005 with a well-recognized surgeon in North America. I am also transabled: I have a desire to be moderately/severely deaf…I’m hoping to make the similarities between transableism and transsexualism known so that more people can understand the transabled person.
>
> A transsexual is a person that feels an incongruity between their genitals and their gender identity…A transabled person is someone who desperately wants or needs to be disabled in some way. A transsexual feels that their body is different from the concept of self they have for theirself. A transabled person is in a similar position…In each case the problem at hand is the incongruity in self-image from bodily reality’.

Secondly, the members of transabled.org positioned their identity incongruence as ‘unchosen’, in the same way gender incongruence was for those with GID. Sean stated:

> ‘We did not choose to have the feelings we have. We haven’t chosen to have BIID any more than someone who is transsexual has chosen one bright morning that they are in the wrong body. It just *is*. Not a choice…(it is) simply just another set of bodily instincts being mis-wired’.

Thirdly, in further support of the notion that BIID was unchosen, the members of transabled.org also highlighted how, similarly to wishes to become the opposite sex, their desires to become disabled had been present since early childhood. Jacob, for example, wrote:

> ‘I read recently in a newspaper an article about a story of a 3 year old boy who wanted to change his gender. It was weird, thinking back that something like this can start so young.
>
> The story continued and eventually the boy turned 5 years of age, and then began wearing girl’s clothes, and the parents eventually supported this change….I’ve been thinking about this a lot…I can’t help but think that wanting to wear braces started for me when I was around 7 years old.’

Fourthly, the members further aligned BIID with GID by discussing the ways in which neither could be treated with psychological therapy or medication, highlighting how, for both of these conditions, reassignment surgery was the only effective cure. Kayleigh explained:

> ‘Various people have claimed (and I have no reason to doubt them) that BIID… doesn’t respond to psychopharmacology or CBT (cognitive behavioural therapy) or other psych therapy.
>
> I mean, this is why TS (transsexual) people get surgical treatment - precisely because the drugs and the psych therapies don’t work. Someone once described it as the only curable psychiatric disease - all the others are treatable, but they don’t turf the patients out never to see them again. Depression recurs. Manic depressives are on pills for life. Sociopaths are pretty much unfixable. GID people? One set of fairly simple surgery and their GID *goes away*…Well. Isn’t that kind

> of freaky? The only “mental illness” where they send you to a urology surgeon and he cures it? Likewise, BIID appears to be curable: if the psychs decide they can’t do anything, one had better talk to an orthopaedic surgeon’.

Finally, whilst the members of transabled.org insisted on the inefficiency of therapy and medication for their BIID, they did note how the use of a wheelchair (as discussed in **Chapter 5**) could alleviate their symptoms. This therapeutic use of the wheelchair was compared to the ways in which cross-dressing was noted to have therapeutic benefits for pre-operative transgender individuals. Sean wrote:

> ‘It is no secret that I believe there are many similarities between transabled and transgendered folks. As such, I draw many parallels in a suggested treatment course…
>
> Just as those with GID need to live full time in their gender of choice before actually going for SRS (sex reassignment surgery) …for those of us who need to be paralysed, using a wheelchair is the only way (short of surgery) to be able to function’.

To summarize, the members of transabled.org compared their experiences of BIID to 5 key, already established and recognised GID symptoms: (1) identity incongruence, which was (2) unchosen, (3) present since childhood, (4) treatable only through surgery and (5) somewhat eased with cross-identity presentations. These symptoms, being officially outlined in the DSM diagnostic criteria and further reinforced in common cultural narratives surrounding GID have come to represent the key semiotics of authentic identity disorder (Brubaker, 2016b; Mason-Schrock, 1996; Sadjadi, 2019). By closely comparing their own experiences of BIID with these symptoms, the members of transabled.org could be seen to make strategic use of these semiotics so as to ‘index’ (Conklin, 1997; Sissons, 2005) the authenticity of BIID and negotiate its status as a formally recognised psychiatric disorder.

Within the literature on the negotiation of authenticity, alongside discussing active ways of aligning with and indexing authenticity, a further, more implicit, process unfolds. It involves defining the authentic in relation to what it is not and distancing from this constituting other, often by labelling it as inauthentic. These types of de-aligning moves are evident in the tourism and post-colonial literature wherein minority groups are described as defining themselves against neighbouring tribes and cultures (Conklin, 1997; Harris, Carlson & Poata-Smith, 2005). However, it is in the diagnosis literature where this phenomenon is discussed in most depth. Here, studies into contested and emergent illnesses have highlighted the way in which, in order to acquire authenticity and certification, sufferers can be seen to clearly distance themselves from peripheral medical phenomena and alternative explanations for their symptoms (to be discussed in more depth below) (Boero & Pascoe, 2012; Dumit, 2006; Whelan, 2007).

In addition to supporting its alignment with GID, the members of transabled.org could also be seen to engage in processes of de-alignment when attempting to negotiate the authenticity of BIID. This involved not only the insistence that BIID was an ‘identity disorder’, but also a clarification of what their desires to be disabled were *not.* As discussed in **Chapter 2**, prior to being proposed as an identity disorder, the desire to become disabled was thought of as a paraphilia (Money, Jobaris, & Furth, 1977). Later, it was also situated as a pathological attempt to gain care and attention, akin to Munchausen’s Disorder (Bruno, 1997). These understandings were labelled (both clinically and colloquially), ‘devoteeism’ and ‘pretending’, respectively (Bruno, 1997). Whilst First’s 2005 study (which coined the term BIID and situated the desire to become disabled as an identity disorder) challenged these previous understandings, their implications and the stigma surrounding them still hung over the members of transabled.org. This was compounded by the fact that within the broader ‘desire to be disabled’ community, some individuals did still express sexual desires and attention seeking motivations. Upon transabled.org, these older understandings were seen to threaten the identity incongruence hypothesis and thus the notion that BIID was a legitimate psychological condition and a ‘disability like any other’. In order to protect these understandings, members de-aligned themselves with the terms devotee and pretender and their connotations. This de-alignment was built into the very architecture of the forum. Transabled.org had a glossary page, written and compiled by Sean, which contained definitions of a number of terms. Here the terms devotee and pretender were explicitly positioned against the definition of transabled as follows:

> ‘Devotee: Someone who is sexually attracted to people with disabilities *because* of their disability.…they are merely attracted to the disabled, for reasons generally unclear.
>
> Pretender: Someone who will "play"…at being disabled. From using a wheelchair in public…to tying one’s leg at home and pretending to be an amputee. Most pretenders don’t want to actually be disabled for real, but just get a feel of things.
>
> Transabled: This is a word I coined that better fits... Transabled, to me, is someone who desperately wants, or needs, to be disabled in some ways. It is generally not a sexually related desire, unlike the attraction of devotees, or the "games" of pretenders. I do NOT pretend to use my wheelchair, I do’.

Alongside these formal definitions, the terms devotee and pretender, and the motivations behind them, were distanced from genuine BIID elsewhere on the forum. For example, many of the members of transabled.org would adamantly deny that their desires to become disabled were related to sexuality. This could be seen to mirror historic de-alignment processes, as carried out by members of the transgender community in relation to the category of GID. As discussed by medical historians and sexologists, prior to the middle of the 20th century, transgender individuals were categorized alongside other so-called sexual perversions of the time (including homosexuality, bisexuality and fetishism) and, by association, were stigmatised, often being denied care and surgical treatment (Meyerowitz, 1980; Valentine, 2007). A large part of the transgender rights movement of the 1980s involved the claim that gender identity was distinct from sex and sexuality, which successfully resulted in GID becoming more widely acknowledged as a phenomenon of identity incongruence, to be medically treated, as well as legally and socially protected (Meyerowitz, 1980; Sadjadi, 2019; Valentine, 2007). The members of transabled.org, could be seen to borrow this historically successful de-alignment tactic, making almost identical claims regarding the nature of BIID. Ben wrote:

> ‘Got to admit, I don’t find anything particularly sexual about wheelchairs, mobility aids, diapers/catheters and the like. The thought of myself being paralysed doesn’t get my sexual juices flowing either…for me, there’s no sexual basis to my BIID at all. I certainly

> don’t think it’ll make me any more attractive to the ladies, probably less if I’m being honest. C’est La Vie’.

Lucas also rejected any sexual motivations behind his desire to become disabled, going on to firmly situate his BIID as about correcting identity incongruence:

> ‘There is nothing that turns me on about paraplegia. My need to become paraplegic is about my need to become who I really am.’

In addition to drawing this distinction between their need to be ‘who they really were’ and the devotees’ sexual motivations, as a further de-alignment move, the members of transabled.org also positioned sexual arousal regarding disability as unethical. Again, this resonates with what is observed in the transgender literature that outlines how moralizing discourses were a constitutive part of de-aligning gender identity incongruence from sexuality (Meyerowitz, 1980; Valentine, 2007). An example of this type of discourse on transabled.org could be found under a section of the forum entitled ‘photos’. The link to this section did not take the visitor to any images; instead it simply took them to a page containing a statement written by Sean which read:

> ‘You will not find photos of people with disabilities on this on this site. This site is not for the voyeuristic devotee to fill hir[33] eyes out.
>
> I do not believe in taking and/or posting photos of people with disabilities, especially without their direct consent. I never have, and never will…So, if you’re looking for a good shot, look elsewhere!’

De-aligning also occurred in relation to the term pretender. The members of transabled.org critiqued the phenomenon of pretending to be disabled for its playful, light-heartedness. By contrast, the members emphasized how their use of the wheelchair was serious and necessary, given that it was a treatment for the genuine disability of BIID. Lisa, for example, in a post titled ‘BIID vs. Pretending for kicks’, wrote:

> ‘It’s very important to distinguish between people who have a genuine psychological/neurological condition (BIID or Body Integrity Identity Disorder) and people who are pretending for kicks …

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[33] Hir is a gender-neutral pronoun, occasionally used on transabled.org.

> I am a member of the first group; I have BIID. To me, using a wheelchair is therapy…For me, it's not a choice at all. I **MUST** wheel. Not because it's fun. But because I can only have fun, or pleasure, or peace, if I'm relieved from the psychological distress of walking'.

The de-aligning processes described above strongly resonate with findings regarding the negotiation of other diagnostic categories, in particular eating disorders. As noted in this literature, individuals with anorexia can often be seen to sharply separate their diagnostic category from 'fakers' (Giles, 2006) or 'wannarexics' (Boero & Pascoe, 2012)- terms which are used to describe individuals who are less serious, lacking in commitment and thus less authentically eating-disordered, as compared to those with anorexia. The term pretender could be seen to operate a similar function in relation to BIID.

What is commonly discussed in the literature regarding the negotiation of authentic identity is, not only the many processes of alignment and de-alignment involved, but why these efforts are so important. As outlined, it is often necessary to acquire an official verification of authenticity, so as to gain access to rights and resources that, for diagnostic authenticity, can include health care benefits and treatments. When it comes to psychiatric disorders, inclusion in the DSM is widely seen as the gold standard of official authenticity verification (Goodwin & McConnell, 2014; Spade, 2003). Discussions on transabled.org illustrate how members were fully aware of the power vested within the DSM to authenticate their condition, and this awareness could be seen to inform many of their negotiation efforts. Being closely aligned with GID and thus included in the DSM would be a significant authentication tactic, in that it would provide BIID with a similar level of legitimacy in the eyes of the medical community, thus offering access to treatment. As Paul wrote:

> 'I believe claiming an analogical relation between BIID and GID is useful. It is the nearest, successful group to us…GID is successful because it is in the DSM, which (makes) the disorder easier to understand to medical professionals…It is the medical profession that decides what should be done or not done (and) as we know people with GID can now get a diagnosis and treatment'.

Evidently, members were aware of the essential need to have BIID included in the DSM if they were ever to receive the rights and benefits they advocated for.

To bring the above observations back to the critical literature regarding the negotiation of authenticity, although the members of transabled.org actively engaged in processes of alignment and de-alignment –thus enacting agency over the negotiation of authentic BIID- this agency can be seen as structurally overdetermined. As many GID critics and activists have outlined, the key symptoms and narratives of transgenderism (which were subsequently borrowed by the members of transabled.org), despite their prevalence, rarely comprehensively represent the reality of transgender experience (Meyerowitz, 2002; Valentine, 2010). Nevertheless, and because of their official diagnostic and cultural status - a result of their being historically constituted by those with medical authority - they have come to represent authentic GID. The result of this is such that individuals with gender dysphoria have historically been required to perform these indexes of authenticity to acquire an official diagnosis and access to treatment (Brubaker, 2016b; Spade, 2003; Valentine, 2010). Similarly, as discussed in the literature on emergent illnesses, the de-alignment moves enacted by sufferers with these types of conditions, whilst increasing the chance of acquiring an official diagnosis, can likewise come at the expense of nuance or accurate representation (Dumit, 2006; Whelan, 2010). As discussed in **Chapter 3**, these processes have been described as a type of 'oppressive authenticity' (Sissons, 2005). In the empirical data discussed above, we see a parallel process taking place amongst the members of transabled.org in their attempts to have their BIID recognised and taken seriously. The members engaged in the process of indexing authentic identity disorder according to top-down definitions, which were historically constituted and authorised by powerful medical bodies. In this sense, although actively negotiating authentic BIID, the members were also, to some degree, subject to a type of 'oppressive authenticity' in relation to the epistemic authority held by medical diagnoses and clinical communities (Sissons, 2005).

Authenticity politics

What is commonly discussed in relation to the type of institutional requirements regarding the indexing of authenticity, as outlined above, is the way in which these processes can result in 'authenticity politics' (Sissons, 2005). This term refers to the ways in which claims to authenticity, alongside the boundaries which determine such claims, can be tightly policed in the service of gatekeeping scarce resources (Conklin, 1997; Sissons, 2005). Whilst authenticity politics is commonly situated as a top-down process enacted by those with a large degree of power, it is also explored as a bottom-up process, carried out at the lay community level. Where this work is particularly relevant to transableism is in relation to trans identity claims, wherein attempts are made, not just to enter an identity category 'from the margins' of it but, instead, to cross a more substantial boundary (Brubaker, 2016b). One notable example of such a claim, which was discussed in **Chapter 3**, can be found in Brubaker's examination of Rachel Dolezal, a woman who, after presenting for decades as African American- only to be 'outed' as Caucasian- described herself as 'transracial', in that she identified as black (Brubaker, 2016a, 2016b; see also McGreal, 2015; Sunderland, 2015). As Brubaker notes, after making this claim on public media platforms, Dolezal was widely rejected, largely by members of the African American community. Brubaker, in comparing this rejection to the increasingly widespread acceptance of the identity claims of transgendered individuals, suggested that it could be explained via reference to the differing culturally and historically contingent understandings surrounding gendered versus racial identities, and thus the differing types of authenticity politics which exist for each. As he notes, within our culture, whilst gender is now understood as a voluntarist, individually subjective property (largely thanks to sexological research and transgender activism (Sadjadi, 2019; Valentine, 2007)), race is thought of as something fixed and essentialist; a hangover of histories of enslavement, oppression and discrimination, all of which relied upon the so-called objectivity of race as a means of justification (2016a). As Brubaker suggests, this belief in the objectivity and essentialism of race is what contributed towards, not only the widespread rejection of Dolezal's proclamations, but also the subsequent attempts, from within the African American community, to police her claims and behaviour. A similar process to that which Brubaker describes took place on transabled.org. During data analysis, in addition to the sub-theme of 'the social construction of authentic BIID' (as discussed above) being coded, a further sub-theme relating to 'the policing of authentic BIID' was also noted. This theme coded data wherein the members of the disability community rejected and policed claims to BIID, a process which appeared to be informed by an underlying belief in the objectivity and essentialism of disability (e.g. a rejection of the idea that disability could be subjectively chosen at will). This theme is discussed below.

As outlined in **Chapter 2**, during the years of its existence, much critical academic and journalistic commentary surrounded transableism and BIID, debating its legitimacy (Charland, 2004; Elliott, 2009; Dyer, 2000). On transabled.org the members would discuss this critical commentary; most commonly, they discussed critical views expressed by members of the disability community. These views were made apparent as members of transabled.org would directly quote from and link to the webpages of disability bloggers who were critical of BIID, or report abusive messages that they had personally received (see **Chapter 4** for a discussion regarding the inclusion of this data in analysis). The main theme of these messages was the outright rejection of the members' claims that BIID was a 'disability like any other'. For example, one disability blogger wrote, 'their ridiculous behaviour is not a disability and should in no way be accepted'. This rejection of BIID as a disability was largely justified by the assertion that disability was not a 'choice'. As one blogger put it:

> 'You cannot choose to be disabled and unable to walk just because it suits you and your sick fantasy. I did not choose my disability. Just like I cannot choose to get up and walk if I wanted to'.

These statements and the justification behind them, strongly resonated with the dismissal, on ontological grounds, of Dolezal's claims, wherein transracialism was described as 'not a thing' (Brubaker, 2016b, p. 4), given that race was not a voluntarist characteristic to be chosen. Alongside rejecting BIID on the grounds that disability could not be chosen, the disabled community also expressed deep offense at the belief held by the members of transabled.org that it could be. As previously discussed (see **Chapter 5**), members saw their wheelchair use as one of the defining characteristics of disability and commonly used wheelchairs in public yet, paradoxically, rarely acknowledged that pain or suffering might accompany disability. All of this could be seen to contribute to the fact that, in the eyes of the disability community, the members of transabled.org held a reductionist and glamourized understanding of disability. One disability blogger wrote:

> ‘The life of a person with a disability seemed glamorous to them. That’s pretty offensive to someone who has a disability…I have many friends who are paralyzed, both quads and paras (quadriplegics and paraplegics). They were more prone to illness and infection. They had to constantly watch out for pressure sores from sitting all the time (this is common for wheelchair users). Joints could lock up, feet could turn in, fingers could tighten to the point of nearly being unable to use them, and bracing was necessary for many of them. Nearly every friend I had who was paralyzed used a catheter. Some of them could take care of themselves, but others needed assistance…
>
> As someone in a wheelchair, I’d give anything to stand up and walk over to get that item just out of reach. I’d love to just get out of bed and go to the bathroom. It’s such a hassle to have to wait for someone to pull down my pants and put me on the toilet. I’d love to be able to get in and out of a pool. That means I’d get to swim when I went on vacation, something I usually cannot do because pools aren’t usually wheelchair accessible. Eating can be hard if you don’t have hands or don’t have hands that work. Having others feed you can be messy. There are so many things that these BIID individuals are overlooking’.

What emerges from this statement is, not only that BIID is regarded as offensive but, once again, the underlying belief in the essentialist nature of disability. That the disability blogger did not choose his disability and cannot choose to opt out of its painful effects, in conjunction with the fact that the members of transabled.org appear to, incorrectly, believe they can make such choices, is where the deep sense of outrage lies. Again, this resonates with much of Brubaker’s account of the way in which Dolezal was condemned. As he describes, whilst Dolezal could, in theory, decide when to be black and when to return to whiteness, many of her critics highlighted the fact that most African American people are unable to escape their bodily realities and, instead, must endure the severe violence and oppression this type of embodiment invites (2016a). By overlooking this, Dolezal, similarly to the members of transabled.org, was seen to be ignorant of her privilege and blind to the embodied realities of those she idealised and fetishized.

Alongside rejecting the very status of BIID as a ‘disability like any other’, disability bloggers expressed a number of concerns regarding the members’ attempts to situate it as such; not only was BIID seen as inauthentic but, furthermore, the fact of its inauthenticity was felt to threaten the disabled community. As they saw it, those with BIID might fraudulently claim the sparse material and financial resources available to persons with disabilities. Again, this resonates with much of what was described in relation to Dolezal, who, as Brubaker outlines, was perceived as threatening given that she attempted to occupy spaces and resources reserved for those with life-long experiences of racial marginalisation (2016a). Regarding transableism, one blogger wrote:

> ‘State benefits geared towards the physically disabled. Do you know how hard it is for many of us to get and maintain these benefits? I do not think it is FAIR to a person born with a disability to be denied a wheelchair while someone with BIID is able to have the state purchase a chair for them’.

In echoing these sentiments, another disability blogger wrote:

> ‘Government assistance is assistance that those born with their disabilities have trouble getting. Adding more people who never should have been disabled to begin with to a waning fund means those born with or those who became disabled through a means out of their control have to contend with those who have BIID for much needed services.’

Again, what is evident from these statements, is that BIID is perceived as threatening, given that, if the members of transabled.org were able to acquire disability, they would take away already scarce resources reserved for those who were ‘born with’ impairment. Again, the implication here is that legitimate disabilities (and thus those entitled to resources) are unchosen.

The assertions that BIID was not a disability, and the offence and threat associated with it, were used, by disability bloggers, to insist that the members of transabled.org did not belong in the disabled community. Again, this mimicked the discourse which was targeted at Dolezal in relation to her attempting to claim membership to the African American community (Brubaker, 2016a). As one disability blogger wrote:

> ‘I know, they aren’t truly disabled. They aren’t deserving of the title of “person with a disability”. I don’t accept them into my community...(They) are fakers, liars, deranged, worthless, hopeless, messed up, jerk off, losers. I want nothing to do with them and I can only hope those of you reading this feel the same way’.

One blogger, in going even further, encouraged other members of the disability community to reject those with BIID:

> ‘(we need) a strong, if not thundering response from our community denouncing these frauds as nothing more than leeches on the backs of people with disabilities who earned and continue to earn the right to be seen as equals in society weakens us further.’

These statements can be situated as a type of bottom-up policing, not only of the rights associated with disability (e.g. community membership), but also of the very category of authentic disabled identity itself. Like race[34] in Brubaker’s example (and unlike gender), for members of the disability community, disability is something which is largely thought of in non-voluntarist terms. In other words, the authenticity politics of disability appear to be founded upon notions of objectivism and essentialism. As such, BIID, which is based upon a subjective belief in disabled identity and a wish to voluntarily become disabled, was perceived, by members of the disability community as having failed to conform to an appropriate authenticity politics of disability. In response, the members of transabled.org’s claims and behaviours were policed and rejected accordingly.

Inevitably, these comments and the policing of authenticity influenced the ways in which the members of transabled.org perceived themselves. Despite their apparent confidence in BIID as a ‘disability like any other’, members, at times, appeared to internalise the disability bloggers’ assessments of them. The

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[34] This comparison is not intended to conflate disability and race or imply that they are the same- they are ‘different differences’. Rather it is intended to highlight how the accepted authenticity politics of each are founded upon similar ontological understandings.

following post by Sean was a direct response to critique from the disabled community:

> ‘How many of us seek reassurance that we are indeed "wheelers"? How many of us need that confirmation that we are wheelchair users "for real"? Why do we feel like frauds when we use our wheelchairs?…we buy into that myth, that hurting untruth. We accept what other people tell us…They want us to believe we are fakes, we are wrong, we are unworthy…we buy into that. So much so we end up internalising all that’.

In addition to internalising and having to fight against the policing directed at them, the members of transabled.org’s overall emotional wellbeing was impacted by the criticisms they received. Karen, for example, in describing her reactions to insulting and threatening comments wrote:

> ‘I did have a psychological meltdown late yesterday evening. It is not trivially easy to comprehend the sheer volume of hate speech. I won’t pretend it’s not tough’.

For a number of members the attacks inflicted upon them by the disabled community brought concrete effects in that they left the community and abandoned their public claims to BIID entirely, citing the rejection of BIID, and the associated abuse and policing, as a reason for doing so. As discussed above, Brubaker situates the authenticity politics surrounding race, and the associated policing of Dolezal’s claims and behaviours, as the key explanation for why transracialism, broadly, and Dolezal, specifically, failed to achieve acceptance, subsequently disappearing from the cultural horizon (2016a, 2016b). The parallels drawn within this chapter between Dolezal and her treatment by the African American community and the members of transabled.org and their treatment from the disabled community, offer us a possible answer to one of the key questions of this thesis, namely why did transableism disappear. I suggest that the failure of transableism can be seen as related to the authenticity politics of disability which, as evidenced by the views expressed by members of the disability community, were founded upon understandings surrounding the objectivist and essentialist nature of disability. Broadly, this rendered BIID *not* a ‘disability like any other’; with any assertions that it was being open for critique.

This then enabled those already inhabiting the disability category to police its boundaries, a process which had tangible effects on the members of transabled.org and their desires to publicly identify with, and advocate for, BIID. In sum, the above analysis leads me to conclude that, although the members of transabled.org made strong attempts to negotiate the authenticity of BIID, the fact that it didn't conform to an acceptable politics of authenticity, and was policed accordingly, had a role to play in its disappearance.

Summary

This chapter has made use of a conceptual framework based on the social construction and negotiation of authenticity and an associated 'politics of authenticity' (Brubaker, 2016b; Sissons, 2005), to analyse how the members of transabled.org attempted to situate BIID, a newly emerging and yet to be verified psychological condition, as a 'disability like any other'. As highlighted, this was done via their attempts to align it with the already established and authenticated diagnostic category of Gender Identity Disorder (GID). It was also done via the ways in which the members de-aligned BIID with devoteeism (a sexual fetish) and pretending. These negotiations were all carried out with the ultimate goal of having BIID officially authorised via its inclusion in the DSM. Alongside these negotiation attempts, however, the members' claims to BIID as an authentic disability were subject to a bottom-up politics of authenticity; just as the members of transabled.org attempted to de-align themselves with devoteeism and pretending, a similar type of process was evident in the disability community's attempts to de-align from BIID. This dealignment- and the policing which accompanied it- could, in many ways, be seen as successful, in that it led a number of the members of transabled.org to leave the community entirely.

What the findings on this chapter thus reveal is that, whilst the authority to authenticate may largely be determined by- and negotiated in relation to- top-down institutions such as the DSM, this isn't always the entirety of the story. As was the case for transableism, bottom-up authenticity politics also had a significant influence on the ability of BIID to be positioned as an authentic diagnosis and 'disability like any other'. This might suggest that all attempts to negotiate diagnostic authenticity are, ultimately, a delicate balance of aligning and de-aligning with certain categories whilst avoiding *being de-aligned* from others. Whilst, in some instances, the right balance may be struck, thus enabling an illness to become more than ‘transient’, as was revealed in this chapter, this was not the case for BIID. In **Chapter 9,** I return to the findings discussed in this chapter, integrating them with those of subsequent empirical chapters, and discussing their broader significance, particularly in relation to the academic literature exploring claims to authentic identities, and the limits of such claims.

Chapter 7

'Sean is the king of the transabled': Centralised ownership and moderation practices on transabled.org

Introduction

During the years of transableism's existence, it was studied from a variety of different perspectives including clinical, sociological and philosophical. Whilst many of the clinical studies acknowledged the existence of the desire to be disabled within online communities, the significance of these communities, including the ways in which their norms and dynamics might have influenced transableism, were not adequately explored (Bruno, 1997; First, 2005; Smith & Furth 2000). This oversight is significant when it comes to exploring the ecological niche of transableism, given that transabled.org was the origin of the concept of transableism, including its broad reconceptualization as a disorder of identity. Whilst, within the sociological and philosophical literature, the dynamics of online communities were addressed in significantly more depth than within the clinical literature, this analysis was, once again, insufficient as, by situating the construction of transabled identity as a collaborative process, the influence of Sean, as founder, exclusive moderator, and so-called leader of the transabled community was overlooked (Davis, 2011, 2012, 2014).

In **Chapter 3**, in an attempt to address this oversight, I reviewed the literature on online communities, examining they ways in which they have been investigated and theorised since their inception. This review led to the observation that, although historically many authors took a utopic view of online communities, seeing them as democratic and collaborative (Leibing, 2009; Malik & Coulsen, 2008), more recent work has begun to study power within these environments, including the role played by individual community owners and moderators in influencing norms, dynamics and so-called collective identities (Busch, 2011; Coulson & Shaw, 2013; Grimmelmann, 2015). As these authors note, online community moderators are often essential to the health, growth and sustainability of the community in question; however, they can also hinder all of these elements, should they become too autocratic, ideological or manipulative. Whilst a substantial body of work investigating this contrast now exists, online community moderation is still acknowledged as an under-developed area of study, with many authors recommending that the black box of moderation practices be brought to critical attention (Akrich & Meadel, 2012; Grimmelmann, 2015; Thompson & Round, 2016). After highlighting these observations in **Chapter 3**, I suggested that a conceptual framework, which examined the centralised ownership and moderation practices on transabled.org, be used to analyse the development of a so-called collective transabled identity, alongside the community's growth and eventual decline.

In this chapter, I use this framework in my empirical analysis; here data coded under the broad theme of 'online community moderation', and its various subthemes, is presented to support this analysis (see **Chapter 4** for details of the development of this theme and **Figure 5** for a visualisation of it). In the first section of this chapter, I draw on the literature on online communities outlining the ways in which they were traditionally viewed as digital utopias and noting how, at first appearances, transabled.org appeared to conform to this description. I then consider the literature on power and moderation practices within online communities and, drawing on my findings, discuss the pervasiveness of centralised moderation practices on transabled.org which were enacted by Sean and fundamentally shaped the development of the so-called collective transabled identity. Investigation into these moderation practices begins by my outlining Sean's early experiences with the desire to be disabled, as documented in his personal blog between 1996 and 2005, and the ways in which these experiences developed to form a definition of transableism. I then note how, as part of the reformatting of his blog into a multi-authored community in 2005, this definition, and the possibilities for transabled identity it afforded, was built into the very infrastructure of the forum, conforming to bottom-up moderation practices as described within the literature (Grimmelmann, 2015). I then describe the more explicit moderation tactics utilised by Sean, including membership selection and the reviewing, deleting and soliciting of content. I argue that these moderation tactics were justified and reinforced by Sean's perceived social status and ideological authority over transableism, as acquired through his creating of the site and being committed to the cause. Whilst these tactics might be perceived as overly restrictive, I note the ways in which they were fundamental to the development, health and growth of the transabled community. This observation allows me to answer one of the key questions underpinning this thesis, namely why did transableism emerge; I suggest that a large part of the emergence of transableism could be attributed to the ownership and moderation efforts of Sean.

After outlining the productive and beneficial aspects of Sean's moderation practices, in the second part of this chapter I discuss how they became detrimental to the transabled community. Towards the latter years of transabled.org, many of the other community members began to critique Sean's position as community leader, his treatment of others and his self-appointed ideological authority, with many leaving the community as a result. Furthermore, being exclusively responsible for community ownership and moderation, became overly burdensome for Sean, creating moderator burn-out. I conclude this chapter by outlining how this analysis allows me to answer the second question underpinning this thesis, namely why did transableism disappear; as I suggest, whilst Sean's centralised moderation efforts enabled the emergence of transableism, they also, paradoxically, contributed towards its failure.

Transabled.org as digital utopia?

Broadly, online communities are defined as 'webs of personal relationships in cyberspace' (Rheingold, 1993, p. 5) which gather on a shared space and orient around a shared topic of interest. Commonly noted characteristics of online communities include groups norms, regular members, frequently discussed topics, common linguistic practices, and shared resources and support tools which are stored and catalogued within the site (Baym, 2003). At first glance, the transabled community conformed to the definition of an online community and contained all of the features and processes described above. To begin with, they gathered on the shared 'space' of transabled.org -a multi-authored forum and commenting platform. Although links to external sites (e.g. other blogs or articles of interest) were occasionally posted to the forum, the community exclusively interacted on transabled.org. Further to this, the transabled.org website was conceptualised, by the members, as a 'shared space' (Baym, 2003). Members would make comments such as 'I love that I have this place where I can come and be myself' (Lucas), and new members were frequently welcomed with comments such as 'Welcome! Come in, look around and make yourself at home, it's good to have you' (Karen).

It almost goes without saying that the transabled community were united by shared interests, namely, (as stated on the introductory statement of the homepage) ‘being transabled, wheelchairs, wannabes, disability, body identity integrity disorder (BIID) and related topics’. These shared interests were reflected in the blog posts written by the community members. The aspects most frequently discussed in blog posts were those analysed in **Chapters 5 and 6**, namely the incongruence between self-image and bodily reality, the desired body image, using wheelchairs in order to pass, the similarities between BIID and GID (including lack of choice, early childhood memories, the inefficiency of therapy and medication versus surgery and use of the wheelchair as therapeutic), the distinctions between BIID and devoteeism or pretending and the status of BIID as a ‘disability like any other’.

As discussed in **Chapter 4**, blog posts were stored in the archive of transabled.org by both date (e.g. ‘May 2007’) and author (e.g. ‘Karen’s thoughts’). They were also arranged according to popular subthemes or areas of interest regarding transableism, for example ‘early memories’, ‘personal histories’, ‘BIID’ and ‘spinal cord injury’. As such, blogs became shared resources which could be easily navigated and browsed by the group and new members alike. As discussed in the online community literature, there is an expectation that existing community members and new arrivals alike will read and interact with community archives, familiarising themselves with the community topic of interest (Akrich, 2010; Baym, 2003; Millen & Dray, 2000). This process was outlined as a clear expectation on the homepage of transabled.org, where a statement read:

> ‘So you'll ask: "That 'thing', transabled, just exactly what is it?". It is hard to define in just a few words, the best way to learn is by going through the site…Explore the site, learn a little bit more’.

Extant scholarship notes that navigating the community archive enables individuals to identify the similarities in their experiences, which leads them to offer support, and form connections based on likenesses (Adler & Adler, 2008; Akrich, 2010; Millen & Dray, 2000). Again, this process was apparent on transabled.org. After reading through the site as directed, community members would begin to find similarities between their experiences and the common BIID illness narrative expressed in the archive. This was evident in the comments which individuals were able to leave under each other’s blogs. In one such comment Ivy wrote:

> ‘I am systematically going through and trying to read every post and every comment on the site. As I read other’s thoughts and stories, I have found myself thinking, I did that too! I did THAT too!’

In academic accounts of online communities, this identification process is further outlined as contributing to the emergence of a strong sense of collective identity amongst online community members (Baym, 2003). Once again, this was evident on transabled.org, as Anna’s note illustrates:

> ‘Finding information about others with similar thoughts and feelings, now made me realize that all those early memories in my life were probably the unavoidable start for my disability. A disability that I think I was born with, and I found a name for here - Body Integrity Identity Disorder… I can now say I am one more member of the Transabled community!’

In what is described above, an almost idyllic image of the transabled.org community emerges and a fairly straightforward process of collective identity formation appears to take place. This type of reading is not unusual within online community scholarship; when this discipline was in its infancy, there was a trend towards interpreting online communities, and the collective identities fostered there, through the lens of ‘digital utopia’ (Beer & Burrows, 2007). As the field evolved, however, greater attention was paid to the various manifestations of power within online communities, including the role played by individual community owners and moderators (Busch, 2011; Coulson & Shaw, 2013; Grimmelmann, 2015). As observed, online community moderators are key in that they commonly control the entire design, content and management of the webpage, alongside possessing a degree of social status and ideological influence. These factors are noted to enable community moderators to shape group norms and, by doing so, influence the development of the community’s collective identity (Busch, 2011; Grimmelmann, 2015; Wanner, 2005). Despite their significance, however, the role played by online community moderators has been under-theorised, due to it being largely invisible to casual viewers and researchers alike (Akrich & Meadel, 2012; Grimmelmann, 2015; Thompson & Round, 2016). After looking beyond the straightforward and idyllic surface appearance of the transabled.org community, it soon became apparent that moderation practices were fundamental to the existence and maintenance of transabled.org. Despite existing as a multi-authored forum between 2005 and 2013, for 9 years prior to this, the site had been a blog, singularly owned and authored by Sean, who remained the sole owner and moderator of transabled.org until the day of its closure. As such, although at first glance transabled.org seemed like a collaborative online community, deeper exploration revealed that that Sean, as website creator, owner and moderator, occupied an extremely powerful position within the community and made use of nearly all of the characteristics and mechanisms available to moderators, including infrastructural design, membership recruitment, social relationships, alongside deleting and editing and soliciting content, as will be discussed in more depth below. The data discussed below was, during data analysis, coded under the sub-theme of 'online community moderation tactics'- further divided into 'history/infrastructure', 'active moderation' and 'mentorship' (see **Chapter 4** and **Figure 5** for more details). The presentation of these sub-themes reveals how Sean, via his role as moderator, could be seen to influence a large part of what took place on transabled.org, including the so-called collective transabled identity.

The ideological history and infrastructure of transabled.org

Before outlining the explicit moderation tactics used by Sean after transabled.org became an online community in 2005, it is necessary to go further back in time to highlight the ways in which his personal history and experiences, as documented in his blog from 1996, informed the very basis of the future development of transabled.org and the so-called collective identity which existed there. This section presents a chronological narrative analysis of the evolution of Sean's blog (see **Chapter 4** for discussion of this method). When Sean first started blogging in 1996, a strongly developed narrative surrounding transableism did not yet exist. At this time, Sean merely wrote about his fascination with disability and documented his various experiments with wheelchairs and other disability aids. Significantly, in these posts, Sean explicitly described himself as a devotee and a pretender; he outlined the intense sexual arousal he experienced when using disability aids, he noted how much he enjoyed the attention he received through being in a wheelchair and he wrote about fluidly 'switching' between pretending versus being 'Sean the AB (able-bodied)'.

I was a few weeks into my fieldwork before I came across these posts as they were quite far back in the transabled.org archive. Understandably, they were surprising, given that they stood in marked contrast to the common transableism narrative that was more immediately apparent on the forum, and aligned BIID with GID (and a permanent sense of identity incongruence), alongside clearly delineating it from devoteeism and pretending. After finding these posts, I then read through the archive systematically, and in chronological order to get a better picture of how these initial experiences might have evolved into the very different transableism narrative which dominated the rest of the forum. It became apparent that, as time moved on, Sean was no longer satisfied with simply using his wheelchair on a temporary basis, for fun and sexual arousal. Around 1997, he began to mention wanting to experience paraplegia (albeit still on a temporary basis). At this time, he also described his desires surrounding wheelchair use escalating. In July of that year, he wrote:

> ‘First, years ago, I wanted to have a wheelchair. Got it… Then I wanted to use it more. Did that, but wanted to go out with it. Went out but wished for a friend to wheel with. Found one but that still wasn’t enough. Had to have a lover to share my wheels with’.

Following this, at the beginning of 1998, Sean met a paraplegic woman and entered into a romantic relationship with her. She accepted and embraced his wheelchair pretending and, within a few months, they were married. Through his new wife, Sean become more involved with the disability community and transitioned to wheelchair use on a near permanent basis. Although Sean’s blog posts had gradually been growing less sexual, it was only after he began interacting with more people with disabilities that he appeared to distance himself from this notion entirely. This distancing appeared to be in response to concerns from the disabled community. In 1998 he wrote:

> ‘I’ve been presenting the concept of wannabes a fair bit lately to PWD (people with disabilities) who had no idea. Seems one of the concerns a lot of them share is how much is it related to sexuality, or a perversion of it.

> Of course, I can't talk for every wannabe…But I would like to stress the fact that my wanting to be a paraplegic has nothing to do with any aspect of my sexuality nor of my libido…
>
> Some people like to compare wannabes to fetishists. Blerch. Given I don't see it as sexually related, I can't accept the fetish label either. But of course, I see that word, fetish/fetishist as rather negative, leaving an impression of deviance and perversity. I don't need nor want this kind of negativity tagged on to me, not by you, not by me, not by *anyone*'.

Furthermore, as the use of the term wannabe in the above post suggests, Sean was moving away from being simply curious about paraplegia and, instead, was expressing a need to be permanently paraplegic. This was no longer fun and lighthearted but caused Sean a great deal of distress: he described his need as 'attacking him' and 'ripping him apart'. As his feelings of 'needing' to become paraplegic grew, Sean also started to discuss wanting to 'educate' other 'wannabes' (many of whom were now following his blog) to the 'reality' of this phenomenon. In outlining this, he wrote:

> 'I'm more and more concerned with educating the wannabe crowd to their own reality… It's hard at times though. Wannabes don't always want to work on themselves…Who made me the Savior??? No one…I simply think I have a fair understanding of the issues at hand'.

It was at this stage that Sean first began to draw tenuous links between his experiences and the GID narrative. In 1999 Sean suggested that wanting to be paraplegic was '(similar) to feeling like a man trapped in a woman's body or vice versa'. Following this, he noted that he wanted 'to explore more…the relation between transgender issues and the wannabe thing'. As he put it 'The more I look at it, the more similarities I see'. In conjunction with this, Sean also began to suggest that his desire to be paraplegic might be a mental illness; here the links between the need for disability and disability itself were first drawn, as he wrote in 2000:

> 'I've thought and heard from several people over the years that being a wannabe is a disability too…We're disabled and using a wheelchair is the tool we have to mitigate our disability…Clearly, being a wannabe

> is not a physical thing. If we want to keep thinking of it as a disability, we don’t have much choice but to call it a mental illness’.

After tentatively making these connections between the desire to be disabled, GID-transgenderism and mental illness-disability, Sean then disappeared for 4 years. In later posts it became apparent that, during this time, Sean’s wife had died; a possible explanation for his withdrawal. Significantly, it was during the years of Sean’s absence that the academic and cultural interest surrounding the desire to become disabled increased. As discussed in **Chapter 2**, the clinical conceptualizations surrounding the desire to become disabled also began to change at this time. Researchers started to suggest that this phenomenon might be an identity disorder, akin to Gender Identity Disorder, and, in 2005, the term Body Integrity Identity Disorder (BIID) was coined following research into individuals who described needing to amputate a limb (First, 2005).

When Sean finally updated his blog again in 2005, this new clinical conceptualization was fully and seamlessly incorporated. Sean’s use of the term wannabe was replaced with the label BIID. Alongside this, he introduced the term transableism for the first time, stating that he had explicitly created this word to ‘hinge on the concept of transsexual’, it being a ‘friendlier’ version of BIID, just like ‘transsexual’ was the ‘friendly’ equivalent of GID. Furthermore, when speaking about his desire to be disabled, Sean now exclusively used the transableism narrative discussed in the previous chapter, which entailed firmly situating it as a mental disorder, or a ‘disability like any other’, aligning its symptoms with that of GID and clearly delineating it from any sexual desire or need for attention. Significantly, Sean’s use of this new transableism narrative, involved him selectively obscuring his personal history. Although his older blog posts could still be found in the forum archives, these posts were not promoted or referenced. Furthermore, Sean also began to insist that he had had the ‘self-identity’ of a paraplegic since early childhood and had long ‘needed’ to correct this incongruence; there was no acknowledgment of the sexual arousal or part-time pretending for fun discussed in previous years.

Alongside incorporating the new clinical conceptualizations, and associated symptoms into his definition of transableism, Sean also used his personal experiences to critique what he saw as the limitations of the clinical boundaries of BIID and the research that had been carried out into it thus far. As he saw it, this research exclusively focused on individuals wanting to become amputees at the expense of those whose self-identities aligned with other disabilities, such as paraplegia (which was the disability he wanted). Sean believed that this exclusion created a harmful divide in the BIID community and threatened the BIID cause. He outlined his determination to increase the visibility of those needing disabilities other than amputations, in particular paraplegia (the disability he wished for).

It wasn't long after all this took place that Sean reformatted his solo-authored blog into a multi-authored forum which he named transabled.org; it was at this stage that Sean's influence as community moderator became evident for the first time. Within the literature, before discussing the types of moderation practices with which we might be more familiar (e.g. deleting comments), a number of authors have drawn attention to how moderation begins even prior to this. As is noted, moderators (particular those who are also site owners) often have exclusive control over the very infrastructure and design of the site in question, including what type of content is included, how it is organized, categorized and annotated, and the structure and flow of the website as a whole (Busch, 2011; Grimmelmann, 2015). This type of bottom-up moderation enables moderators to set the possibilities for discourse and thus the boundaries of identity, often informed by their own ideological understandings (Busch, 2011; Grimmelmann, 2015).

These bottom-up moderation practices were all evident on transabled.org. When reformatting his blog, Sean used WordPress, a content management system which allows an individual to build their own website from the ground up and personalise it by selecting particular architectures and layout templates and adding permanent content. Crucially, the architectures, layouts and content that Sean chose strongly reflected his understandings of what constituted transableism, as arrived at through his 10 years of evolution and development. For example, the introductory statement and glossary of the transabled.org forum contained definitions of devotees, pretenders, and transableism, distinguishing the former two from the later. Similarly, the website section entitled 'photos' contained a message criticizing 'voyeuristic devotees' and directing them away from the site. Further to this, the definition offered for transableism additionally emphasized the ways in which those desiring disabilities other than amputations were traditionally, but wrongfully, overlooked.

Other significant layout and content which could be seen to reflect Sean's views and experiences included the organization of content according to sub-themes: pages for 'stories' (fiction about transableism) and 'early memories' (self-explanatory) and a section entitled 'don't miss'. Posts filed under this later section included 'Letter from a para' (an exchange with a paraplegic man detailing his experiences), 'An email exchange with Dr. First about BIID' (to be discussed in **Chapter 8**), 'A comparison between transsexuality and transableism', 'What do I mean by "just another disability"?', 'It taints everything it touches' (a discussion of the all-pervasive pain caused by transableism), and 'Cure vs. Treatment – Protocol' (a discussion of the inadequacy of therapy and medication versus surgical treatment for transableism). Thus, conforming to what is discussed in the literature (Busch, 2011; Grimmelmann, 2015), the infrastructure and design of transabled.org could be seen to encourage particular ways of discussing transableism, whilst excluding others, both implicitly and explicitly. Many of these possibilities were based upon Sean's personal history, ideas and understandings of what constituted transableism and, in light of this, the surface reading of transableism as an apparently collective identity and collaborative accomplishment, can be reconsidered.

Membership selection, active content moderation and social status

Within the literature, in addition to discussing bottom-up practices as enacted at the level of infrastructure, a number of more explicit and active moderation mechanisms are outlined (Busch, 2011; Grimmelmann, 2015). Very commonly noted is control over community membership, where community moderators often have the power to bestow or withdraw membership based upon their personal requirements or ideas regarding how the community should function (Busch, 2011; Grimmelmann, 2015; Thompson & Round, 2016). This moderation practice was evident on transabled.org; the site was not open for anyone to spontaneously join or post on, instead, all contributions were pre-reviewed by Sean.

This process, which was outlined prominently on transabled.org, involved those wishing to join the community emailing Sean, providing him with details of what their desired disability was, when they began feeling that way, and what they thought they could bring to the site. Following this, the individual might then be required to provide one or two sample blog posts. This type of highly selective, exclusion-based membership (as opposed to a default of open inclusion (Grimmelmann, 2015) is outlined within the literature as being enacted where concerns about ‘lurkers’ or ‘trolls’[35] are present, and the desire to foster bonds of commonality between members is expressed (Grimmelmann, 2015). This was evidently Sean’s goal as further criteria for membership included not engaging in ‘hate speech’, agreeing to commit to two new entries a month (to protect against members ‘lurking’ or only writing only a handful of posts and then disappearing), and being willing to provide a biographical paragraph to appear next to blog posts (to provide contextual details on BIID history for other members to identify with). In the interests of collective identification Sean also noted that he was ‘particularly keen to hear from members who need to have a disability other than an amputee’.

Although not as commonly discussed as practices which involve pre-reviewing individuals who have expressed an interest in joining the community, the active solicitation of suitable members, by community moderators, is also noted in the literature (Akrich & Meadel, 2012). As Akrich & Meadel (2012) describe, moderators may contact individuals who they deem appropriate for the community in question, either face to face or via private email, encouraging them to join the site. Although this practice is, within the literature, noted to be rare, it was standard upon transabled.org. Sean spent a lot of time on internet chat forums dedicated to disability related topics. It was common for him to meet individuals on these sites and invite them to join transabled.org. An example of this could be found in Laura’s first post to transabled.org:

> ‘Sean found me when I was a bit lost on a chat room…I’ve been chatting to and then emailing with Sean for a while now…he has been encouraging (begging!) me to write something for this site…at first I was a bit hesitant but I guess he’s worn me down (I’m *joking* thank you Sean). So, here goes’.

Hand-picked individuals, such as Laura, were seemingly selected on the basis that their interests and opinions aligned with Sean’s definition of transableism, which, notably, included the wish to be a paraplegic. Indeed, this was even

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[35] Lurkers are individuals who visit online communities and read the contributions of others without posting themselves. Trolls are individuals who join online communities so as to abuse and harass others (Baym, 2003).

commented upon by the hand-picked members themselves. Lucy, for example, said:

> ‘The main contributors (to this site) are mainly paras yes (those who wanted to become paraplegic), but then that is partly because many of us have had Sean reach out to us and help us make sense of a lot of the mess…until Sean got busy there really was no place for us para BIIDs to go with full understanding and acceptance’.

Although, as mentioned, this type of active and selective recruitment is described as rare within the online community moderation literature, similar processes have been extensively discussed elsewhere within research into other types of social groupings including New Religious Movements (Barker, 1990; Dawson, 2011), terrorist groups (Hofmann & Dawson, 2014), and cults (Lalich & Lee, 1996). As is noted here, individual recruitment efforts are often carried out by a ‘charismatic’ (Weber, 1968), knowledgeable and senior group member, with the goal of growing the community, whilst simultaneously ensuring that members conform to its vision, identity and ideology. Whilst certainly not as malign as some of the processes described within this body of literature, Sean’s membership recruitment tactics can be seen as similarly active, selective and conducted so as to foster a particular transabled identity.

Alongside discussing membership selection, scholarship also highlights the ways in which moderators shape and manage the content which members contribute. This is carried out through a number of different mechanisms. Firstly, ‘ex ante’, or before-the-event, (Grimmelmann, 2015) moderation involves moderators pre-reviewing content prior to it being posted on the site, a standard practice on transabled.org. An additional ex ante moderation tactic involved Sean putting out calls on the forum, encouraging members to write about specific themes relating to transableism. Examples included BIID and (lack of) choice, successful post-surgery stories and the status of BIID as a disability. These themes can, once again, be seen to reflect Sean’s personal definitions surrounding transableism. Similar types of behaviour- wherein moderators solicit posts based on their own interests and preferences- is also noted within the literature (Akrich & Meadel, 2012; Squirrell, 2019; Thompson & Round, 2016).

In addition, content moderation has also been described as occurring ‘ex post’, or after-the-fact (Grimmelmann, 2015). Ex post moderation also took place on transabled.org: although Sean pre-reviewed all blog posts, he did not review comments (shorter messages, not necessarily written by official community members, which appeared underneath blog posts). Nevertheless, he moderated them after the fact. When managing this type of content, Sean primarily took a ‘soft’ approach (Grimmelmann, 2015 see also McGillicuddy, Bernard & Cranefield, 2016): for example, should comments stray away from discussing transableism and peripheral themes, Sean would intervene to direct them back on track by making statements such as:

> ‘Interesting as this discussion is, it’s got nothing to with transableism. Please can we try and stay on topic and take your other conversations elsewhere ☺’

Alongside this, Sean also carried out ‘hard’ comment moderation (Grimmelmann, 2015 see also Busch, 2011; McGillicuddy, Bernard & Cranefield, 2016), at times deleting comments entirely and preventing the offending users from re-commenting (via tracing and blocking their Internet Protocol (IP) addresses). This was mostly done in relation to comments which were deemed critical of transableism and the forum. Although, for obvious reasons, the original comments were not available to read, Sean often described deleting comments for these reasons. In outlining one of these occasions, he wrote:

> ‘(the commenters) are more angry than anything, and are not here to try and have an honest and open dialogue. Obviously I don’t expect everyone to understand or accept. But if people come here, I expect them to at least show an open mind and a willingness to listen. This is not what has been displayed here’.

Thus, in addition to reviewing and soliciting suitable community members, all Sean’s content moderation practices, could be seen as aiding the development of the so-called collective transabled identity; content that affirmed this identity was solicited and posted for the rest of the community to read, whereas content that challenged or strayed from this identity was either not published or was deleted.

Online community moderators are not only noted to control website content; they are also described as possessing social status amongst community members by means of their long-standing dedication to the site and community (Busch, 2011; Grimmelmann, 2015; Thompson & Round, 2016). Once again, this was apparent upon transabled.org wherein Sean was acknowledged and celebrated as a central figure in the transabled.org community. This was evident through the ways in which other community members referred to him, officially, as their 'leader' and, informally, with terms such as 'the king of the transabled'. The other members of transabled.org justified Sean's leadership status by referring to his creation of the website and his commitment to the transabled community and cause. Ken, in writing on this topic, said:

> 'Leadership, teamwork, group efforts, all familiar buzzwords of the 80s…My definition of leadership is being able to inspire an organization made up of differing individuals to achieve a common goal.
>
> A leadership role was assumed by Sean who started this website, I take my hat off to him. He took initiative and has furthered our cause'.

As a result of their social status, leadership roles and commitment to the community, moderators are noted to be bestowed with ideological authority in relation to core community topics and the groups' collective identity (Busch, 2011; Seering et al., 2019; Thompson & Round, 2016). This type of ideological authority was commonly assigned to Sean by the other community members. Alongside his developing and leading the website, a large part of Sean's authority also appeared to emerge from his perceived knowledge and experience, as manifest in the length of time he had spent reflecting on transableism and his associated long-term and full-time use of a wheelchair. Molly, in a post that outlined this, wrote:

> 'Many people see you (Sean) as a person who knows it (Transableism) very well, as a person who is a step forward.
>
> Like the saying 'the man with one eye is king in the valley of the blind'…The man who lives 100% of his public life from a wheelchair by his own choice is king in the valley of the transabled'.

When moderators are granted social status and ideological authority, other community members can be seen to defer to them, seeking their advice, following their guidance and treating them with admiration (Seering et al., 2019; Thompson & Round, 2016). This was commonplace on transabled.org; Sean often advised other members on issues such as coming to terms with their transableism, purchasing a wheelchair, wheeling for the first time, finding a therapist and ‘coming out’ as transabled to family and friends. In describing the role Sean had played in guiding her, Nina wrote:

> ‘Before I spoke to you Sean, I was planning to buy a chair, send it to a P.O. Box, buy storage space to hide it from my boyfriend…Since speaking to you I have told my boyfriend and other close friends about my thoughts…I truly feel that I’m much better off having spoken to you’.

Sean himself acknowledged that he played an important role as mentor to the other community members. He often wrote about how he had helped members with issues surrounding their transableism and described his satisfaction at being able to do so. In one instance he wrote:

> ‘I have been corresponding with Kaitlyn for nearly 10 years, and at first, she never said she had BIID. A few years later she admitted that she was denying to herself the possibility she had BIID for fear of the impact it would have on her if she let it out. More recently, she’s acknowledged to herself, and to us, that she has BIID. It’s a huge step to take…I feel proud to have helped her reach this place’.

This type of long-term, heavily influential relationship dynamic was not unique to Sean and the 2 members referenced above. Indeed, Sean engaged in lengthy interactions (including private communications and face-to-face meet ups) and could be seen to foster identification with transableism in relation to a number of other community members. Significantly, within another of these relationships, Sean’s influence appeared to be so powerful that he managed to convince a community member that she needed to be paraplegic, as opposed to blind (like she had originally thought). By means of his social status and perceived ideological authority, Sean played a significant role in the lives of many members of transabled.org and their identification with the so-called collective identity of transableism. These observations go beyond the type of data outlined within the online community moderation literature; nowhere within this body of work is a moderator described as having such a profound effect on a community member that they go from denying a collective identity to fully embracing it (as was the case with Kaitlyn). Again, these observations appear to more accurately conform to the type of dynamics described in the literature on New Religious Movements (Barker, 1990; Dawson, 2011), terrorist groups (Hofmann & Dawson, 2014), and cults (Lalich & Lee, 1996) where individuals are often described as adopting new identities or ideologies via their relationships with charismatic and senior members of the group in question.

In the above 2 sections, I have outlined how, whilst at first appearing to be collectively constructed and democratically owned, transabled.org operated through a centralised model of community ownership and moderation. Under this model, Sean- the site owner- enacted mechanisms including bottom-up infrastructural design, membership selection, content management and the development of personal relationships. This enabled Sean to foster a particular transabled identity which was largely delineated in accordance with his personal history and experiences. Whilst these moderation mechanisms could be critiqued for being too autocratic, what is crucial to note is that, within the literature, moderation practices are outlined as essential to ensuring the health and growth of online communities, including the development of the collective identities which constitute them (Coulson & Shaw, 2013; Grimmelmann, 2015). This is particularly keenly observed in instances where, as on transabled.org, moderation is centralised and enacted by one individual who is also a committed and involved member of the community in question. Alongside the above described data being coded under the sub-theme of ‘online community moderation tactics’, during data analysis, when these tactics were also seen to have been beneficial to the transabled community in some way, they were also coded under the sub-theme ‘online community moderation benefits’. What this revealed was that, conforming to what is observed in extant literature, Sean, and his centralised moderation practices, played a vital role in relation to transabled.org and transableism. This was clearly apparent; without him, the community- as the place where common experiences could be shared, free from irrelevant content and abuse- would, in all likelihood, not have existed. This fact was widely acknowledged by the community members themselves, who would frequently make comments such as

‘Thank you so much for this site Sean, it has helped me so much, please keep it up!’ (Nina) and ‘Your generosity in putting up with the attackers and the lurkers makes the gift of self-acceptance available to those who receive it’ (Richard).

The above observations thus help us to answer one of the key questions underlying this thesis, namely why did transableism emerge: I suggest that a large part of this emergence can be attributed to Sean’s creation and ownership of transabled.org, alongside his centralised moderation efforts. Of course, Sean was not entirely responsible for the emergence of transableism. As discussed in **Chapter 5**, part of why transableism emerged was related to the way it was caught within the cultural polarity of authentic versus inauthentic disability. The findings of this chapter, however, can be seen to directly compliment those discussed in **Chapter 5**. Whilst transableism offered individuals with inauthentic disabilities a release by enabling them to temporarily pass as authentically disabled, this possibility was fostered by Sean. Through his creation of the notion of transableism, Sean tapped into a more broadly held need regarding the desire to be acknowledged as authentically disabled. Beyond this, he provided a place for transableism to flourish, by managing the site in such a way that a precisely delineated ‘collective’ identity developed there, free from abuse and alternative viewpoints. Unfortunately, this delicate balance of factors, complimentary to the emergence of transableism, did not last for ever, as I will now discuss.

Conflict over moderation practices and moderator burn out

Whilst online community moderators are noted to be essential to the health and growth of the group in question and are commonly treated with deference and respect, this is not always the case. When moderators are perceived to be overly ‘manipulative’ (Squirrell, 2019), ‘autocratic’ (Busch, 2011) or acting in ways that are contradictory to the needs of the community, their position and methods have been critiqued (Busch, 2011; Collins, 1992; Thompson & Round, 2016). Although wholly centralised moderation as on transabled.org, is noted to be relatively rare, when it does occur, it is described as particularly vulnerable to criticism, with theorists highlighting how it can foster resentment and conflict (Busch, 2011; Grimmelmann, 2015; Thompson & Round, 2016). Towards the later years of transabled.org, this was evident. During data analysis, alongside the sub-theme of ‘online community moderation benefits’ being coded, the inverse: ‘online community moderation challenges’ was also observed. A further sub-theme of these challenges was conflict over Sean’s moderation style (see **Chapter 4** and **Figure 5** for discussion and visual representation of these themes). What this data revealed was the ways in which many members began to challenge Sean’s general leadership status and near exclusive ideological authority. In a post defending himself against this type of attack (the original attack was deleted), Sean wrote:

> ‘It seems some people see me as a community leader for our wee community. It also seems some people resent or envy this position of leadership I have been given by others…
>
> I’ve been (blogging on transabled.org) for a long time - nearly 14 years now. Some of the people who appear to resent me were not even 10 years old when I started blogging about BIID. So, if there is envy, they should consider that it takes time to get known. Time and hard work’.

Alongside critiquing his general leadership status, the way in which Sean used this status within his personal relationships (as discussed in the previous section) was also challenged within the later years of transabled.org. Joseph, for example, in a post directed at Sean[36] wrote:

> ‘You pulled me into this abyss alongside you, and now I suffer with you. You weren’t content alone? You had to drag me down with you? I’m paralyzed with fear, agony, and pain. You brought this out of me. You’ve adopted me into a family I never wanted to be a part of.’

Not only was Sean’s influence, in and of itself, challenged, the other members of transabled.org also critiqued how Sean used this influence to encourage particular behaviours and ways of identifying with transableism. For example, a number of members appeared to critique Sean’s insistence on them using a wheelchair, outlining the ways in which he had persuaded them to do so by, incorrectly, saying that it would help with their distress. Again, Sean could be seen to defend himself against these accusations, by referring to his experience and authority:

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[36] Although, as discussed throughout this chapter, Sean often deleted negative comments directed at him, some, such as Joseph’s quoted here, remained for reasons unknown.

> ‘I’ve recently been called "intolerably arrogant" and accused of thinking that my " way of pretending and my experiences are the only way that pretending should be done"
>
> (but) My opinions are not just out of the blue, they developed over the years, partly as a result of doing so much thinking. Another fact that may give me prominence is that I have been using a wheelchair, 100% of my public life, for a long, long time. "The voice of experience", I guess. I know what I’m talking about.’

Accusations of Sean being over-controlling can be seen to conform to examples discussed within the literature, wherein moderators are perceived to have a large degree of ideological authority, and thus their assumed control over the identity boundaries within the community are contested (Busch, 2011). As a number of theorists have noted, when conflicts over moderation occur, they can be hugely detrimental to the community; its common narrative can become incoherent, members may leave and, at times, the community fails entirely (Grimmelmann, 2015; Squirrel, 2019). Significantly, all of the critiques directed at Sean began to occur and became noticeably heightened towards the later years of transabled.org. It was also within these years that traffic to transabled.org slowed (as commented upon in numerous posts by Sean). Alongside this, longstanding members began to leave the community at this time, with some directly stating that Sean’s position, influence and moderation methods were the reason for their leaving. Lucy, who had tried to leave the community several times before finally being successful in 2012 outlined this when she wrote:

> ‘At first I thought you were helping me, I saw you as a father figure. Now you just tell me what to do. My family are worried about me, they are worried about this man I always talk to on here (referencing Sean), they say your influence is not good for me and I agree’.

In addition to critique being discussed within the online moderation literature, authors have also highlighted the negative effects of moderation practices on moderators themselves. Moderation, despite the power and prestige it offers, also takes a great amount of physical and emotional labour and often involves financial scarifies (Coulson & Shaw, 2013, Grimmelmann, 2015; Thompson & Round, 2016). In the latter years of transabled.org these impacts could be observed. A further sub-theme coded under ‘online community moderation challenges' was 'moderator burn out': the data coded under this theme reflects the observations in the academic literature. To begin with, Sean became frustrated at the lack of content produced by other members and appeared exhausted and resentful at having to bear sole responsibility for updating the site. As he wrote:

> 'I was asked today:
>
> What's up with the site? No new posts for two days???
>
> I'm afraid my knee-jerk reaction was a bit abrupt. I'm sorry about that.
>
> I do have things to say, but some of these require some digging (both research and soul-searching). And I've not been particularly well physically these last few weeks. I have no energy to do all the hard thinking required for writing some of these things.
>
> This site is for everyone. We all benefit from it. But it's got to be participatory as well. It can't all be just y'all sitting and anxiously awaiting the next instalment'.

Alongside transabled.org taking a toll on Sean's time and emotional resources, towards the end he also began to highlight the pressure it placed on him financially. He noted how, had he put money into a savings account instead of into transabled.org, he would have thousands of dollars. Alongside simply mentioning these costs, Sean also utilised them in attempts to elicit donations from the other members to help with the running of the site. These attempts were never successful, being either met with silence (a lack of comments under the blog post) or excuses (the other members would state how poor they were or would claim that they didn't want to divulge their real identities in setting up a payment). In a post expressing resentment towards these excuses, Sean wrote:

> 'I'm disappointed that not more of you came forward to help with the fundraising… It's your business, of course. It just smarts a little that I've given so much of myself without really ever asking anything in return, but the one time that I do ask people to give a hand, they don't'.

Existing scholarship notes that the physical and emotional labour of moderation, alongside its financial costs, is taxing, unsustainable and can potentially contribute towards moderator burn out, particularly when moderation is concentrated in the hand of just one person (Coulson & Shaw, 2013, Grimmelmann, 2015; Thompson & Round, 2016). This could be seen to take effect on transabled.org. After expressing, with increased frequency, the types of complaints and resentments outlined above, Sean began to suggest that the labour required to maintain transabled.org was too great and hinted at giving the task up entirely. He wrote:

> ‘I don’t have any jellybeans. I think I was greedy and ate all my jellybeans ahead of time. Now, I’ve got nothing. This sponge is bone dry, nothing to give…
>
> To keep going like this would be to make myself a martyr to the BIID cause. I have no great desire nor belief in martyrdom…I’m reminded of the final line of that Traveling Wilburys song: "Get out, it’s the end of the line"’

Shortly after posting this, Sean did appear to burn out for good, in that, around August 2013, he permanently closed transabled.org, citing ‘personal reasons’.

Thus, although in the early years of transabled.org, Sean’s centralised moderation tactics were positively received by members and could be seen as essentially enabling the community and collective identity, as the years went on this began to change. Sean’s power, perceived manipulation and apparent ideological authority were critiqued, leading members to leave the community. In addition, moderating transabled.org was no longer a pleasure and Sean became exhausted, a fact which, although not explicitly stated, was hinted at when the community was closed. All of these observations help us to answer the second key question underlying this thesis, namely why did transableism disappear: I suggest that, although Sean’s centralised model of moderation enabled the emergence of transableism, paradoxically, it also lead to its demise.

Summary

In order to analyse the development of a so-called collective transabled identity, alongside the community’s growth and eventual decline, this chapter examined Sean’s role as leader of transabled.org through the conceptual framework of online community moderation. As discussed, moderation practices were pervasive on transabled.org, fundamentally shaping the development of the so-called collective transabled identity. Sean’s ideology and definition of transableism, as informed by his previous experiences, were built into the very infrastructure of the forum from the bottom-up. Sean also engaged in more active moderation process including membership selection and the reviewing, deleting and soliciting of content, all of which were justified and reinforced by his perceived social status and ideological authority. These tactics, whilst being restrictive, were fundamental to the health and growth of the transabled.org community and the development of collective transabled identity.

After outlining the beneficial aspects of Sean's moderation practices, in the second part of this chapter I discussed how, at times, they appeared less positive. Towards the latter years of transabled.org's existence, many of the community members critiqued Sean's position as community leader, his treatment of other individuals and his self-appointed ideological authority. Many left the community as a result of these conflicts. Alongside this, Sean could also be seen to burn out as a result of his exclusive moderation responsibilities. Ultimately, the observations drawn in this chapter have enabled me to address both of the questions underpinning this thesis. To begin with, Sean's centralised moderation efforts tapped into a collectively held need to be acknowledged as authentically disabled and fostered the emergence of transableism, meaning that they were a fundamental part of its ecological niche. Paradoxically, however, Sean's efforts and tactics become a victim of their own success and, ultimately, also contributed towards the failure of transableism. These observations can, more broadly, be seen to point towards the inherently fluctuating and unstable nature of elements of an ecological nice, and thus the niche in its entirety. Evidently, what was once a facilitative part of a transient mental illness can, over time, and with shifting perspectives or relational dynamics, become detrimental. In **Chapter 9**, I return to these findings, integrating them with findings from the other empirical chapters, alongside discussing their broader significance, particularly regarding emerging research into online community moderation practices. In the next chapter, I explore the above described tension- between the facilitative versus detrimental effects of Sean's moderation practices- further, through an analysis of the health advocacy efforts of transabled.org.

Chapter 8

‘It is up to us to fight and to educate’: Health advocacy efforts on transabled.org

Introduction

Whilst the most recent clinical studies into the desire to be disabled acknowledged the existence of this phenomenon within online communities, the significance of these groups, including how they might have influenced this phenomenon as a ‘collective’ identity, has not been adequately investigated (Bruno, 1997; Dyer, 2000; Elliott, 2009; First, 2005; Smith & Furth 2000). In the previous chapter, in addressing this oversight, I explored how the development of transabled.org and a so-called collective transabled identity was significantly shaped and influenced by Sean, via his creation of transabled.org and his continued ownership and moderation practices. This chapter addresses a second, interrelated, flaw of the existing clinical work, namely that, alongside ignoring the how the concept of transableism was fostered at the lay level, this body of work also failed to consider how these lay understandings might have impacted clinical research. Whilst much of this clinical research actively recruited from online communities, the impact of lay involvement, particularly regarding future diagnostic and treatment proposals, was, again, left unexamined. These oversights are significant to explorations into the ecological niche of transableism, not merely because transabled.org was the origin of the concept of transableism, including its reconceptualization as a disorder of identity, but because this community was heavily involved in lay advocacy, to the extent that it substantially influenced research projects and agendas.

Chapter 3 reviewed the literature on health advocacy communities. As noted there, although communities surrounding shared illnesses have long existed, in the West in the 1990s they could be seen to change in nature, moving from simple support groups to politicized communities engaged in the production of collective illness identities and experiential epistemologies, which were used to challenge traditional medical authority (Akrich, 2010; Brown et al., 2004; Rabeharisoa, 2006; Rabinow, 1996). These new health advocacy communities are described as having been further ‘supercharged’ (Hagen, 2012) through the application of digital technologies, including the structures, features and characteristics on online communities, which lend themselves well to the development of a collective identity and a bank of shared knowledge (Akrich, 2010; Leibing, 2006; Whelan, 2007). These new types of health advocacy communities, particularly those fostered online, have been hugely successful in intervening upon medical knowledge, advocating for research into cures and treatments, reformulating diagnostic boundaries, and resisting stigma and pathologization (Brown et al 2004; Leibing, 2009; Malik & Coulsen, 2008). Whilst this body of work advances the discussion, in that it has contested the assumption that scientific knowledge is a one-way, top-down accomplishment, it, nevertheless, contains a significant flaw. These depictions of health advocacy communities also fall foul to the types of critiques directed at online communities in general. Online health advocacy communities have been viewed through a similarly utopic lens where the knowledge creation and advocacy processes that take place there are assumed to be democratic and collaborative. Once again, the role of influential individuals, including community owners and moderators, are overlooked.

This chapter builds on the conceptual framework regarding online community power and moderation used to study Sean's role in the creation of transabled.org and the development of transabled identity, to study his influence over the community's lay advocacy efforts and their interactions with the medical community. Data coded under the broad theme of 'health advocacy efforts', and its various subthemes, is presented to support the analysis (see **Chapter 4** for details of the development of this theme and **Figure 6** for a visualisation of it). This chapter expands upon the literature on online health advocacy communities, outlining the history of these communities and their key characteristics, noting how, on the surface, transabled.org appeared to conform to these descriptions. The analysis then draws upon more in depth empirical evidence to illustrate the ways in which Sean's influence, alongside contributing towards the development of a so-called collective transabled identity, also fundamentally informed the lay advocacy efforts of transabled.org. This occurred at the intra-community level: Sean appeared to be very aware that, if the group were to be taken seriously by the medical community, there was a need for a collective identity, coherent experiential epistemological and clearly defined advocacy goals. Unlike the other members of transabled.org, he could be seen to work hard at developing these attributes. Sean's lay advocacy efforts also occurred at the extra-community level: Sean, in addition to influencing the group's internal epistemologies and goals, also took on the role of spokesperson and mediator, translating these intra-community messages to the medical community, and facilitating interactions between the two. Whilst these efforts appear to counter the notion that health advocacy communities are democratic and collaborative they, nevertheless, could be seen to have some level of success in that they facilitated the development of health knowledges and political goals within the transabled.org community and enlisted the interests of researchers. These observations help us to answer the question of why transableism emerged. In building upon findings outlined in the previous chapter regarding the significance of Sean in developing the collective transabled identity, I suggest that part of the early popularity of transableism could be attributed to Sean's role as health advocacy community manager, spokesperson and mediator. Here, Sean's power and influence over the community as a whole was extended into his management of the health advocacy efforts of transabled.org, efforts which were, in turn, legitimised and naturalised by his community leadership status.

In the second part of this chapter, as before, I explore the ways in which Sean's health advocacy community efforts, whilst initially fruitful, ran into challenges. These challenges occurred at the intra-community level: towards the later years of transabled.org, a number of members disagreed with the epistemologies and goals outlined by Sean, resented his ideological authority and, as a result, left the community. Challenges also occurred at the extra-community level: Sean was, ultimately, unable to facilitate effective interactions between transabled.org and the medical community. This was evidenced by the fact that many of the community members were disinterested in or resistant to taking part in clinical studies, despite Sean's encouragements. I conclude this chapter by outlining how these observations help us to answer the second question underpinning this thesis, namely why did transableism disappear. As I suggest, whilst Sean's role as health advocacy community manager, spokesperson and mediator initially facilitated the emergence of transableism, his efforts weren't sufficient enough to sustain it in the long term. This indicates that, although a health advocacy community may benefit from the input of a leader and spokesperson, ultimately, for such a community to be successful, its members need to be united and equally committed to its success.

Transabled.org: A health advocacy community

Support communities for health conditions or illness experiences, have long been observed across time periods and cultures (Turner, 1978). In the Western world in the 1990s, following their migration online, they proliferated and took on new characteristics, distinguishing them from previous incarnations. These new communities have been assigned various terms including ‘embodied health movements’ (Brown et al., 2004), ‘emergent concerned groups’ (Callon & Rabeharisoa, 2008) and ‘epistemological communities’ (Akrich, 2010; Leibing, 2009; Whelan, 2007). For clarity, I refer to them under a more general description: health advocacy communities. Each of these definitions, in originating from different sub-disciplines and having been developed in relation to different conditions, has slight variations. They all, however, emphasise the same three key, interlinked characteristics, that could be found on transabled.org. The first relates to the importance, placed by the community, not only on the shared health condition, but also the sense of collective identity based upon this (Brown et al., 2004; Rabeharisoa, 2005; Rabinow, 1996). In other words, the condition in question is not only central to the individual sufferer’s definition of herself but is acknowledged as shared by, and thus connecting her to others. This was evident upon transabled.org; as described throughout this thesis, the members of transabled.org understood themselves to have a shared health condition (BIID), collectively identified with its symptoms, and noting their similarities, described themselves as ‘members of the transabled community’.

Within the literature, this collective identity is often additionally described as involving a recognition that the illness in question is a site of oppression and source of inequality (Brown et al., 2004; Whelan, 2007), a process that has its roots in broader shifts regarding identity politics and self-definition based upon bodily attributes, (Rabinow, 1996; Schilling, 1993; Young, 1990). This additional layer was evident on transabled.org. Not only did the members collectively identify with BIID, but this collective identity was experienced as a site of shared marginalisation. This view had often been formed in response to negative treatment, misunderstanding and a lack of acknowledgment at the hands of individual doctors and the medical community more broadly (Brown et al., 2004; Whelan, 2007). Members often described feeling personally dismissed and patronised by doctors in relation to their BIID. Aaron, for example, described feeling this way after being told that his BIID wasn’t getting better because he was ‘failing’ at therapy. Similarly, Sean felt this after being told to try Zen Buddhism to cure his BIID. Lucas, in outlining this dismissal and the negative impacts it had, wrote:

> ‘Doctors don’t understand our condition, and nor do they want to. If they did, they’d be putting effort into researching it and figuring out ways to help us. What happens instead is they mistreat us and provide us with improper healthcare…improper health care prevent(s) us from living a socially active and healthy life’.

As Lucas’s description makes evident, negative treatment from doctors is not only situated as oppressive, but, as the use of plural pronouns indicates, is understood to be shared and uniting, thus reinforcing the collective aspect of BIID identity.

In response to experiences such as those described above, the members of transabled.org would express outrage. They also displayed a deep scepticism for medical authority, often describing psychiatrists as ‘quacks’ and ‘dopes’. This sense of scepticism could then be seen to contribute towards the development of the second characteristic of health advocacy communities, which is epistemological in nature. As is outlined in the literature, the emerging presence of collective identities and shared experiences within health advocacy communities is noted to facilitate the exchange of ‘experiential’ and ‘embodied’ knowledges (Akrich, 2010; Leibing, 2009; Whelan, 2007). This, in combination with the associated scepticism regarding clinicians enables the group to shift epistemological authority from the realm of medicine to that of their own shared and common expertise, as grounded in lived reality. Following this, scientific knowledge is often deprioritised in favour of the ‘experiential credential’ (Whelan, 2007). Again, this was evident on the forum where the advice and opinions of doctors was contrasted to and supported by the members’ claims to a superior experiential epistemology regarding their condition. As discussed in **Chapter 6** for instance, the members of transabled.org outlined the inefficiency of therapy and medication; on the forum, this assertion was further supported by the members sharing stories of their lived experiences with these treatments. Monica wrote:

> ‘I have been told over and over again by doctors to get therapy for (my BIID) and god knows I went along with this. I can’t count how many different therapies I’ve tried…But it just doesn’t work. And why would it? I know what’s wrong with me, my identity doesn’t match my body, it’s as simple as that, I’ve known this all my life. Why can’t doctors understand it really is that simple’.

Just as is described in the topical literature, Monica’s actual embodied experiences were sharply contrasted to doctors’ more abstract understandings and presented as the more ‘simple’, and thus correct, form of knowledge about transableism.

As previously discussed, alongside evidencing the inefficiency of drugs and therapy, the members of transabled.org additionally outlined the effectiveness of surgery as a treatment for BIID. They drew upon their lived experiences in order to support these claims. Whilst experiential accounts of surgery were much less common than those regarding medications and therapies (only a handful of members had had surgery), they were, nevertheless, assigned great importance. Furthermore, members who hadn’t personally experienced surgery frequently referenced these accounts, attributing a great degree of validity to them, thus assigning them the ‘experiential credential’ (Whelan, 2007). Monica, for example, in writing about Olivia, a transabled.org member who had amputated her own leg, stated:

> ‘I trust Olivia’s story, she has been through it, everyone thought she was crazy, but it worked for her. It makes me certain that surgery would work for me’.

The above described combination of a marginalised shared identity, medical mistreatment and misunderstanding, as contrasted to ‘trusted’ lived experiences, could be seen to contribute towards the development of the third attribute characterising health advocacy communities that is, as is discussed in the literature, political. Recognition of a collective identity, and the associated prioritising of experiential epistemology, can be seen to encourage a health advocacy community to develop a sense of ‘oppositional consciousness’ (Brown et al., 2004) in relation to the medical community. This was evident on transabled.org: Lucas for example wrote:

> ‘I want to work alongside them (doctors) but it seems like it’s us versus them’.

Extant scholarship describes oppositional consciousness, alongside the group’s realisation that they possess legitimate knowledge regarding their condition, as forming the basis for a health advocacy community’s political action, including attempts to intervene upon scientific discourse and lobby for better research, treatments and cures (Akrich, 2010; Brown et al., 2004; Whelan, 2007). Reflecting this, the feeling of ‘us versus them’ as expressed on transabled.org, is largely what could be seen to form the basis for the group’s advocacy efforts and goals. As noted in **Chapter 6**, the members of transabled.org wanted BIID codified in the DSM and legitimised by the medical community so that, ultimately, diagnosis and surgical treatment would be made available. In outlining the ways in which these goals, and the associated advocacy efforts, had been formed in relation to ‘oppositional consciousness’, Sean wrote:

> ‘Asking surgeons or medical doctors for a procedure such as a spinal cord transection or amputation leads to outright refusal…I am TIRED of waiting for researchers to do the work they should be doing and aren’t…
>
> This is why I have been so dedicated to this group over the last few years. Doctors don’t understand us and harm us with their ignorance. It is up to us to fight and to educate them and to keep fighting for transableism to be taken seriously’.

As is evident from the above descriptions, transabled.org appeared to fall into the category of a health advocacy community, in that it clearly displayed all three defining characteristics for these groups. However, more complex dynamics were at play that challenged and complicating existing understandings of how health advocacy communities operate.

Intra-community efforts

Research into health advocacy communities notes the ways in which these groups have achieved success regarding their political efforts, in that they have influenced research, secured new treatments and diagnoses, or contested existing medical practices (Epstein, 1995; Scott, 1990; Shapiro, 1993). This health advocacy community success is closely correlated with many of the intra-community factors previously outlined, namely the existence of a strong collective identity which gives way to a coherent experiential epistemological and clearly defined advocacy goals. These elements are described as providing the group with comprehensibility, credibility and a successful set of tools to be used towards effecting change in relation to the medical community (Akrich, 2010; Brown et al., 2004; Dumit, 2006). Significantly, however, and despite outlining the necessity of these elements, within the literature, the individual members of health advocacy communities are situated as being equally aware of these needs and, by association, equally devoted towards the development, management and prioritisation of the group's political tools and goals. In other words, a rather homogenous picture of health advocacy communities is presented that lacks an analysis of the role which might be played by influential individuals in developing the intra-community factors that subsequently shape the group's success. After looking below the surface of transabled.org, it became apparent that Sean, as community founder and owner, held a heightened awareness of the need for these political tools and, by association, played a primary role in attempting to develop them.

In the previous chapter, I discussed how despite its initial appearance as democratic and collaborative, nearly all transabled.org activities, including the formation of a collective transabled identity, were heavily influenced by Sean by means of his position as owner and moderator, and the material control, ideological authority and social status this granted him. Specifically, he could be seen to align transableism with the diagnosis of BIID (and by association GID), alongside distinguishing it from devoteeism and pretending. Furthermore, he was influential in emphasising paraplegic manifestations of transableism, with an associated focus upon wheelchair use. In extending upon these observations, the above delineations of transableism appeared to be made not only for reasons outlined in the previous chapter (namely that this definition aligned with Sean's personal history and experience) but also with the success of transabled.org, as a health advocacy group in mind. Comparable to similar discussions in the literature, Sean appeared to be aware that, if the group were to be taken seriously by the medical community, there was a need for a strong collective identity, a coherent experiential epistemological and clearly defined advocacy goals (Akrich, 2010; Brown et al., 2004; Whelan, 2007). Upon the forum he could be seen to work hard at developing these attributes. The data presented below was, during analysis, coded under the sub-theme ‘intra-community efforts’; this theme was designed to capture Sean’s efforts to develop epistemologies and goals within the transabled.org community (see **Chapter 4** and **Figure 6** for more details).

In terms of recognising the need to develop a coherent experiential epistemology, when discussing BIID and devoteeism, Sean insisted that the two were distinct and strongly emphasised the practical necessity of separating them. He connected the term devoteeism to the out-dated, controversial and much stigmatised label ‘apotemnophilia’ (Money, Jobaris & Furth, 1977), and outlined how this association was a significant barrier to the acceptance and treatment of BIID:

> ‘BIID and devoteeism should NOT be mixed and matched…Reason being is that, aside from being DIFFERENT, devotees have somewhat of a more negative perception than BIID sufferers. In a way, it makes it harder to make BIID accepted if it’s tied to a sexual deviance…society perceives “philias” as the lowest of the low…Think of pedophilia and necrophilia to name two…Because of apotemnophilia, transabled people have been compared often enough to pedophiles, and not very favorably either. I believe that as long as it is perceived as such, the likelihood of us ever getting diagnosed with BIID and having access to surgery is remote, at best’.

This insistence on drawing a distinction for practical purposes, was also evident in Sean’s discussions of pretending:

> ‘The label ‘pretending’ has been categorized alongside things like Munchausen’s…people with Munchausen’s are generally wanting of attention which people with BIID are not.
>
> So yes, I want to distance BIID from pretending…I want to distance BIID from Munchausen’s…In fact, I want to isolate BIID and I want medical professional to study it and gain a better understanding of it’.

This can be seen to reflect much of what is discussed within the literature on health advocacy communities. For example, Whelan (2007), in her work on an endometriosis community, outlines how its members are explicitly aware of the need to distinguish their condition from peripheral phenomena such as pelvic pain, polycystic ovary syndrome and gendered mental health diagnoses, in order to, similarly to what Sean describes, acquire credibility, research resources and treatments. Dumit (2006) also makes this observation in his research on chronic fatigue syndrome and multiple chemical sensitivity communities. Where the above examples depart from this literature, however, is in the fact that, whilst Whelan and Dumit describe *all* the members of their groups as possessing this awareness and motivation, upon transabled.org, this was exclusively expressed by Sean. For example, although, during data analysis, the sub-theme of ‘political awareness’ (coming under the broader sub-theme of ‘intra-community efforts’) was coded multiple times in relation to Sean’s blog posts, it was never coded for any of the other members.

Alongside distinguishing BIID from devoteeism and pretending, Sean’s attempts to emphasise paraplegic manifestations of transableism also appeared to be carried out with the success of transabled.org in mind, in that they were targeted towards intervening upon and expanding existing medical knowledge (Brown et al., 2004). Sean would frequently criticise what he saw as an unfair over-emphasis on amputee manifestations of BIID (both within the broader BIID community and within research), at the expense of paraplegic types. In outlining this, he wrote:

> ‘(I’m) sick and tired of amputee elitism…For years, amputee wannabes have pretty much held that they were they only “true” wannabes…I’ve been told I couldn’t *possibly* have BIID, since I didn’t want to be an amputee. I’ve also been told (in so many words) that I was sick and perverted for needing to be a paraplegic…
>
> Because of this elitism, any research is biased towards amputee wannabes, which continues to promote the concept that the only impairment people with BIID need is amputation! I’m tired of it.
>
> The reason why I focus so strongly on those of us needing to be paras on this forum is that...as long as only those of us needing to be amputee get the attention, the others are going to be ignored and we’re not going to see solutions that work’.

Again, this political awareness and urgency wasn't shared by the other members of transabled.org and, during data coding, was entirely absent in their communications. Indeed, to the contrary, some members appeared to not understand this urgency at all. As Lucy wrote:

> 'I need to be a para and yes I do get annoyed at amp wannabes and sometimes wish the researchers would want to talk to us, but at the end of the day I don't see why it's as important as you (Sean) make out. We should be grateful that we get left in peace if anything'.

Unlike Sean, Lucy seems to be unaware that 'being left in peace', whilst 'amp wannabes' receive researcher attention, would be detrimental to having her type of transableism recognised and treated.

Alongside discussing the importance of having a clearly delineated condition and coherent experiential epistemology, theorists studying health advocacy communities have also highlighted the need for groups to have commonly shared medico-political goals if they are to be successful (Brown et al., 2004; Epstein, 1995; Scott, 1990). In addition to attempting to delineate the epistemology of transableism, Sean also attempted to influence the goals of the transabled health advocacy movement, so that they were singularly aligned. This was mostly done in relation to the DSM. As discussed in **Chapter 6**, by outlining the ways in which BIID was similar to GID, the members of transabled.org were able to argue that it should be placed in the DSM (as, at this time, GID was). Whilst the majority of the members of transabled.org appeared to support this inclusion, arguing that it would bring them legitimacy and authenticity, some did not. Harriet, for example, argued against BIID's inclusion in the DSM on the grounds that this manual had begun to lose its credibility, arguing that it was 'not taken seriously by many anymore' and had 'lost (its) status of a psychiatric bible'. Michael, another member of transabled.org, saw the potential inclusion of BIID in the DSM, not only as unnecessary, but as potentially harmful. He wrote:

> 'The DSM is part of the problem (hurting people by denying their nature and personality), not of the solution. It CAN be a tool of therapists if they have to write reports, and maybe it can be used for statistics, but then statistics deny individuality as well, and by this hurt our souls…Nobody needs any legitimation of his or her feelings'.

Sean would always respond to arguments such as Harriet’s and Michael’s, making clear attempts to convince these members that they were wrong by outlining the ways in which inclusion in the DSM was an essential goal for the transabled health advocacy movement. In a direct response to Michael’s statement above, he wrote:

> ‘I don’t see the DSM as the be-all and end-all (and) I don’t need BIID included in it just because I need (my feelings) legitimized…But over the last 20 years, my personal experience with doctors, psychiatrists and psychologists, as well as the experience of the numerous people who have spoken to me about it, tells me that medical professionals haven’t got a clue about what BIID is. Most of them have never heard of it. If they have heard of it, they misunderstand it and assume it can be handled like Body Dysmorphic Disorder, or OCD, or some such. The amount of HARM that has been done to transabled folks because doctors didn’t get it is huge.
>
> (I have experienced this) …and I wish for all the young folks with BIID growing up, ashamed, guilty, confused, in pain, that they won’t have to go through what *I* had to go through. And inclusion in the DSM…would be a step in that direction’.

In addition to the unnecessary and even harmful role of the DSM, another argument against it was discussed on the forum. Some members of transabled.org were concerned that, by including BIID in the DSM, transabled individuals would be vulnerable to the types of mistreatment historically inflicted upon transgender people at the hands of the medical community. Ashleigh, for example, who was both transgender and transabled, wrote:

> ‘The Standards of Care for transabled people…would most certainly begin the way treatment for us transfolk began in the early 20th century: either lock it up, lobotomize it, or shun it.
>
> This is part of the reason why I’m so averse to the idea of having BIID officially classified as a mental illness - despite the advances in understanding of the mind, and human behavior, this is STILL the prevailing response of the mental health professional community to anything new’.

Once again, Sean responded to this line of argument, highlighting its flaws and outlining the ways in which BIID's inclusion in the DSM was essential:

> 'I completely, utterly and absolutely disagree with that Ashleigh… :) I would much prefer to see BIID listed in the DSM, because it has to be listed *somewhere* before medical professionals take us seriously…
>
> I certainly am aware of the conflict happening in the GID community…for what it's worth, if GID is removed from the DSM, a very real and direct impact of it would be that SRS and hormones and other "treatment" would no longer be available through health insurance…So while the advocacy done by those of you against the inclusion in the "shrink's bible" is valuable, it might have a rather devastating impact on many of your brothers and sisters'.

Within academic literature transgender rights movements have been commonly seen as successful health advocacy communities in that, by successfully advocating for Gender Identity Disorder to be renamed Gender Dysphoria in the DSM-V, they have been effective in the partial depathologisation of transgenderism (Drescher, 2010, 2015; Nichols, 2008; Winters, 2005). Significantly, however, whilst the internal 'conflicts' regarding inclusion of GID in the DSM, as referenced by Ashleigh and Sean, are documented within this body of work, little attention has been paid to what these conflicts looked like on the ground. Although Valentine (2007) comes close to this through his discussion of the ways in which various racial, class and gender privileges could be seen to influence the trajectories taken by transgender rights movements, he does not explore individual, micro-level interactions, such as those which took place between Sean, Harriet, Michael and Ashleigh. All this is to say that, whilst transgenderism has now been partially depathologised within the DSM, there is little awareness of how the voices of particular individuals within transgender communities might have come to stand in for the group as a whole by being especially influential or persuasive, as, within the transabled community, Sean was.

To summarize, not only did Sean use his position as community owner and moderator to influence the collective transabled identity, he also significantly influenced its health advocacy goals and efforts. These efforts appeared to be largely successful given that the overall definition of transableism, as featured on the website, clearly distinguished it from devoteeism and pretending and emphasised paraplegic manifestations. Furthermore, and despite occasional disagreements, the overall political goal of transabled.org, as prominently featured on the website, was inclusion of BIID in the DSM-V.

Extra-community efforts

Alongside describing the intra-community factors that make health advocacy communities successful, various external factors, dynamics and influences are also noted in the literature. A crucial extra-community factor is the groups' ability to mobilise scientists, doctors, researchers and other prominent individuals or political groups (Conrad & Schneider, 1980; Epstein, 1995; Scott, 1990). Within these investigations, unlike those regarding intra-community factors, some attention has been paid to the role of influential individuals in facilitating this engagement. Epstein (1995), in particular, in his work on AIDS activist groups, explores how a large part of the success of these communities in the 1980s could be attributed to the way in which prominent leaders possessed a high degree of social capital and cultural competence; they were largely young, able-bodied, white, middle class, educated men, many of whom were doctors and lawyers. This, alongside the way in which these individuals familiarised themselves with medical jargon and existing scientific research (what Epstein terms a 'credibility tactic' (1995, p. 411)) is described as enabling them to present themselves as authoritative and, by doing so, enrol supporters behind their claims (Epstein, 1995; see also Fuller, 2015). Although Epstein's analysis pays crucial attention to individuals, this is rarely reflected in work elsewhere, much less in relation to online health advocacy communities (for somewhat of an exception see Akrich & Meadel, 2012). Furthermore, whilst Epstein examines the various attributes and tactics which give individuals credibility in the eyes of the medical community, he appears to situate these individuals as neutral, representative spokespersons, as opposed to analysing how they might also hold power and influence at the lay community level thus influencing, from the very offset, the types of messages presented to medical communities. This oversight is significant in relation to transabled.org as, in addition to shaping coherent epistemologies and goals for the transabled community, Sean also attempted to translate these messages to the medical community (during data analysis, these efforts were coded under the sub-theme ‘extra-community efforts’. See **Chapter 4**, **Figure 6** for details).

Before outlining these extra-community efforts themselves, it is necessary to discuss how Sean took on this role as health advocacy community spokesperson to begin with, and how this was justified to the rest of the community members. Although, in his work, Epstein discusses the credibility tactics utilised by influential individuals in relation to the medical community, including knowledge of existing science and the confident use of medical jargon (1995), he doesn’t discuss how these might be used to similarly acquire authority at the lay level. On transabled.org, this appeared to take place; Sean read all the existing research on transableism and BIID and made the other community members aware of this:

> ‘I read a lot of the publications I can find that discuss BIID. I’m sure I’ve missed some, but I’ve read most of what is available. Why? Because we need to be informed when we talk to different "interest groups" about BIID…I’ve (also) personally learned to handle medical professionals on this topic. I know my stuff and I’m comfortable educating them…
>
> Does that mean I expect everyone to read up? Hell no! These texts are usually fairly dry reading, and often use convoluted "academic style". And they can really depress or anger the reader with BIID’.

Here not only does Sean present himself to the rest of the community as educated and confident in communicating with professionals, but he also appears to absolve the other group members of also taking on this burden. This appeared to be successful: similarly to as discussed above regarding the sub-theme of ‘political awareness’, during data analysis the sub-theme of ‘academic research’ (falling under the broader sub-theme of ‘extra-community efforts’) was coded multiple times for Sean and never for any of the other community members. Sean’s use of academic research as a credibility tactic, appeared to be effective, in that it enabled him to acquire the position of spokesperson for the transabled health advocacy cause. In discussing this, Lucy wrote:

> ‘As we know, Sean knows the most about transableism. He has the experience, he has thought about it and lived it AND he has read all those loooong papers. He is the best one to talk to the doctors for us.

> You only need to read through this site to know he can put this strange transabled feeling into words (better than I can for sure!)…And he’s probably even read more than they (the doctors) have!’

These observations stand in stark contrast to those outlined within much of the existing research into online health advocacy communities, where, when familiarisation with scientific research and medical jargon is discussed, members of the communities in question appear to be situated as equally educated on these elements (Akrich, 2010; Dumit, 2006; Whelan, 2007). Nowhere with this literature is a situation, such as that described above (wherein this knowledge is held by one member alone) discussed.

Having acquired and justified his position as spokesperson, Sean then made attempts to engage the medical community with his intra-community epistemologies and goals. During transabled.org’s active years, Body Integrity Identity Disorder was being researched and proposed for entry into the DSM-V by Dr Michael First. As discussed in **Chapter 2,** First initially became aware of this phenomenon with the arrival of the internet and online communities. In the early 2000s he carried out a study with 50 individuals desiring limb amputation, a number of whom had been recruited from online sources (2005). First’s study did not recruit participants from transabled.org, which had yet to become fully established. The results of this study were published in 2005, wherein the diagnosis of BIID was first suggested. This diagnosis, undoubtedly informed by First’s sample, focused almost exclusively on amputee-manifestations of this phenomenon. However, in the years following, and prior to the publication of the DSM-V, First undertook additional research which sought to further explore BIID, build a bigger evidence bank around it and explore manifestations other than desire for amputation. Crucially, this research was initiated by a conversation that First had with Sean. In May 2007, Sean’s frustrations with the amputee bias surrounding BIID appeared to come to a head. At this time, he described having an argument on another internet forum, wherein a number of individuals had told him that the diagnosis of BIID did not and should not include those who wanted a disability other than an amputation. Sean retorted, but ultimately decided to take his frustrations directly to First and emailed him asking for clarification. Sean posted First’s reply to transabled.org. A section of this post reads as follows (Sean, quoting First, emphasis Sean’s own):

> '**I think a case could easily be made that paraplegia vs. fully functional peripheral neuroanatomy could fall under body integrity identity (disorder) and that any other major bodily function, like sight or hearing, could fit in there as well.** When I did my original study, I did interview two people who wanted to be paraplegic using my amputation-focussed interview (changed the questions from amputation to paraplegia) and the paraplegia version seems pretty much the same as the amputee version. Of course, since I only interviewed two people this is a bit speculative….(so) **you are right that at the time I came up with the term BIID, I did have insufficient data to include other forms of impairment**'.

In adding his own comments and introducing the follow-up study, Sean then wrote:

> '(so) here we have it. BIID currently and technically does not include any other condition than amputation, but likely solely because of insufficient data…What can we do about it? Well, another study to gather more complete data, of course! Dr First is now looking at doing a follow-up study to his original study. Stay tuned! News at eleven!'

As promised, six months after this conversation took place, First did initiate a follow-up study which, unlike the 2005 one, aimed to investigate non-amputation manifestations of BIID. Alongside taking on the role of spokesperson, communicating with First and initiating this second round of research, Sean also took on a mediator role as part of his extra-community efforts. He went back and forth between the transabled community and First, translating the various interests of both parties in attempts to make the study successful. The first stage of this (in November 2007) involved Sean facilitating the recruitment of participants from transabled.org by posting a call for participants to the site. Alongside posting this call-out, Sean strongly encouraged the members of transabled.org to respond to it, reassuring them of various concerns they had (e.g. over anonymity, call costs and ethics) and informing them that Dr First was a 'genuinely kind and caring' man who would help them to understand their own BIID better. Sean's role as mediator between First and transabled.org, also saw him take on administrative duties; he answered questions and queries on First's behalf, scheduled interview times for community members, kept them up to date on First’s working hours and holiday schedules, and posted ongoing updates on the study, which included a number of further recruitment calls at later dates. Sean also posted comments emphasising the importance of the research and highlighting the need for members to ‘do their bit for BIID’; as he described it ‘(taking part in this study) is the only way we can ever hope to see surgery as an accepted alternative for BIID’. It was evident that Sean took on the role of mediator, with all its associated labour, largely because he was so keen to have his transableism epistemology and goals explored and actualised. In outlining this he wrote:

> ‘I am personally very excited by this follow-up study, as it is the first systematic look at BIID including conditions other than amputation by the medical profession…This is very exciting for those of us who need to be paras. And for all of us who need to see our goal of becoming disabled (who we really are) made available as a treatment’.

Significantly, the above observations challenge a great deal of what is discussed in relation to health advocacy communities within existing literature. Whilst this body of work situates advocacy and political mobilisation as a defining characteristic of advocacy groups (Brown et al., 2004), little attention is paid to who facilitates this mobilisation, how these individuals have, in the first place, come to occupy spokesperson roles and how this might influence the messages given.

So far I have discussed how Sean’s two-folded efforts sought to ensure the success of transabled.org as a health advocacy community. He worked at the intra-community level, to ensure that the so-called collective identity of transableism aligned to a singular and coherent epistemology. He also attempted to ensure that the group had a united set of goals. Sean carried out these tasks with an explicit awareness that they would offer transabled.org credibility in the eyes of the medical community. Sean also took on the role of spokesperson and mediator, translating these intra-community messages and goals to the medical community, and facilitating interactions between the two parties. Whilst, similarly to online community moderation practices, these process might be seen as overly restrictive or autocratic, they, nevertheless, appeared to benefit the transabled health advocacy cause by facilitating the development of health knowledges and political goals within the community and enlisting the interests of researchers.

These observations help us to answer the first key question underpinning this thesis, namely why did transableism emerge. In building upon findings outlined in the previous chapter regarding the significance of Sean in developing the so-called collective transabled identity, I suggest that part of the early popularity of transableism could be attributed to Sean's role as health advocacy community manager, spokesperson and mediator in relation to the medical community. Here, Sean's power and influence over the community as a whole was extended into his management of the health advocacy efforts of transabled.org; just as he set the boundaries regarding so-called collective transabled identity, he also took charge of delineating epistemologies and goals and presenting these to the medical community. Again, his ability to carry out these tasks was legitimised and naturalised, not only by his community leadership status, but also by additional credibility tactics, such as reading academic papers. In the previous chapter I outlined how Sean's community ownership was, in the early years of transabled.org, effective at ensuring the internal growth and success of the transabled community. This observation is here extended to reveal the ways in which his influence also raised the profile of transableism externally, thus further impacting its growth in the early stages. As we know, however, the health advocacy success of transabled.org was temporary; First's follow up study was never published and, in 2012, BIID failed to enter the DSM-V. In the final section of this chapter I explore why this might have been the case, with reference to Sean's health advocacy community efforts and the implications of these for the rest of the community. The data presented below was, during analysis, coded under the sub-theme 'health advocacy community challenges' (see **Chapter 4**, **Figure 6** for more details).

Health advocacy community failure

Alongside exploring the various factors which make health advocacy communities successful, authors have also looked at elements that cause them to fail. Just as success is associated with various intra-community factors including the development of a collective illness identity, coherent experiential epistemology and clear advocacy goals, failure has been associated with a lack of these attributes (Barker, 2002; Brown et al., 2004; Dumit, 2006). However, and just as with the explorations into how these attributes are positively fostered, little work has examined internal group dynamics regarding their failure to develop or be sustained. These oversights were significant in relation to transabled.org for several reasons. First, although Sean attempted to distance transableism from phenomena such as devoteeism and pretending (in an attempt to present a coherent experiential epistemology), these attempts were contested on a number of occasions. In terms of devoteeism, several members of transabled.org challenged the distinction that had been drawn between transableism and sexuality. Laura, for example wrote:

> ‘I want to mention sexuality and how it relates to BIID…In my circumstance, I have never had a sexual impulse or thought that didn’t involve my preferred disability. That’s just always how it’s been. And I’m totally unsure if that’s because the only time I’m ever relaxed and calm enough to become aroused is if I’m thinking about or engaging in what I feel to be my true self, or if it’s just a weird paraphilia. Regardless, my entire sexual identity consists of these fantasies’.

Other members even more explicitly challenged these distinctions. For example, Lisa, in drawing upon her own experience with both phenomena, alongside her broader observations, wrote:

> ‘Devoteeism and BIID: NOT two distinct phenomena…Clearly, there are many people who are either one, or the other. But the fact is that devoteeism and BIID go hand in hand, as evidenced by the huge percentage of people who experience both…
>
> The percentage of transabled people who are devotees is staggeringly higher than that of the general population. That should tell us that it’s not merely some random coincidence’.

Despite openly discussing sexuality in this way, the members who did so were clearly aware that it was a contentious topic of conversation for Sean. Laura, for example, expressed fears that her ‘controversial’ admissions would lead Sean to ban her from transabled.org, writing ‘maybe (admitting this) means I’m not allowed here. You’ll have to tell me’. Lisa expressed similar fears. She also drew critical attention to Sean’s motivations for separating the two phenomena, highlighting them as misguided. For example, in directly addressing Sean regarding BIID and devoteeism, she wrote:

> ‘I know you will resent and disagree with what I am saying (but) I don’t think it’s a good idea to hide the truth about a cause in order to promote the cause’.

As the above comments evidence, members of transabled.org were not only angered by the ways in which their experiences were excluded from definitions of transableism, as put forward by Sean, they were also resentful of the fact that this exclusion had been incorporated into Sean’s advocacy efforts- his attempts to ‘promote the cause’. Although Sean did not ban Laura or Lisa from transabled.org, he did chastise them for expressing their opinions and reiterated his claim that any association with devoteeism would damage the chances of BIID being clinically accepted. Challenges and resentments regarding Sean’s definitions of transableism could also be found in relation to pretending and his over-emphasis on paraplegic manifestations of BIID. Here, he was similarly accused of being ‘biased’ and of failing to represent the experiences of the community as a whole.

Alongside the members challenging Sean’s epistemological distinctions, some also remained unconvinced by his arguments regarding the inclusion of BIID in the DSM. Again, these members expressed resentment that Sean was pursuing this goal, at the expense of nuance, and without regard for their opinions. In a post addressed at Sean, which outlined this, Michael wrote:

> ‘I know from my own thoughts and from conversations that we all have different ‘feelings’ on the DSM. There are some of us who do not think transableism should be in there…
>
> All kinds of classification systems are not able to span the dimensions of the human soul. There is always an INDIVIDUAL with an individual history, individual feelings, individual wants and needs, individual ways and approaches, individual perception and individual aims and fate…
>
> I feel like I am not being heard when I say this though, I know others feel the same. I don’t want my feelings to be ignored. I don’t want to be crushed under a category. But sometimes it feels like this opinion is ignored’.

In the literature that explores the development of collective experiential epistemologies and shared goals within health advocacy communities, authors note the ways in which some illness accounts must be dropped or subsumed in order for singularity and coherence to emerge (Whelan, 2007). However, in order for this process to be successful, it must be democratic and the overall plurality of voices and viewpoints must be preserved (Akrich, 2010; Allsop, Jones & Baggott, 2004; Whelan, 2007). As Whelan (2007) notes in her analysis on an endometriosis community, individual members must be able to recognise their experiences within the overall group account; if they reject the group's ability to represent them, they would likely withdraw from the community. Whilst Whelan doesn't identify incidents of this taking place, this was evident on transabled.org. In response to the conflicts, perceived exclusions and resentments discussed above, some members chose to leave the community. This decision is explained by Bill in his final comment on the forum for Sean:

> 'What happened to the good old days of being turned on by braces and wheeling for the joy of it. It seems like no one can talk about this anymore and I don't want to be a part of it. This community is getting me down and spending more time here just breeds misery and obsession. I'm off!'

In the previous chapter I discussed how, towards the later years of transabled.org, in response to Sean's position as community leader, his treatment of others and his self-appointed ideological authority, many members left the community. Conflicts and departures over a perceived lack of representation and plurality can be seen as an extension of this.

In addition to these intra-community failures, Sean's efforts as extra-community spokesperson and mediator were also not wholly successful. For example, despite repeated attempts, Sean struggled to get the other members to take part in the BIID follow-up study discussed above. This lack of willingness to take part in the study can, broadly, be categorised into three explanations. Firstly, there were the members who actively disagreed with both Sean's transableism epistemology and his health advocacy goals; as discussed earlier, these individuals had an interest in sexuality and pretending for fun and were resistant to their experiences being medicalised via DSM entry. These members drew upon these arguments when explaining why they would not take part in the follow-up study. Secondly, a number of members, whilst, in theory, supporting the medicalisation of transableism, expressed concerns over stigma and anonymity, citing these as reasons for not taking part in the follow-up study. These members enjoyed the safe, pseudonymous nature of transabled.org and worried that engaging with a clinician would threaten this in some way. As Peter put it:

> ‘I would love to take part (in the study) but it seems too complicated. I am worried that my wife would question why I was on a long phone call to an out-of-state doctor’.

The third explanation for the lack of willingness to take part in the study directly relates to Sean’s leadership status. As discussed previously, Sean almost exclusively controlled the external communications of the community, and, at times, actively encouraged the other members to avoid responsibility for this task. This may have worked to encourage passivity in the other members, to the extent that they didn’t see it as their role to engage in research. Whilst this explanation is somewhat theoretical, in that no members directly voiced such apathy, it was hinted at in comments made by Sean. In one particularly frustrated post he wrote:

> ‘I am making my bit for the cause. But we need that critical mass. If you don’t do your bit, we are not going to see resolution any time soon…So, don’t just sit there, lurking...Participate. Make a move, even if it’s just talking about BIID with your medical professional…All the effort I put in doesn’t mean that you don’t have to, I need y’all to help me, you can’t just expect me to drive this ship all alone and then wake up in 2 years and find you’ve got the results you want because of me…One person alone can’t do this. It’s tiring and it won’t work’.

Regardless of the reason, the members’ reluctance to take part in the follow-up study had a significant impact. It was evident through ongoing posts made to the forum that First’s follow-up study could not recruit enough participants. For example, in April 2009, nearly 18 months after he had posted the initial call for participants, Sean re-issued this call on the forum, emphasising that the study was still 20 participants short. Ultimately the results of this follow-up study were never published and, as discussed extensively throughout this thesis, BIID never made it into the DSM-V. When I interviewed First regarding the follow-up study, he couldn’t remember why it didn’t get written up but noted how difficult it was to recruit participants. He also noted that his hypotheses were complicated by many individuals appearing to sexually fetishize disability and wheelchair use. Both observations support the data from transabled.org discussed here.

All of above the observations can be used to help us answer the second key question underlying this thesis, namely why did transableism disappear. I suggest that, although Sean's role as health advocacy community manager, spokesperson and mediator in relation to the medical community facilitated the initial success of transableism, his efforts weren't sufficient. Sean was unsuccessful in fully establishing a coherent experiential epistemology and shared set of goals, and his attempts to do so led to conflict and community attrition. Furthermore, whilst he successfully enlisted the initial interests of the medical community, these interests came to nothing when the other community members failed to engage in research. Whilst this later point could be interpreted as a failure of Sean's leadership efforts, in truth it is more complicated than this. What the findings here indicate is that whilst a health advocacy community may benefit from having a dedicated leader and spokesperson, ultimately there is only so far that the efforts of one individual can go. In order for a health advocacy to be successful, its members must be united, both in terms of agreed upon epistemologies and goals, and in terms of enthusiasm and commitment to the cause. Transabled.org was not united in this way and I suggest that this was one of the key factors contributing towards its failure.

Summary

In this chapter I have addressed one of the key flaws within existing clinical research into transableism, namely the ways in which this body of work, despite acknowledging the existence of this phenomenon within online communities, failed to consider how lay involvement might have impacted research outcomes. This chapter has also addressed one of the flaws identified in the existing social scientific research into lay advocacy communities. This research, whilst paying much closer attention to lay-expert interactions, has largely viewed the knowledge creation and political processes which take place within lay advocacy groups to be democratic and collaborative, thus overlooking the role played by influential leaders, spokespersons and mediators.

As discussed, whilst, on many levels, transabled.org conformed to definitions of a health advocacy community, deeper exploration revealed that its goals and efforts were not democratically distributed but were largely coordinated and executed by Sean. This was done both at the intra-community level, via Sean's awareness of the need for a clearly defined experiential epistemology and advocacy goals, and his subsequent attempts to shape such attributes. It was also done at the extra-community level via Sean's attempts to position himself as a credible spokesperson for the transabled.org community, engage the interests of researchers and act as community mediator. Similar to the discussion in **Chapter 7** on the various successes and failures of Sean's efforts to establish and moderate the transabled community as a whole, this chapter discussed successes and failures in relation to his health advocacy community efforts. As noted, both Sean's intra and extra-community efforts could be seen as successful in that they contributed towards coherent epistemologies and goals and attracted the interests of a key researcher. Nevertheless, these intra and extra-community efforts were flawed in that they created conflict and community attrition. A lack of unity regarding epistemologies, goals and commitment to the cause was also revealed to be detrimental. These observations allow for a more comprehensive understanding of the answers to the two central questions underpinning this thesis. Although Sean's role as health advocacy community manager, spokesperson and mediator facilitated the initial popularity of transableism, and was thus a fundamental part of the transableism niche, his efforts, alongside the division of advocacy labour within the community, proved unsuccessful and unsustainable in the long-term. In the next and final chapter (**Chapter 9),** I integrate these findings with those from the other empirical chapters, alongside discussing their broader significance, particularly regarding research into health advocacy communities.

Chapter 9

Why did transableism emerge and why did it disappear? Discussion and concluding remarks

Introduction

This thesis has explored the emergence and disappearance of transableism on transabled.org. This exploration was informed by gaps in existing transableism knowledge. Whilst, during its existence, transableism was studied from a variety of academic perspectives, no research investigated its rapid growth and subsequent failure to achieve formal medical recognition. The primary aim of this thesis was to fill this gap in transableism scholarship and the central research questions underpinning this project were (1) why did transableism emerge and (2) why did it disappear? The aim and research questions of this thesis are also situated within broader sociology of diagnosis and medical sociological debates. Specifically, this enquiry used the conceptual framework of 'transient mental illness' (Hacking, 1998) to approach transableism, as, in recognizing the culturally and historically contingent nature of certain conditions, questions of emergence and disappearance sit at the heart of this approach. Unlike many alternative medical sociological explorations into psychological conditions, the transient mental illness approach doesn't rely on a singular explanation for a condition's existence. Instead, it uses the metaphor of an 'ecological niche' to outline how particular illness manifestations are able to flourish when a number of cultural factors and social conditions come together to, for a time, provide a stable home for the condition in question (Hacking, 1998).

This chapter discusses the key findings of this thesis, responds to the research aim and questions and presents the 6 contributions to knowledge made by this thesis. In exploring transableism as a transient mental illness, this thesis has presented 4 key findings, outlined in each of the empirical chapters (**Chapters 5, 6, 7 and 8**). Although the significance of these findings was previously discussed, in this final chapter I return to each of the key findings in turn highlighting how they offer further contributions to knowledge in that they can be situated against existing scholarship, including (1) the disability studies literature (2) scholarship that explores claims to authentic identities (3) the literature on leadership and moderation practices within online communities and (4) the health advocacy community literature. After outlining the broader academic contributions made by each of my findings, I return to the overall aim and research questions at the heart of this thesis. Although in the empirical chapters I outlined how each of my findings individually responded to questions of why transableism emerged and disappeared, in this chapter I use the overarching framework of an ecological niche to integrate these various explanations into one holistic answer. This constitutes the fifth contribution to knowledge by filling a gap in existing transableism scholarship and providing a detailed empirical explanation for transableism's emergence and disappearance. This leads me on to a discussion of the sixth contribution to knowledge made by this thesis. By applying the ecological niche model towards the empirical study of transableism, I outline the ways in which this thesis has contributed towards broader medical sociological literatures by removing the transient mental illness model from the realm of abstract theory. I offer a framework and reflections on the application of this model, for use by future scholars. I conclude this chapter by reflecting upon my research journey and discussing the limitations of this study. I use these reflections to outline recommendations for further enquiries into transient mental illnesses, including potential future resurgences and manifestations of the desire to be disabled.

Broader contributions

This thesis had 4 key findings, outlined in each of the empirical chapters. Not only did these findings respond to the research questions underpinning this thesis, they can also be situated against existing literatures, offering further contributions to knowledge.

(1) The first key finding of this thesis, as outlined in **Chapter 5**, was that contrary to descriptions within clinical literature, the members of transabled.org were not 'able-bodied' individuals but suffered with what are culturally understood to be inauthentic disabilities (e.g. invisible, fluctuating conditions). Relatedly, the disabilities that the members desired (largely paraplegia or amputation, with a focus on wheelchair use) conformed to understandings surrounding authentic disability (e.g. physical, visible, stable). Transableism offered benefits to the members of transabled.org in that it enabled them to temporarily pass as

authentically disabled, an experience which was validating and went some way towards countering their previous experiences of inauthentic disability stigma. These experiences with disability and expressions of transableism were reflective of a broader ‘cultural polarity’ (Hacking, 1998) surrounding authentic versus inauthentic disability, which emerged as an unintended consequence of the disability rights movement. This later observation offers an explanation for why transableism emerged when it did; transableism drew upon and reflected the central understandings and discourses of the cultural polarity of authentic versus inauthentic disability and provided the members a ‘release’ (Hacking, 1998) from the experience of being caught at its intersection.

These observations contribute not only to understandings of transableism itself, but also more broadly to the disability studies literature. During its existence, transableism was largely rejected by disability scholars and activists and, to date, has not been used in support of critical disability theory (Stevens, 2011). However, by revealing the ways in which transableism was informed by conceptualisations surrounding authentic versus inauthentic disability, the findings discussed here align transableism with much of the scholarship and aims of those working within the field of disability studies. As discussed in **Chapter 3**, many disability studies scholars have noted the existence of the polarised understandings attached to authentic and inauthentic disabilities and have outlined the negative impacts of these understandings on those deemed inauthentically disabled (Wendell, 2001). As is noted, individuals deemed inauthentically disabled are denied social legitimacy and access to resources and, should they attempt to claim them, are tasked with having to prove that their disabilities are legitimate (Mills, 2017; Wendell, 2001). In critically analysing this burden of proof, many theorists have also drawn attention to the strategies utilised by those with inauthentic disabilities. Of particular note is the work of Siebers into what he terms ‘the disability masquerade’; this term refers to the ways in which individuals ‘disguise one kind of disability with another or display their disability by exaggerating it’ (2004, p. 4). Often this takes place through the strategic use of disability aids, notably wheelchairs, which are not entirely or consistently necessary (Renfrow, 2004; Siebers, 2004). It is a tactic commonly used by those with invisible, inconsistent or hidden disabilities with the goal of presenting as authentic and receiving help, resources and legitimacy.

The members of transabled.org's understandings of transableism and their related behaviours (e.g. wheelchair use to pass as authentically disabled) can be situated on a spectrum with this disability masquerade, albeit taken to its most extreme conclusion. As such, transableism, rather than being counter to disability studies literature, can be thought of as representing and illuminating a crystallised microcosm of the more widespread behaviours related to the disability binary and the management of inauthenticity stigma. Thus, rather than transableism being rejected or overlooked by disability scholars and activists, the insights surrounding it could be used to further highlight and critique the oppressive effects and counterproductive strategies which emerge out of the disability binary. The use of the example of transableism towards this end is timely. As discussed in **Chapter 3**, the disability binary was consolidated following the disability rights movement in the 1980s. Although, since that time, much scholarly and activist work has been done to acknowledge and raise awareness of invisible disabilities (Bolt, 2014; Moore et al., 2016), there is evidence that the disability binary still persists, with further work suggesting it has become more deeply entrenched by austerity programmes designed in response to the 2008 global financial crisis (Briant, Watson & Philo, 2013; Heeney, 2015; Hughes, 2015). As this body of work highlights, ideas surrounding inauthentic disability (e.g. as invisible, non-apparent and fluctuating) were, following the financial crash, used to justify overall cuts to disability welfare alongside the introduction of more punitive, harmful testing regimes and eligibility criteria (Briant, Watson & Philo, 2013). This was carried out under the guise of protecting the tax-payer and 'legitimate' disability claimants from so-called fraudulent individuals (Hughes, 2015). The attitudes underlying these reforms were additionally noted to have been informed by and informative of media portrayals, which positioned those with invisible disabilities as counterfeit, further reinforcing the disability binary within cultural and social understandings (Briant, Watson & Philo, 2013; Runswick-Cole & Goodley, 2015). Given that, in the wake of COVID-19, we are about to enter into a global recession and an age of even greater austerity (International Monetary Fund, 2020), the ways in which transableism illuminates the disability binary remain relevant to disability scholars who aim to critique popular understandings surrounding disability and their detrimental effects.

(2) The second key finding of this thesis, as discussed in **Chapter 6**, revealed that, in addition to desiring disability, many of the members of transabled.org attempted to construct and negotiate the diagnosis of BIID itself as an authentic 'disability like any other' (their words). They used a number of strategies to do this. For example, they attempted to align BIID with the already established and authenticated diagnostic category of Gender Identity Disorder (GID) by indexing similar symptom profiles. They also attempted to delineate what transableism was not, namely devoteeism (a sexual fetish) or pretending. These negotiations were carried out with the ultimate goal of having BIID officially authorised via its inclusion in the DSM-V. All of these strategies could be seen to reflect much of what is outlined within the literature surrounding the construction and negotiation of authentic identity, as developed within the fields of tourism and post-colonial studies (Silver, 1993; Sissons, 2005). As is noted within this literature and, as was discussed in **Chapter 3**, tribes and toured populations are commonly forced to negotiate the authenticity of cultural identity by indexing it according to essentialist understandings, so as to be granted official certification and access to rights and resources (Conklin, 1997). As was also noted in **Chapter 3**, similar processes have been observed within the sociology of diagnosis literature (Dumit, 2006); crucially, however, diagnostic negotiations haven't been explicitly aligned within social constructivist approaches to authenticity. The findings of this thesis, by drawing these comparisons, contribute to the diagnosis literature by suggesting that processes of diagnosis negotiation by explicitly theorised through social constructivist approaches to authenticity.

This contribution has significant implications, not only for the comparison it allows, but also because it enables us to draw upon critiques developed within social constructivist approaches to authenticity and apply them processes of diagnostic negotiation. As I discussed in **Chapter 6**, although the members of transabled.org felt that negotiating the authenticity of BIID was empowering in that, if successful, it would enable them to access legitimacy and resources, ultimately they experienced a type of 'oppressive authenticity' (Sissons, 2005). This is a term used within the tourism and post-colonial literature; it refers to the way in which the indexing of authenticity often takes place in relation to essentialist, top-down definitions. As discussed in **Chapter 6**, the members of transabled.orgs's attempts to negotiate the authenticity of BIID were done in relation to narrowly delineated medical categories, at the expense of nuance or real agency. Future sociology of diagnosis scholars might seek to explore how comparative processes of diagnostic negotiation are similarly informed by diagnostic categories, thus ensuring that the authority to legitimatise suffering and illness identity remains with medical authorities. Beyond this, future work might also seek to explore whether and, if so, how individuals with contested or undiagnosed illnesses find ways to index and authorise authentic suffering, outside the boundaries of official diagnosis.

A further finding to emerge from **Chapter 6** was that, despite attempting to negotiate the authenticity of BIID, its status as an authentic disability was rejected by members of the disability community, who supported an essentialist, as opposed to voluntarist, ontology of disabled identity. As noted in **Chapter 6**, this offered one theory as to why transableism might have disappeared; the fact that transableism was heavily policed by the disability community caused a number of members to leave the community and abandon their public claims to BIID entirely. Not only do these observations contribute towards understanding the failure of transableism, they also contribute more broadly to scholarship exploring claims to authentic identity, and the limits of such claims. In **Chapter 6**, I theorised the policing of the members' claims to disabled identity through the work of Brubaker, who studied the racial identity claims of so-called transracial woman, Rachel Dolezal (2016a, 2016b). Just like the members of transabled.org, Dolezal's claims to an African American identity were rejected on the basis that, similarly to disability, racial identity is understood to be essentialist as opposed to voluntarist. Within his work, Brubaker uses this finding, regarding the underlying essentialist ontology of racial identity, to critique popular understandings of identity which he describes as having arisen within the context of Western liberalism and associated academic theories of reflexive modernity (e.g. Giddens, 1991). As he notes, these contexts and frameworks commonly emphasise how previously fixed identity categories have undergone a massive destabilization, resulting in the widespread assumption that identity is now fluid and open to voluntary self-fashioning. However, as Brubaker highlights, his analysis of Dolezal, transracialism and the underlying essentialist ontology of race contests these assumptions, revealing an underexplored counterpoint of contemporary understandings surrounding identity. As he notes, alongside the enlarged scope for choice and the discourse of self-reflexivity which now surrounds identity, there have been simultaneous concerns provoked about unregulated or illegitimate identity claims which, paradoxically, have led to increased efforts to police certain types of identity claims in the name of objectivity and innateness. This has resulted in a tension emerging between the language of choice and subjectivity versus reality which sees a renewed reliance on essentialism (Brubaker, 2016a, 2016b).

The findings discussed in **Chapter 6** of this thesis, regarding the ways in which BIID was policed and rejected according to an essentialist ontology of disabled identity, offer support to Brubaker's observations and, broadly, can be used to further challenge theories regarding the enlarged scope for choice which is now said to exist in relation to identity. This observation is further confirmed by what was discussed above regarding the ways in which diagnoses, whilst often negotiated at the lay level, ultimately rely upon and reproduce essentialism. More specifically, however, observations regarding the policing of BIID offer insight into the underlying ontology of disability and the limits which exist in relation to claims to disabled identity; this builds upon Brubaker's work as, although he explored racial and gendered identity, he did not address disability. As discussed in **Chapter 3**, one of the central aims of the disability rights movement was to challenge the assumption that disability was essentialist and biologically objective and, instead, emphasise its contingent and socially constructed nature (Oliver, 1990). Further to this, whilst the social model of disability did not rely on the language of subjectivity, more recently, this type of language has emerged in relation to disability; increasingly, within institutional settings, individuals are asked whether they 'self-identify as having a disability' (Aquino & Bittinger, 2019; Hahn, 1993). Whilst, on the surface, both the social model and the language of self-identification can be seen to conform to the anti-objectivism inherent within theories of reflexive modernity, the findings of **Chapter 6**, contest this. This contestation is evident in the fact that, when it came to policing the members of transabled.org's claims to disabled identity, the disability community situated disability as objective and unchosen thus, in many ways, replicating the essentialist language and objectivist ideology of the medical model of disability. This tension- between the language of construction and choice versus the reality of how claims to disability are assessed- has been highlighted elsewhere (Mills, 2017; Roulstone, 2015). Here, theorists have drawn attention to how notions of disability self-identification are little more than rhetoric, given that being granted official disability status, and associated rights and resources, still requires various objective measurements (such as a medical certificate, social care assessment or official diagnosis) to be met (Mills, 2017; Roulstone, 2015). Future scholars exploring claims to disabled identity will find the observations drawn from transabled.org useful and may use them to further interrogate the contradictions which exist in relation to language versus the reality of authenticity politics in practice.

(3) The third key finding of this thesis, as discussed in **Chapter 7**, was that whilst, on the surface, transabled.org appeared to be a democratic and collaborative online community, this was deceiving. Instead, the development of a so-called collective transabled identity was significantly influenced by a centralised model of community ownership and moderation. Sean, via his use of a wide range of moderation mechanisms, heavily influenced the development of transabled identity. Whilst in the early years of transabled.org, this centralised moderation model either went unchallenged or was welcomed by the other community members, in the later years it created conflict, community attrition and moderator burn out. What was concluded from these observations was that, whilst Sean's centralised moderation efforts fostered the grow of transabled.org and enabled the emergence of transableism, they also, paradoxically, became a victim of their own success and contributed towards its failure.

These observations not only offer insight into why transableism emerged and disappeared, they also contribute to the literature on power and moderation in online communities. As discussed in **Chapter 3,** online community moderation is still acknowledged to be an under-developed area of study, even more so in relation to the moderation of small-scale communities with individual centralised moderators who are also members of the communities in question (Grimmelmann, 2015; Thompson & Round, 2016). Relatedly, whilst there is a substantial body of work dedicated to exploring the success, sustainability and/or failure of the development of collective identity within these smaller-scale online communities, moderation practices often remain unexplored in relation to these factors (Akrich, 2010; Baym, 2003; Leibing, 2009; Whelan, 2007). By providing an in depth illustration of such moderation practices, the observations in **Chapter**

7 have contributed towards opening the black box of centralised moderation practices, providing examples of these practices in action and revealing the ways in which they influence the internal dynamics and long-term sustainability of the community.

One particularly important point to emerge from these findings was the multifaceted, longstanding and entrenched ways in which centralised community moderation operated on transabled.org. As was discussed, the moderation model on transabled.org was born out of Sean setting up the community, designing and building the website and its architectural affordances, using this bottom-up ownership to facilitate top-down moderation, all of which was justified by, and reinforced, his social status and ideological authority. A further significant observation related to the way in which moderation practices on transabled.org were not static. Instead, they were received and interpreted differently over the life course of the community, thus revealing how a once successful and flourishing moderation model can become unsustainable over time. Within existing academic research into online community moderation, there is a tendency for types of moderation tactics (e.g. ex ante, ex post, architectural, social) to be studied in isolation (Grimmelmann, 2015; Thompson & Round, 2016). Little work explores how these types of tactics might mutually interact and reinforce one another, as was the case on transabled.org. Further to this, there has also been a tendency to study moderation at a particular moment in time as opposed to over a sustained period (Busch, 2011; Thompson & Round, 2016). This has led theorists to label moderation tactics within an individual community as *either* positive and facilitatory *or* autocratic and detrimental, with little work exploring how this can shift over time, as was the case on transabled.org.

Future theorists of online communities can thus draw upon the findings of this thesis and, when studying centralised moderation practices, focus on interconnection and evolution over time. As discussed in **Chapter 4** the choice of digital ethnography over microanalysis (Subrahamanyam, Greenfield & Tynes, 2004) allowed holistic attention to be paid to all aspects and practices on transabled.org, including relationships and power dynamics. This method proved to be extremely effective for this goal. As discussed in **Chapter 7,** prima facie, transabled.org appeared to be a democratic and collaborative community; it was only after immersing myself in the website and reading all the archived content chronologically that I was able to identify the centralised model of moderation underpinning transabled.org. As discussed in **Chapter 2,** this moderation model had not been identified within previous work into transabled.org where microanalysis, as opposed to ethnography, had been used (Davis, 2011, 2012, 2014). This contrast reveals the value of digital ethnography when studying online community moderation practices, suggesting that future research projects would benefit from using this method.

Alongside offering suggestions to future online community researchers, the observations of **Chapter 7** might also be beneficial to those wishing to establish online communities themselves. Given that the centralised model of moderation on transabled.org eventually lead to conflict and burn-out, those wishing to create supportive and sustainable online communities might look to implement more distributed, democratic moderation practices. Hopefully, this would go some way towards avoiding the types of challenges experienced by transabled.org in its latter years, thus safeguarding against eventual community failure.

Since the closure of transabled.org in 2012, the internet has changed significantly. Arguably, small-scale, pseudonymous, attribute-based communities, such as transabled.org are not as common as they once were, having been usurped by the ever-increasing number of social networking sites (SNSs) (Ellison & boyd, 2013). In line with this, the most recent academic work into moderation has largely focused upon algorithmic, external and commercial moderation practices[37], given that these commonly underpin SNSs (Gillespie, 2019; Roberts, 2016, 2019). Whilst the change in internet culture and evolution of moderation practices may appear to indicate that qualitative, ethnographic studies of small, independent communities are no longer relevant, this assumption is misguided and even risks further black boxing centralised, human moderation. Whilst the growth of SNSs, alongside algorithmic, commercial moderation, is undeniable, influential individuals remain present within these environments. For example, on SNSs such as Facebook and Discord, private groups can be set up, which are then internally moderated by leading group members (termed 'admins'), who are able to set their own community rules

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[37] Algorithmic moderation refers to automatic, machine detection of harmful content and pre-emptive removal. Commercial and external moderation is not done by community members but outsourced to workers employed by the platforms in question (Gillespie, 2017).

(Discord, 2020; Facebook, 2020). Furthermore, certain types of SNSs, such as Reddit and Tumblr, can be seen to more closely mimic older types of online communities in that sub-threads are set up around particular topics or identities, which are also internally moderated by individual members (Reddit, 2020; Squirrel, 2019). Finally, although SNSs have increased in popularity, independently owned and moderated communities, such as transabled.org, still exist, with many theorists acknowledging that, under the current socio-political climate, they have become even more ideologically polarised than their predecessors (see, for example, online terrorism groups (Dawson, 2010), far right groups (Bliuc et al., 2020), the ‘manosphere’[38] (Ging, 2017) and anti-vaccination groups (Hoffman et al., 2019; Schmidt et al., 2018)). Thus, following the observations outlined in **Chapter 7**, it is recommended that future researchers investigating any of the types of environments described above do not assume that moderation is exclusively algorithmic, but instead pay attention to the presence of influential individuals and centralised moderation practices.

A final observation related to the findings of **Chapter 7** was the way in which certain practices on transabled.org exceeded those noted in the literature on online community moderation. Alongside carrying out traditional moderation practices, Sean also sought out and recruited members whom he believed would conform to the identity and ideology of transableism. He maintained close, personal relations with these members, influencing their trajectory towards identifying as transabled. Whilst these recruitment efforts and close mentorship relations have not been explored within the literature on online community moderation, they have been identified and extensively studied within literature on other types of offline social movements including New Religious Movements (Barker, 1990; Dawson, 2011), terrorist groups (Hofmann & Dawson, 2014), and cults (Lalich & Lee, 1996). This body of work, rather than studying these relational dynamics in isolation, has instead situated them as a paradigmatic example of charismatic authority, a proto-typical model of leadership outlined by sociologist Max Weber (1968). As part of his broader investigations into power, Weber was interested in ‘legitimate authority’, or the way in which power becomes justified and recognised by ruler and ruled alike. Weber outlined three ideal-typical forms

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[38] The manosphere is a catch all term for misogynistic online communities, including Men’s Rights Activists (MRAs), involuntary celibates (incels), pick up artists (PUAs) and so-called revenge porn communities (Ging, 2017).

of legitimate authority: traditional authority, where obedience is paid to those who occupy inherited and sanctioned positions (e.g. kings and chiefs), legal-rational authority, which is vested in an office and based upon established and impersonal orders (e.g. elected officials within modern bureaucracy) and charismatic authority. This later model emphasises how authority is bestowed upon an individual on the basis of them being perceived to have special personal qualities, including unique insight, exemplary powers or knowledge and the ability to form emotional connections and close identifications with others. This belief in special personal qualities has been used to explain how an individual might put forward unconventional or counter-cultural ideas, facilitate support from a community of followers, and, from that, lead a revolutionary social movement.

The body of work which has identified and investigated the presence of charismatic authority within offline social movements has offered much sociological insight, in that it has been able to explain how collectively held, yet seemingly irrational beliefs can grow and spread (Barker, 1990; Dawson, 2011). To date no work has used the model of charismatic authority to seek similar explanations within online groups who hold irrational or extreme beliefs[39]. This represents an area of opportunity, especially given that, as was observed in **Chapter 7,** the leadership practices on transabled.org exceeded those described within the moderation literature, and displayed the types of relational dynamics characteristic of charismatic leadership (e.g. close, emotional bonds, one-on-one mentorship, belief in a leader's ideological authority). Following this, future theorists of small, centrally moderated communities, particularly those with a counter-cultural ideological basis, might look to identify the operation of charismatic authority within these environments. A fruitful area of enquiry might be an exploration of the ways in which charismatic authority intersects with and legitimises centralized models of moderation, thus further enabling an influential individual to foster an online community with a strong sense of collective identity.

(4) The last key finding of this thesis, as outlined in **Chapter 8**, built upon the observations of **Chapter 7** to discuss how, in addition to establishing and moderating the community, Sean also led the health advocacy efforts of

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[39] One piece of research looks at charismatic authority held by popular YouTubers over their followers (Cocker & Cronin, 2017). However, YouTube followers do not conform to definitions of online communities or groups, given that they have no connection to each other.

transabled.org. Initially, these efforts were extremely successful in that they facilitated the development of coherent health knowledges and political goals within the community, alongside enlisting the interests of researchers. As was discussed in **Chapter 8**, this observation further contributed towards explaining why transableism might have emerged. Alongside responding to the research question, however, the observations regarding Sean's successful health advocacy efforts have a number of broader implications. Firstly, they challenge the assumptions inherent within clinical research, both into transableism and other types of health conditions. Clinical literature has a tendency to assume that patients passively wait to have their health conditions researched and labelled by doctors in an entirely top-down process (Frank, 1995; Hacking, 1995, Kleinman, 1988). The observations outlined above contest these assumptions by revealing how transableism and BIID epistemologies were developed and refined at the lay level, and then actively brought to the attention of the medical community.

Whilst similar types of observations regarding lay involvement in research have been outlined within the social scientific literature on health advocacy communities (Akrich, 2010; Leibing, 2009; Whelan 2007), the findings from transabled.org also contest assumptions inherent within this body of work, taking the analysis one step further. Within this literature, lay epistemologies, goals and communications with medical communities are portrayed as collectively orchestrated. However, as the findings from transabled.org indicate, this body of work may have overlooked the presence of an individual co-ordinating these efforts. Although leadership and moderation practices are acknowledged to be black boxed within studies into online communities in general (Grimmelmann, 2015), this appears to be even more pronounced within studies of online health advocacy communities (see for example Akrich, 2010; Leibing, 2009; Whelan 2007). This omission is particularly striking given that the development of a strong collective identity and a shared epistemology, alongside the ways in which these are communicated to external parties, have all been identified as facilitating the success or failure of a health advocacy community. When it comes to the success or failure of a health advocacy community, the stakes are extremely high. Success may mean official medical certification and access to treatments, whereas failure may mean suffering and delegitimation or the disappearance of a diagnostic category entirely (Brown et al., 2004). Thus, given that one of the key observations to emerge from **Chapter 8** was the way in which the model of centralised leadership on transabled.org extended into the development of collective illness identity, epistemologies, and communications with the medical community, future work aiming to investigate the success or failure of a health advocacy community should prioritise identifying and studying the presence of an influential leader.

Alongside revealing the initial successes reaped by Sean's health advocacy efforts, the findings of **Chapter 8** also revealed how, ultimately, these efforts weren't sufficient. Sean was unsuccessful in fully establishing a coherent experiential epistemology and shared set of goals for transableism. Not only did his attempts to do so lead to conflict and community attrition but the lack of shared goals also meant that a large proportion of the community were disengaged with clinical research. Not only do these observations contribute towards understanding the failure of transableism, they also make additional contributions to the health advocacy community literature. Whilst, as discussed above, future health advocacy community scholars are encouraged to identify the presence of an influential leader, they should also take care to examine the limits of centralised models of leadership when it comes to co-ordinating shared epistemologies and goals. A fruitful area of enquiry might look to identify conflicts over shared goals, whether and, if so, how such conflicts get resolved and what degree of nuance regarding illness epistemology is acceptable versus detrimental.

Alongside contributing to scholarly work, the above observations will also be useful to those in positions of leadership within health advocacy communities. As was discussed in **Chapter 8**, transabled.org community attrition and disengagement largely arose as a result of Sean's attempts to narrowly delineate the transableism epistemology- a process which involved denying many of the other members' experiences (e.g. with devoteeism and pretending). Following this, health advocacy community leaders would do well to allow space for a variety of opinions and experiences to be expressed. This recommendation can be seen as connected to points made earlier (within the discussion of the findings of **Chapter 6**), regarding the ways in which the legitimisation of authentic suffering and illness identity might take place outside of the boundaries of formal diagnostic criteria. If lay communities are to avoid replicating the 'oppressive authenticity'

(Sissons, 2005) enacted by narrow diagnostic criteria they should allow members to discuss the full spectrum of their experiences, even if such experiences fall outside of formal, clinical understandings. Of course, in doing so, communities do run the risk of diluting the illness epistemology and failing to achieve established goals, as was Sean's fear regarding transableism. Nevertheless, if a community is to ensure its members feel represented and included, it should avoid the mistakes made by transabled.org and strike a more appropriate balance between coherence versus nuance.

The ecological niche of transableism

This thesis has used the conceptual framework of transient mental illness (Hacking, 1998) to explore questions of transableism's emergence and disappearance. The model of transient mental illness doesn't rely on a singular explanation for a condition's existence. Instead, it uses the metaphor of an ecological niche to outline how particular illness manifestations are able to flourish when a number of cultural factors and social conditions come together to, for a time, provide a stable home for the condition in question (Hacking, 1998). As has been discussed throughout this thesis, several findings regarding transableism's emergence and disappearance were identified. Within the empirical chapters, I outlined how these findings individually responded to the question of why transableism emerged and disappeared. Through use of the ecological niche model, these findings can now be integrated.

Regarding transableism's emergence, I suggest that transableism emerged because of a combination of factors: it reflected and expressed broader cultural understandings and tensions surrounding authentic versus inauthentic disability, it enabled individuals who were caught within this binary a 'release' (Hacking, 1998) from their distress; transableism was also facilitated by the centralised model of online community leadership which, for a time, successfully fostered a coherent group identity and provided a language through which the 'release' from inauthenticity stigma could be expressed. This model also facilitated the health advocacy efforts of transableism, enlisting the interests of clinicians, increasing the likelihood that transableism be officially medically certified. Together, these factors comprised a transableism ecological niche which, at the time of its existence, gave transableism resonance and enabled it to flourish and spread.

As outlined above, an ecological niche not only enables the existence of a transient mental illness, but it does so within a specific time and place. This observation enables us to reflect, not only on why transableism emerged, but why it did so in 1997 in a particular type of online community. Regarding the time frame, a large part of the chronology of transableism was, as discussed in **Chapter 5**, bound up with the disability rights movement and the way in which this movement implicitly structured cultural understandings regarding authentic versus inauthentic disability. As outlined in **Chapter 3**, the disability rights movement did not occur until the 1980s (Oliver, 1990). Prior to this time such stark and well-developed binary understandings and attitudes surrounding authentic and inauthentic disability did not exist; instead, all types of disability were equally and collectively pathologized and stigmatized (Goffman, 1963). This thus explains why transableism did not emerge until the late 1990s. A transableism ecological niche, being so heavily informed by the disability binary, simply would not have been possible prior to that time.

Regarding its emergence in a particular place, whilst, unlike in Hacking's work, transableism was not bound to a geographical location, it originated and spread online. Whilst previous scholarship theorised that the emergence of transableism was tied to the development of the internet and online communities (Davis, 2012; Elliott, 2003), the findings of this thesis both support and challenge these observations. As discussed in **Chapters 7 and 8**, much of the transableism ecological niche was constituted by the centralised model of online community ownership and moderation that existed upon transabled.org. What this indicates is that the 'place' to which transableism was bound was not online communities per se, but transabled.org specifically, in that this location contained and enabled an almost complete control of ideology, discourse and action related to transableism. Whilst the internet arguably made this sort of space possible (offline environments under the exclusive architectural and conversational control of one individual are extremely rare), it did not make it inevitable. This is not to say that the mode of leadership and moderation found on transabled.org is entirely unique to transableism (indeed, as outlined in the previous section, this mode may exist in many other online spaces). Instead, this observation is intended to draw attention to the importance of distinguishing this mode of leadership from others found within online communities and highlight its specificity in constituting the place of the transableism niche. Future studies in to online borne transient mental illnesses should look to draw similar distinctions; instead of describing the place of such illnesses as online communities in general, they should examine the specifics of the platform in constituting the niche in question.

A final point regarding the place of transableism can be made, although this point is largely theoretical, and not reliably rooted in the findings. It is theorised that, beyond the place of transabled.org, sufferers of transableism might only have existed in Western, developed nations, where material and social benefits for those with so-called authentic disabilities are available. In countries with no such benefits, where all forms of disability are universally stigmatised, it is highly unlikely that transableism would have flourished. This is because, as discussed above, a constitutive part of the transableism niche was the way in which it offered sufferers a 'release' (Hacking, 1998) from inauthenticity stigma, by enabling them to pass as authentically disabled and temporarily enjoy the benefits that accompanied such passing. Whilst it did appear as if the members of transabled.org were located in Western countries with disability benefits (in that they were familiar with the English language, the Americans with Disabilities Act (ADA) and the Diagnostic and Statistical Manual of Mental Disorders (DSM)), due to the historic and pseudonymous nature of the field site, these locations could not be verified. Any future studies into potential resurgences of the desire to be disabled (to be discussed in more depth later) should seek to verify sufferers' geographical location so as to test the accuracy of this theory.

In addition to offering explanation for why transableism emerged, the ecological niche model also offers an explanation for why it disappeared. As Hacking outlines in his work, the ecological niche which enables a transient mental illness is a synchronicitous and delicate balance of all of the factors which comprise it. What this means is that, in addition to enabling culturally and historically unique illness manifestations, an ecological niche is precarious. If one factor comprising the niche weakens or disappears, this ultimately affects the existence of the whole niche and, as Hacking outlines, should an ecological niche disappear, then the condition will also.

Regarding transableism's disappearance, in line with Hacking's theory, I suggest that transableism disappeared because the transableism ecological niche did. Although this niche initially provided a stable home for transableism, as time went on, elements of it weakened. Whilst, as discussed in the previous section, the cultural polarity of authentic versus inauthentic disability still persists today, the ability of transableism to exist at its intersection declined, as BIID failed to conform to an accepted authenticity politics of disabled identity and was policed accordingly. Further factors weakening the ecological niche of transableism included the decline in efficacy of the centralised model of community leadership. This not only caused conflict, a weakening of the collective identity and community attrition, but it impacted the health advocacy efforts of transableism and thus the possibility of it becoming officially medically recognised. The weakening of these once facilitative elements of the transableism ecological niche meant that a hospitable home for this condition no longer existed, thus bringing about its disappearance.

These observations, regarding the disappearance of the transableism niche, have broader implications. Primarily, they raise questions regarding the long-term sustainability of any type of transient mental illness which originates in a lay movement (both on and offline). As discussed, the rejection of BIID as a legitimate diagnosis, alongside the decline in efficacy of the centralised model of community leadership, were both heavily constitutive of the failure of the transableism niche. These findings appear to indicate that, if a lay-borne[40] transient mental illness is ever to acquire long term success, it needs to evolve beyond a local, centrally organised mode of existence and become more formally recognised. Thus, rather than the disappearance of transableism in 2012 being unique to this condition, this disappearance might, instead, be representative of the naturally brief life cycle of all types of lay-borne transient mental illnesses, which fail to become broadly institutionalised. Future scholars of lay-borne illnesses might seek to test this theory by examining how long these types of conditions are able to be sustainable without broader recognition.

As was discussed in the introduction to this thesis (**Chapter 1**), although transableism has been studied from a wide variety of perspectives, no enquiry explored questions of its emergence and disappearance. Furthermore, although in the early 2000s, a number of philosophers suggested that newly emerging manifestations of the desire to be disabled might be explained through Hacking's

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[40] The term 'lay-borne transient mental illness' is here used as shorthand to refer to any type of transient mental illness which originates in a lay movement, as opposed to a clinical setting.

ecological niche of transient mental illness approach (Charland, 2004; Elliott, 2003), no empirical research was carried out to test this theory. As such, the above analysis, in applying Hacking's model towards the in-depth study of transableism, has contributed towards existing transableism knowledge by offering novel insights into why the condition emerged and why it disappeared. This leads me on to the final contribution made by this thesis.

Beyond transableism: Reflections on the use of the transient mental illness model

The above analysis regarding the ecological niche of transableism, whilst not offering one concise answer for the questions which underpin this thesis, provides more a more complex, holistic explanation regarding transableism's emergence and disappearance. As discussed in **Chapter 1,** within medical sociological debates, various explanations for culturally and historically specific conditions have been put forward including labelling processes (Link & Phelan, 2013), sick role theory (Parsons, 1991), social functionalism (Littlewood, 2002), the influence of cultural contexts and moral values (Blaxter, 1978; Jutel, 2009), pharmaceutical imperatives (Healy, 1997) and social inequalities (Farmer, 2004; Reiss, 2013; Showalter, 1985) (see **Chapter 1** for definitions). In **Chapter 1**, in providing justification for use of the ecological niche model, I outlined how these models can be seen as reductive in that they attribute the existence of a condition to a single factor. By not reducing the question of transableism's existence in this way and, instead, integrating insights from many of the above theories, the findings of this thesis have demonstrated the superiority of the the ecological niche approach to transient mental illness. Following this, it is recommended that this model be used in future medical sociological enquiries. Although, within existing literature, Hacking's ecological niche theory has been widely discussed in relation to its philosophical arguments (Brossard, 2019; Elliott, 2003; Tsou, 2007), there is a comparative lack of research which has implemented it in sociological, empirical research (Brossard, 2019). Because of this, few examples of how the ecological niche theory might be applied in practice exist; this may have discouraged sociologists from using it, creating a vicious circle wherein the ecological niche model remains in the realm of abstract theory. This thesis, by providing an in-depth, empirical exploration of the ecological niche approach, has thus made a significant contribution to the medical sociological literature which can be used by future theorists of transient mental illnesses.

In addition to simply offering support for the use of Hacking's ecological niche framework, reflections and insights gained through the course of this research project also reveal some of its limitations. When he first coined the ecological niche metaphor, Hacking outlined how it was made of many varying factors, leaving these open to investigation according to the condition in question (1995). In his later and better-known work, however, Hacking refined his model, specifically emphasising 4 key 'vectors'[41] constitutive of an ecological niche, suggesting that these be the focus for researchers (1998). These 4 vectors are cultural polarity (how an illness is lodged between and representative of two core oppositional tensions within a society), release (how an illness, despite the pain it causes, offers some benefit to its sufferers), observability (the way in which an illness is made visible to potential sufferers and doctors, and society more broadly[42]) and medical taxonomy (how, in order for a transient mental illness to emerge, it must fit into a pre-existing system of medical taxonomy, making it comprehensible and of interest to clinicians[43]) (Hacking, 1998).

When I first began my data collection and analysis, guided by Hacking's advice, I attempted to identify and then fit my data into these 4 vectors. However, I soon found this to be too restrictive. Whilst, as highlighted within this thesis, I found the notions of cultural polarity and release to be extremely applicable to my data, I found that doggedly perusing the vectors of observability and medical taxonomy came at the expense of exploring nuance and unexpected insights. Regarding the vector of observability, whilst it was apparent that transableism was made observable to its sufferers via the online community, I felt that, by exclusively using observability to frame my data, the more interesting complexities of the centralised model of community leadership on transabled.org were lost. Whilst,

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[41] Hacking's use of the word vector is a metaphor taken from mechanics, wherein 'force vector' refers to a force acting in a direction which, when combined with other forces, brings about a resultant force. When applied to ecological niches it is used to refer to 'different kinds of phenomenon, acting in different ways…whose resultant may be a possible niche in which a mental illness thrives' (Hacking, 1998, p. 81).

[42] For example, in his work on Multiple Personality Disorder (MPD) Hacking notes how this condition became highly 'observable' in the United States in the 1980s via sufferers appearing on daytime television chat shows and publishing memoirs (1995).

[43] For example, in his work on dissociative fugue, Hacking notes how, when this condition first emerged in the late 19th century, it appeared to conform to either the existing hysteria or epilepsy taxonomy, making it of interest to clinicians of the time (1998).

indeed, many of the members first identified with transableism after having come across transabled.org, this observation obscured how this community, and the collective identity which existed there, was facilitated by Sean's creation, design and moderation. Regarding the vector of medical taxonomy, I found this to be too simplistic. As discussed in **Chapter 2**, it was well documented within the literature that the most recent instantiation of the desire to be disabled was beginning to be conceptualised as an identity disorder and was proposed for entry into the DSM-V under the label 'Body Integrity Identity Disorder' (BIID). As also discussed in **Chapter 2,** what this literature didn't explore was the way in which these clinical conceptualisations were informed by online communities, in particular the health advocacy efforts of transabled.org and, again, the ways in which these were facilitated by the centralised model of community leadership. Further to this, simply identifying the vector of medical taxonomy also didn't leave space to explore how the disability community policed and rejected the proposed diagnosis of BIID.

The way in which Hacking has prescriptively outlined the 4 vectors of cultural polarity, release, observability and medical taxonomy, has been critiqued elsewhere (Brossard, 2019; Halim, 2009). Here theorists, echoing my experiences, have noted how these vectors are overly restrictive, given the wide variety of both transient mental illnesses, and ecological niches which support them. Thus, following these observations and my research experiences, I suggest that future theorists of transient mental illnesses do not rigidly or exclusively focus upon Hacking's 4 vectors but rather, in line with his earlier work, remain open to the fact that an ecological niche may be comprised of any number of varying factors. This is not to say that the 4 vectors are irrelevant and should be abandoned entirely; this is evident, given the value I found in using the vectors of cultural polarity and release. Instead, I suggest that they be used as a flexible starting point, as opposed to a definitive framework.

Limitations of this project

The main limitation of this project was its scope. When this research project was first conceived, the desire to be disabled was almost entirely absent from the internet, the cultural horizon and from academic research, however, over the last few years it appears to have made a small resurgence. As discussed in **Chapter 1**, since 2018, there has been activity on some sub-Reddit threads discussing the desire to be disabled. These discussions can largely be seen to move away from the identity incongruence discourse which characterized transableism and BIID and, instead, draw upon neurological explanations, research and terms, including xenomelia (Brugger, Lenggenhager, & Giummarra, 2013) and Body Integrity Dysphoria (BID) (Reed et al., 2019). This resurgence is intriguing and research into it might have contributed to the findings of this thesis by providing points of comparison between this new manifestation versus transableism, alongside the ecological niches surrounding each. Unfortunately, however, due to limited time resources related to the stage in this project when this resurgence was identified (2018), research into this new manifestation fell outside of the scope of this thesis. Because of the restrictions identified, the scope of this project is chronologically limited to 1996-2013, situationally restricted to transabled.org and theoretically limited to the study of the desire to be disabled in its manifestation as transableism: a disorder of identity incongruence which aligned with the clinical description of BIID. Despite not being able to address the resurgence of the desire to be disabled within this project, it is, nevertheless, strongly recommended as a project for a future enquiry that might seek to use the same ecological niche approach adopted in this thesis. Not only would this provide data for an interesting comparative project on transableism, but it would also offer overall support for the notion that transient mental illnesses can reappear under different manifestations, supported by slightly different niches, within various cultural and historical moments (Hacking, 1998).

An additional limitation of this project was the way in which, whilst I was able to analyse some power relations, namely those manifest within online community ownership, I was unable to investigate others. Within other types of social movements, in particular those where the framework of charismatic authority (as discussed above) is used, gendered power analysis features strongly (Barker, 1990; Dawson, 2011, see also Epstein, 1995; Whelan, 2007). Here theorists note how the cultural capital and social power possessed by men increases their likelihood of becoming a community leader, and enhances their authority and influence once this position is occupied. Throughout this research project, my attention was drawn to the fact that many of Sean's close mentorship relations (as discussed in **Chapter 7**) appeared to be between him and much younger, female community members. These observations, however, were based upon the self-reported ages and genders of all parties which, given the pseudonymous nature of the community, may not have been accurate. As such, I did not feel that an analysis of gendered power dynamics could be reliably incorporated, as it has been within the literatures just cited. For obvious reasons, analysis of other potential structural power dynamics, including race, class and sexuality, was also not possible. Whilst this was a limitation for this project, future studies into transient mental illnesses- particularly those with centralised models of community ownership and health advocacy- might seek to reliably collect and analyse this demographic data.

A final limitation of this project was related to the way in which some data was unavailable for analysis due to the fact that Sean had deleted it (as discussed in **Chapters 7 and 8**). Whilst it was useful to incorporate Sean's justifications for these deletions into the analysis, further insight would have been gained by examining the content of the deleted comments themselves. By examining the content of comments deemed unacceptable within the community, the analysis regarding the ways in which Sean resisted nuance and disagreement would have been further enhanced. If current resurgences of the desire to be disabled were to be studied, this limitation regarding deleted community content might be less apparent. Within these new communities, disagreements might not be deleted or, if they were, the researcher, in carrying out real time ethnography (as opposed to historic) might have the opportunity to observe them prior to their removal. Even if this were not possible, ethnographic observations could more easily be supplemented with interviews in communities which, unlike transabled.org, are currently active.

Summary

This chapter has discussed the key findings of this thesis, responded to the research aim and questions and outlined the 6 contributions to knowledge made by this research. The first 4 contributions related to the broader significance of findings discussed within the empirical chapters; these findings contributed to knowledge within the disabilities studies literature, literature that explores claims to authentic identity and the limits of such claims, literature on online communities in general and health advocacy communities specifically. In the second part of this chapter, I used the overarching framework of an ecological niche to bring together the various explanations for transableism's emergence and disappearance into one holistic answer. I suggested that transableism emerged due to a transableism ecological niche and disappeared when this niche weakened. By filling gaps in existing transableism scholarship, this analysis of the ecological niche of transableism constituted the fifth contribution to knowledge. The sixth contribution to knowledge came from suggestions regarding the broader applicability of the transient mental illness model to medical sociological enquiry. In the final part of this chapter, I discussed the limitations of this study, namely its chronological scope and the inability to analyse particular power dynamics, or deleted content, given the pseudonymous nature of the field site. Whilst these factors were identified as limitations, I also noted the potential for them to be built upon and incorporated into the study of future resurgences and manifestations of the desire to be disabled.

Concluding remarks

The questions underpinning this thesis were ostensibly simple- why did transableism emerge and why did it disappear? Before embarking upon my PhD, I somewhat naively imaged that this research project would provide me with neat, logical answers to these questions. I wasn't sure what these answers would be, but I anticipated finding clarity and feeling satisfied when I came across them. It soon became apparent, however, that this would not be the case. After immersing myself within transabled.org, the facts of transableism's emergence and disappearance became more complex, not less. I soon saw that there was not one explanation behind this phenomenon but many different forces at play.

I have outlined these varying forces throughout this thesis; transableism was about entrenched cultural ideas regarding authentic versus inauthentic disability, it was also about the suffering of those caught within these notions. It was about the need to have disabled identity recognised and authorised; this also meant that transableism was implicated in debates surrounding what counts as disability to begin with, including how, and by whom, this gets decided. Alongside reflecting broader structural-cultural issues surrounding disability, transableism was also inseparable from the local, micro-social dynamics which surrounded it. Transableism owed much of its existence to the development and evolution of power and hierarchy within the transabled community. Whilst in many ways being unique to transabled.org, these dynamics were also representative of much more recognisable patterns and struggles found within communities across time and culture. The dynamics found within transabled.org spoke to how people exist in groups, how those at the top of hierarchies come to have power, and how power can impact upon group identity and the position and recognition of the community at large. In summary, whilst at the beginning of PhD, I imagined that my research would provide me with insight in transableism, it is now apparent that transableism has much more to teach us about the culture surrounding it, alongside micro-social processes which are potentially acultural and ahistorical.

When starting this project, alongside imagining that it would offer me simple answers to the questions of transableism's emergence and disappearance, I also, again naively, assumed that these answers would be distinct. I imagined that one explanation would exist regarding transableism's emergence and another separate explanation, would exist regarding its disappearance. During the course of this research, however, this was also revealed not to be the case. The many different factors surrounding transableism could all, in varying ways, be seen as equally implicated in both transableism's emergence and its disappearance. Within the social sciences, there has been a tendency to approach questions of success and failure separately. There seems to be an assumption that an element contributing to the ecosystem of a social phenomenon is either facilitative *or* detrimental (Hacking, 1998). As the findings of this thesis have revealed, however, ideas and identities which initially flourish because they resonant with one group might, after coming into contact with another group, be rejected, decreasing their initial popularity. Equally, dynamics within a group are rarely stable; leadership which was one experienced as positive and nurturing may, over time, become oppressive and a source of conflict. Relatedly, the task of leadership itself, having originally been creative and fulfilling, might later become exhausting and frustrating to an individual. No idea, identity or dynamic is ever stable, all are vulnerable to change, and each can be implicated in both the success or failure of a social phenomenon.

To summarise, in addition to the ways in which this thesis has answered questions of transableism's emergence and disappearance, alongside contributing to knowledge regarding disability, identity claims, processes within online communities and wider medical sociological literatures, 2 broader conclusions can be drawn. Firstly, the study of a culturally and historically specific social phenomenon, such as a transient mental illness, has much to tell us, not only about the phenomenon itself but also, more generally, about the culture surrounding it and the micro-social processes constitutive of it. In addition, what was once facilitative to a social phenomenon may, with exposure to new forces or simply the passage of time, become detrimental, given the inherent instability of ideas, identities and social dynamics.

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