

‘A Constant Disparity’: Anthropological Contributions to the Study of Body Integrity Identity Disorder (BIID)

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Abstract

Body Integrity Identity Disorder (BIID) is a contested neurological condition, which causes individuals to feel they have an ‘incorrectly abled embodiment’ (Davis, 2014) resulting in feelings of disconnection from and discomfort with their own bodies. To alleviate this disparity, many seek out amputation or other radical surgery to treat what feels like an intrusive limb or sense, at great risk to themselves. BIID is heavily stigmatised and largely understudied as a condition, gaining notoriety primarily through sensationalist media reports and commentaries. Highly publicised cases of BIID have resulted in public debates about the ethics of elective surgery and the legitimacy of illness experiences, but the perspectives of people with BIID are often discounted or not considered fully, allowing misconceptions to develop. This thesis presents qualitative data collected from email-based interviews and observations of internet forums, focusing on understanding lived experiences and explanatory models. This thesis demonstrates the importance of social support and disclosure in the management of BIID symptoms, and investigates these close relationships further. This thesis ultimately aims to contribute to the demystification of BIID, aligning with the goals of emerging phenomenological literature in the field of disability impairment and chronic illness studies in anthropology. This thesis demonstrates that the experience of BIID is one that is deeply embodied, and that perceivably deviant behaviours are attempts to achieve a sense of normality and wholeness.

Statement of Originality

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

(Signed): Josephine Ricciuti

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CHAPTER 1: INTRODUCTION

Body Integrity Identity Disorder (BIID) is a contested neurological condition, which causes individuals to feel ‘incorrectly able-bodied’, as Davis (2014. p, 433) put it. Cases typically involve individuals who are non-disabled and ‘healthy’ by conventional Western norms, identifying a limb or sense (such as sight, hearing or touch) as not being a part of them, and therefore stressful and disabling. Often, these disparities create immense distress for individuals, leading to feelings of being ‘over-complete’. People with BIID often consider radical surgery and amputations as one of the only available treatments for BIID; however, these surgical interventions are denied to them based on complicated issues around legality, consent and autonomy. In extreme cases, sufferers seek to alleviate their symptoms through unregulated and illegal surgical means, at significant physical risk to themselves. In most extreme cases self-made tools, black-market surgery and the use of harmful chemicals and substances are used to cause damage, so that surgery becomes a requirement. With mass-media contributing to the stigmatisation of BIID through sensationalist reports on these extreme cases, many people with BIID tend to be secretive, seeking refuge and social support in digitally-mediated spaces, such as support-forums and chat-rooms. Pioneering research into BIID focuses on its key symptom as being a preoccupation with the desire to amputate a healthy limb (Khalil and Richa, 2012) stemming from a perceivable mismatch between the physical body and inner map. More recent studies lead me to conceptualise BIID as more than a desire for amputation, and closer to being an issue of ‘incorrect embodiment’, with an inability to align with the self being at stake for people with BIID.

Thesis aims

This thesis aims to contribute active voices—the current perspectives of people with BIID—to discussions around the condition, combining secondary research with digital fieldwork conducted in 2019 to do so. Through this thesis, I aim to demonstrate that BIID is a deeply embodied experience, and that the goals of sufferers are fixated around a need for normalcy and obtaining a feeling of completeness, as opposed to being a desire for disability. As biomedical perspectives and approaches have not yet expressed these needs accurately, I instead align with arguments which call for the use of phenomenological methods to better represent what people with BIID need and seek. This thesis asks the following questions:

I: What are the explanatory models of BIID according to people who have it? How useful are current clinical understandings in revealing the symptoms, causation, progress, and treatment goals of people with BIID?

II: BIID has been compared to medically accepted conditions such as Body Dysmorphic Disorder (BDD¹), so why is it still so stigmatised from a medical perspective? How do people with BIID manage their symptoms against the stigma they encounter?

III: How can phenomenology—a perspective which focuses on lived experiences—enrich accounts of BIID? What do embodied perspectives reveal about the needs of people with BIID? Can an ethnographic approach capture and present these experiences?

¹ BDD is a mental illness where individuals obsessively feel that a part of their appearance is unattractive or flawed.

IV: How significant are digitally-mediated spaces in facilitating social support? Do online communities have any other significant influence on the experience of BIID?

This thesis demonstrates that the root causes and invisible pain of BIID confounds biomedical frameworks. As people with BIID are not validated within these dominant biomedical systems, they are vulnerable to heavy social stigma, and are forced to navigate their challenging symptoms of disparity independently. Sufferers cope with and manage their BIID in different ways including through gaining social support from digitally mediated spaces, disclosing their symptoms to others close to them, engaging in illness narrative construction and enacting ‘simming’ practices, which are practices and behaviours people with BIID perform to resemble the impairment they need. All of these practices are performed outside of biomedical frameworks and are tailored to specifically address the needs of individuals.

Social and medical models of disability

To understand the needs of people with BIID, it is important to make distinctions between ‘impairment’ and ‘disability’, and the meanings these terms have for people. According to Davis (1995) the medical term ‘disability’ implies that there is a fault with the body in some capacity, leading individuals to diverge from normal standards. The medical model of disability—which is organised around biomedical notions of disability—situates a diagnosis as being rooted within the body. The model further posits that these impairments should be corrected or cured through clinical treatments, paying little regard to autonomy and desires of individuals. The medical model prioritises the maintenance of ‘normal’ bodies, and tends to not accept abnormalities. The medical model fundamentally assumes that impairment is an individual fault, which should be corrected to fit into society. In contrast, the ‘social model of

disability' described by Oliver (1990) considers cultural, political, economic and social barriers which influence the lived experiences of people with impairments. This model assumes that disability is generated by society against individual impairment. The social model contends that disability is a relational category built around the failure of society to provide adequate care and resources such as social support, education around impairments and tangible assistance to people who need it. This thesis aligns with disability as being socially elaborated, as opposed to being innately physical. It uses Jung's 2002 definition (cited in Goodley 2010, p. 09) which specifically states that disability is socially constructed, acting as a 'label, a signifier, that inaugurates consignment to an identity category, which signifies disadvantage and oppression' and physical impairment as 'the functional limitation within the individual caused by physical, mental and sensory impairment' (Disabled People's International Definition, 1981).

Language within this thesis

Colloquialisms such as 'transabled,' 'wannabes' and 'pretenders' are frequently used to describe the BIID community; however, these terms are losing their favour. Many subjects and community members share that they feel that the terms 'transabled' and 'transability' likens BIID too closely to the experiences of those who are transgender, and fear that it may be construed as offensive by the trans community and counterproductive in their own medical validation. In a similar strain, the terms 'wannabes', 'devotees' or 'pretenders', while prevalent in previous publications about BIID, are frequently interchanged with one another. 'Wannabes', 'pretenders' and 'devotees' are labels used to refer to people with *Apotemnophilia* meaning a love of amputees (Money, 1977) or to people who experience arousal over disability, which is

considered as being a paraphilic disorder.² As a result of these mischaracterising labels, these terms tend to be avoided by people with BIID, even though there are similarities in their ‘acting out’ of disability. Given these concerns, this thesis does not label informants or members of the BIID community as ‘transabled’, ‘wannabes’, ‘devotees’, or ‘pretenders’; however, the influence of these comparisons in past literature is acknowledged.

Medical background

Various psychological, neurological, and biological theories have been proposed on the origins of BIID, yet no formal clinical or psychiatric bodies have legitimised it as a diagnosable condition. Currently, BIID is not recognised as a condition within the Diagnostic and Statistical Manual of Disorders (DSM) despite psychiatrists—such as Dr Michael First who coined the term ‘BIID’—and other professionals advocating for its inclusion based on its similarities with other conditions such as gender dysphoria (First, 2005; White, 2014; Frey, 2018). In terms of co-morbidities, individuals with BIID report high rates of anxiety and depression from being disconnected from their bodies, and feelings of envy from interacting with others who possess the impairments they desire. In some cases, the dysphoria and anxiety from being incorrectly embodied can result in suicidal thoughts and ideation, adding urgency to debates around treatment-seeking (Dua, 2010; White, 2014). To alleviate pain and discomfort from the intrusive limb or sense, many people with BIID actively participate in a ‘rehearsal’ for amputation or disability with prosthetics or mobility aids, either in private or sometimes in public (Frey, 2018, p. 108) through a practice some call ‘simming’.

² Some professionals consider BIID as being a part of paraphilia, which is an umbrella term for non-conventional and non-normative sexual preferences to the point of mental obsession (Frey, 2018, p. 243).

Neurology: The body schema, body image and impairment

As individuals with BIID are non-psychotic, the mismatch between their internal body image and physical body is thought to arise from a neurological abnormality (Sedda and Bottini, 2014) with studies also suggesting that the condition has potential neurological origins; based on research on the body schema, body image, embodiment, and phenomena such as ‘phantom limb pain’ (PLP) (Brang, McGeoch and Ramachandran, 2007; Frey, 2018). Driving these studies are the neurological concepts of the ‘body schema’ and the ‘body image’³ which according to Pitron and de Vignemont (2017) are entangled and vulnerable to impairment (de Vignemont 2010). Studies also propose that the left side of the body is the most common area for the affected limb to be (Dua, 2012), supporting the theory of BIID being caused by defects within the parietal lobe, a part of the cerebral cortex which governs a person’s inner mapping process. If there is an abnormality in this area, then a person with BIID may fail to include their affected limb or sense into the mapping of their physical form (Frey, 2018. p, 243).

Demographics of BIID

Due to stigma, people with BIID conceal their needs and desires from professionals, as well as from well as people within their personal lives. For this reason, obtaining reliable information about BIID has been a challenge for researchers. Studies into the condition have shown that amputee-based embodiments are most desired, with fewer subjects identifying with the desire to produce other impairments, such as blindness, paraplegia and profound deafness. This thesis research takes these findings into account, contributing additional descriptions of

³ Although closely related and at times confused with each other, the body schema and body image are separate parts of human neurology. The body schema governs perception around limb positioning and internal mapping, whereas body image details how an individual perceives themselves.

lived experiences and reiterating BIID's diversity as a condition and ability to present desires extending from limb loss (First and Fisher 2011; White, 2014).

Sex and gender

First's (2004) psychiatric study was one of the pioneering investigations into BIID, providing initial demographic information on this understudied condition. First's data indicated that an overwhelming majority of people living with BIID are white, college-educated, and cis-gendered males, which set a precedent for conceptions about BIID. This finding lead to discussions around gender and misogyny from structural perspectives and how female-identifying individuals with BIID are at a much higher risk of experiencing delegitimation (meaning that their experiences are invalidated) because of their gender. Their gender also means that female-presenting people with BIID are at a higher risk of being 'degendered, desexualised, and economically and socially marginalised' (p. 152) by key stakeholders, such as psychiatric practitioners and researchers.

The anthropological approach

The intersection between anthropology and disability impairment studies seems intuitive, and has been pointed out by many researchers and theorists, who position disability as a 'profoundly relational social category' and therefore suitable for cultural analysis (Ginsburg and Rapp, 2013, p. 53). As the grounded and long-term goals of anthropological research presents ample opportunity for assessing critical power discrepancies within societies, how individuals and groups manage their experiences within these dynamics are of great interest to disability impairment theorists. The qualitative and person-centred methods commonly used by ethnographers are seen as key to the diversification of disability studies more generally, due to their

explanatory insights and ability to prioritise the experiences of the ‘marginalised’, within the power relations they are part of (Cushing, 2006, p. 109). The increasing use of self-reflexivity from ethnographers through field-work contributes to the vivid analysis of culture that disability impairment scholars advocate for, delivering in-depth qualitative insight into the experience of disability, especially when researching in the ethnographer’s home cultural context.

Disability impairment researchers are calling for a inclusion of the ‘active voices’ of people with disabilities in research, with less emphasis placed on the perspectives of non-disabled people’s *response* to disability’ (Cushing, 2006, p. 109) with qualitative methods suggested as being key to capturing and representing the subjectivities of individuals with disabilities. In comparison, quantitative tools such as close-ended surveys are seen as being too constricting for subjects to express their embodied experiences with complex pain, and at times surveys rely too heavily on medical discourse and terminologies which mischaracterise the views of people with disabilities (Wieseler, 2018).

Computer-Mediated Communication (CMC) has also had a significant impact on how individuals who experience stigma construct their identity and congregate. Online spaces do not necessarily separate or split away from offline interactions, contributing to the usefulness and validity of digital research approaches in uncovering the opinions, goals and sentiments of stigmatised people. As digitally-mediated spaces are extensions of personal and cultural environments, they present ample opportunities for individuals to communicate within neutral and egalitarian spaces, which feel natural and comfortable for active users (Hine, 2017).

Methodology

To address the research questions, two data collection methods were used: continued digital observations of the online communities people with BIID participate in, and email-based interviews with a small sample of informants. Digital spaces included Reddit, Tumblr and archived BIID support-groups. These spaces were ideal for analysis, as they are structured around community interactions, offering a variety of textual and visual content to be publicly posted and re-shared between users. Personal details do not need to be disclosed on these digital spaces during the sign-up process, keeping users anonymous and becoming an ideal choice for those who wish to remain unidentified. While this assumption of anonymity is mostly valid, there are still ways for individual identity to be discovered, with users often starting up private and ‘invitation only’ chats to avoid this. This project only focused on observing public posts. In addition to creating these posts and comments, online users can also privately message other members and interact with posts through ‘likes’, ‘reblogs’, and ‘karma votes’. I communicated with potential informants through inbuilt chat and inbox functions through some of these sites, and used hashtags such as #BIID, #Transabled and #Apotemnophilia⁴ through search functions to survey tagged content such as text-posts, blog posts, visual art, GIFs and questions shared by users.

Digital research was conducted over a six month time-frame, and aside from posting introductory questions to community members, I did not contact any people within these spaces first. To establish contact with the community, I made an introductory post on an active forum and introduced myself as a researcher. I posed general opening questions within this post

⁴ The term ‘Apotemnophilia’ was a term previously used to describe BIID. While people with BIID do not align with this label, some do still tag their content with it.

(e.g. *What is a common misconception about BIID?*) and invited members to reach out to me if they were interested in learning more about the project or participating. This was an intentional choice, as I wanted to be as least imposing as possible. I explained the thesis goals to interested users, outlining their rights as informants and assuring them of their confidentiality and anonymity throughout the project. I also provided informants with a digital copy of a ‘participant information consent form’ (PICF), approved by the Macquarie Human Research Ethics Committee (Appendix III) to review, consent to and keep. If users were still interested in participating and had given their initial consent, we would either stay on the site and communicate through the in-built ‘chat box’, or we would move our discussions over to email to begin speaking more extensively. As I wanted to keep our discussions as fluid as possible, interviews were structured around Kleinman’s explanatory model approach, and I asked my informants open questions such as ‘Can you tell me about yourself and when you became aware of your BIID?’ , ‘What does BIID feel like for you on a day-to-day basis?’, ‘What do you think causes your BIID?’ and ‘What kind of treatment do you think you should receive for your BIID?’ and concluding with questions such as ‘Do you have any hopes or concerns about BIID and treatment?’ so I could better understand their personal stories, and communicate their perceptions and experiences within this thesis.

Advantages and limitations

There are several advantages to using a digital approach for this thesis and its orienting questions. Given that BIID is so stigmatised and understudied, online forums gave subjects and informants an added assurance of anonymity, while the instantaneous nature of digital messaging meant that discussions were able to flow rapidly, or pause when necessary. There are, however, also limitations in applying a digitally-based approach to understanding the lived-

experiences of stigmatised individuals. These disadvantages primarily relate to informants having the power to be deceptive when interacting with researchers, or succumbing to instances of ‘groupthink’, referring to biases in decision-making and expression structured around shared sentiments, language and opinions. Additionally, because users are able to obscure their identities, there is a risk of being contacted by ‘trolls’, who are individuals who purposefully seek to antagonise others through sharing unapologetically negative vitriol or disrupting research. The heightened potential for deceit and a masking of intentions is an unavoidable reality of the digital medium, and was guarded against through frequent clarifications and reviewing of data. A final limitation was the fact that I was not able to engage in any face-to-face interviews, which meant that I was not able to analyse non-verbal forms of expression (pauses, signs, facial expressions) to reflect on any subtle emotional nuances, tensions or moments of comfort.

Ethical considerations

The research received approval from the Macquarie University Human Research Ethics Committee (Appendix II). As some of the sites observed are public (e.g. Reddit), they are openly accessible and observable, so ethical considerations were used to protect my informants. Firstly, I considered whether or not community members, especially those who experience the most stigma, were open to having their posts observed, a concern I took seriously. Though the internet is also seen as ‘anonymous’ or protective of identity, it is still possible to search for names and content, which can later be traced back to original posters. Screenshots were taken of posts for analysis, and later deleted to protect my informants and other community members privacy. To safeguard the anonymity of these subjects, the sources of first-hand data are not disclosed within this thesis, as many of the virtual spaces are still active,

and sharing exact digital addresses could jeopardise their privacy and confidentiality. To anonymise the informants further, they have also been given pseudonyms, with any other identifying details being altered or omitted completely. Text posts from the subjects I have observed have also been slightly altered so that they are not traceable through future searches through engines or databases (Warner, 2009; British Board of Psychological Ethics, 2017). Finally, the names and locations of medical professionals informants have consulted with have also been obscured to protect their both identities and patient–practitioner relationships.

Project informants

I spoke directly with five key informants through in-depth email-based interviews, over a four month time-frame. The informants self-identify as having BIID, and as having incorrect embodiments. They have not had any surgical interventions to alter their bodies, and have not made plans to do so. None have disclosed instances of self-harm or intentions to do so. Four have disclosed their symptoms to others outside of the digital community such as family members, friends and medical practitioners, and one has consulted multiple medical practitioners for treatment. Three subjects desire an amputation: two desire below-the-elbow (BE) arm amputations one left, and two right. One also desires a double above-the-knee leg amputation (ATK). Two informants desire complete paralysis: one starting from the waist down (L2—L4 lumbar region), and the other starting from the neck down (C4—C5 cervical vertebrae region). Two of the five informants said they participate in simming activities, meaning they prepare for or enact their desired impairments within their private spaces or in public. This could mean that an individual who desires a below-the-knee amputation may use crutches or a wheelchair to enact or *simulate* the physical low mobility that they need. All five informants identify as female, and two identify as trans women. All informants are adults, over

the age of 18 years, however their age has been slightly altered to better protect their identities. Table 1 summarises the personal characteristics of the five key informants I spoke with for the thesis.

Table 1. Personal Characteristics of project informants/interviewees (Alphabetised)

Pseu- donym	Disclosure outside of forums	Age	Gender Identity	Existing Physical Disabilities	Desired Change to the Body	Swimming Participant
Lux	No	N/A (18+)	Female	No	Paralysis, Neck Down. (starting from C4- C5 Spinal Region)	No
Millicent	Yes (Ro- mantic Partner/s)	38	Female	No	Paralysis Waist Down (starting from-L2 Spinal Re- gion)	Yes
Perse- phone	No	N/A (18+)	Female	No	Right BE and Dou- ble BK amputa- tion	No
Sienna	Yes (Ro- mantic Partner)	29	Female	No	Double ATK Am- putation; Left Arm BE Ampu- tation	Yes

Verity	Yes (Medical Professionals, Family Members and Immediate Social Circle)	N/A (18+)	Female	No	Right BE Amputation	No
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This thesis is organised into five chapters. The next chapter ‘The weight of the biomedical gaze’, outlines the delegitimizing impacts of biomedical culture and reductionism for people with BIID, providing context into how the invisible and non-normative symptoms of BIID can be misunderstood and stigmatised. The third chapter ‘contesting labels’, discusses how people with BIID use online forums and communities to relegitimize themselves, and learn about their symptoms and methods of coping in contention with the stigma they face. The fourth chapter ‘phenomenological perspectives’, presents accounts from three informants, and seeks to explore how the paradigm of embodiment can contribute to the study of BIID and demystify misconceptions around the condition. It presents accounts of swimming and narrative construction to outline how people with BIID independently make sense of their symptoms and dysphoria. It also presents a meditative exercise from an informant to demonstrate how BIID is felt. The final chapter ‘conclusions’, summarises the accounts and arguments made throughout the thesis, and makes final reflexive comments and suggestions for future research.

CHAPTER 2. THE WEIGHT OF THE BIOMEDICAL GAZE

The lived experiences and explanatory models of individuals cannot be analysed without an understanding of the ethnomedical systems they are embedded in. As all the informants are from contemporary Western contexts, they are by extension adherents of biomedicine, structuring their explanations of causation, symptom treatment and healing trajectories around this system. While recognising the contributions of biomedicine in understanding and treating disease or healing illness, there are inherent cultural qualities transmitted through biomedical culture which negatively affect individuals with BIID. ‘Biomedicine’ is an all-encompassing term used to describe the dominant ethnomedical systems within contemporary Western societies, such as Australia and the United States, which are characterised by a preoccupation with the use of pharmaceuticals as a means of curing, with empirical studies and a focus on the practitioner’s ‘logic’ over a patient’s ‘belief’. Its classifications, clinical procedures, and cultural characteristics are reproduced within a multitude of contexts, due to its efficacy and historical roots, contributing to its presence in the lives and contexts of many Westerners (Kleinman, 1995).

Biomedicine is, however, classed as ignorant to human suffering, due to its focus on physical phenomena over subjective experience; a pattern which has been critiqued extensively (Quinlan, 2004; Kleinman, 1995). Kleinman (1988; 1997) explains the relationship between reductionism and biomedicine, claiming that the medical system is focuses on the natural state of the body as the root and basis of medical knowledge, insinuating that all disease can be identified and treated through empirical observations and clinical interventions. The biomedical focus on the ‘natural’ state of the body positions disease and sickness as amoral, and depen-

dent on organic, biological phenomena. Due to the value placed on finding the *root* of sickness, an over-reliance on the ‘organic’ and ‘natural’ explanations of disease is heavily drawn out by practitioners, which can overlook equally important social, emotional and spiritual determinants of illness. Good (2000) argues that to understand why biomedical culture has this approach, researchers should cultivate an understanding of how medical socialisation shapes clinicians into viewing the human body as compartmentalised. Good terms this learned and clinical type of seeing as the biomedical gaze, noting that practitioners are motivated to seek the most ‘essential’ explanations of disease. This concentration on the organic origins of disease creates palpable frustration for people with psychological or immeasurable symptoms, further complicating their challenging experiences. Due to this clinically oriented hyper-focus, people with contested and non-visible symptoms forgo disclosure and seeking external medical relief. Often, the emotional damage from being told that some of their personal and deeply felt experiences are entirely made up, or fantasies (Ware, 1992) is enough to make individuals distrustful and disillusioned with biomedical care. Biomedicine is also characterised by the preoccupation on the mind-body split, meaning that physical ailments, disease, emotion and subjectivity are separated from each other and seen as existing as binaries. Explaining these dualistic characteristics of biomedical culture, Kirmayer (1988) contends that human suffering tends to be pathologised, and that these systems over simplify complex lived experiences. Kirmayer (1988) explains:

... mind—body dualism is so basic to Western culture that holistic or psychosomatic medical approaches are assimilated to it rather than resulting in any reform of practice. Distress is dichotomized into physical and mental, real and imaginary, accident and moral choice. The duality of mind and body expresses a tension between the unlimited world of thought and the

finitude of bodily life. It provides a metaphoric basis of thinking about social responsibility and individual will. (p. 83)

Damaging assumptions about moral character, the validity of invisible symptoms and the delegitimation of my subjects' experiences can be attributed to this cultural system, as a core part of how they relate to others is based around them navigating stigmatising attitudes which argue that their symptoms are 'mental, imaginary, or a moral choice' as Kirmayer (1988, p. 83) points out. The following section highlights how these cultural perspectives filter down, and also come to impact people with BIID, much in the same way that they have emotionally impacted others with chronic or psychological illnesses.

The hypocritical oath: 'Doing no harm'

I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug. – *The Hippocratic Oath (Modern Version) (Lasagna, 1964)*

Ill-informed assumptions about BIID from professionals create palpable frustration for sufferers; exacerbating already high levels of friction between them and vital biomedical stakeholders. There are significant flaws rooted in clinical paradigms, the most salient of these being from perspectives which position health as being a matter of physicality, or 'matter-over-mind'. Online community members and many of my subjects are transparent about their desires to receive surgical interventions as a form of treatment. Not surprisingly, many cite the Hippocratic Oath—or doctor's code—as being one of their most significant obstacles to obtaining their desired treatment. The set of values from the oath essentially outline the ethical

expectations of physicians, providing structures for decision making within the medical arena. The oath contends that physicians cannot intentionally or needlessly inflict *harm* on a patient in any capacity, and must endeavour to accommodate for the wellbeing of those in their care. Therefore, the notion of ‘harm’, and what is suitable for one person, and not others comes up as a central point of discussion, for both my informants and medical scholars. Speaking to BIID and the use of radical surgery more specifically, Bayne and Levy (2005) highlight that reductionist perspectives are especially contradictory, and question why the autonomy of people with BIID is disregarded in decision-making processes which involve their own bodies. Bayne and Levy clarify their point by comparing the radical surgical interventions people with BIID seek to popular and consensual cosmetic surgery procedures that people without underlying medical conditions are permitted to have; such as rhinoplasty, tummy-tucks and eye-lifts. They argue that the ethical differences between both sorts of procedures are minimal and that surgery for people with BIID is potentially life-saving, whereas cosmetic surgery is usually not. Interestingly, BIID has in the past been seen as a sort of extreme ‘body-modification’, and while this idea is not accepted by many people with BIID, the fact that others can receive drastic changes—though not disabling—while people who are in pain cannot, baffles my informants and the BIID community. One online community member expresses their frustration over this principle, and very clearly articulates their pain:

Don’t you think it’s possible that leaving me with my unwanted limb intact causes me even more pain and suffering in the long run? Doesn’t that count as doing harm unto others? Or do doctors not count mental suffering as something that is real? (Anonymous discussant, Tumblr post)

Often, rigid conceptions surrounding ability and disability cloud the ability of practitioners to direct adequate attention to the needs of people with BIID, with many of informants telling me about the fears they have of being ‘immediately locked up in an institution’, before even having the chance to talk about their symptoms with a doctor or psychiatrist. Sienna speaks to this issue further:

At this point in time, I feel there isn’t going to be any benefit in visiting a medical professional, seeing as there aren’t really any in this area of BIID. I feel they wouldn’t be able to tell me anything that I didn’t learn or try for myself already. The medical field is just very focused on not doing harm and the doctor’s code, so the chances that anything would come from visiting would be pretty much zero. (Sienna, email interview)

The stigma that holds back people with BIID is evident and strong, and understandably, their motivation to seek help through biomedical avenues is minimal. While there is harsh opposition from the general public and bioethicists about providing BIID patients access to elective surgeries—because the efficacy of these procedures has not been examined through longitudinal studies—not all professionals view these interventions as innately harmful or unethical. Dr Christopher Ryan, an Australian psychiatrist who specialises in BIID and neuropsychological disorders, is informed by a patient-centred perspective, and argues that surgical interventions for BIID can fulfil a practitioner’s duty of care, as these surgeries may provide permanent pain relief and symptom resolution, drastically reducing the harm that independent interventions cause (Ryan, 2008). Reynolds (2018) aligns with this perspective, arguing that stakeholders should embrace ambiguous and non-normative needs to create a ‘humbler’ medicine, which is inclusive of the diverse needs of people. Through understanding different ways-of-being, and being open to the desired treatments of people with BIID, biomedical

practitioners are able to better fulfil their duties of care, provide treatment for their patients and accept the distinct needs of those who are seeking help.

Productive bodies and prejudice

Being productive and maintaining independence are implicit values tied into capitalist Western contexts and political economies. The desire to acquire a disability in any capacity goes against the medical model of disease and sparks ongoing debate. People with BIID fail to align with these ‘normal’ desires, are othered, devalued and taken as delusional by stakeholders and the general public. Masson (cited in Baril and Trevenen, 2015) contends that some of these reactions may be due to the fact that Western society and culture uses a binarised perspective when analysing individual abilities and bodies, and delivers totalising judgements of individual people based on conventional notions of ability–disability. Masson (2013) explains that:

The ability–disability system normalises and favours specific corporal forms and functionalities that create ‘cultural capital’ and ‘privileges of normality’ for people who can claim it. ... At the same time, it devalues forms and functionalities that do not conform to norms defined in terms of impairment, inability and disability... Social organisation is entirely structured on the assumption of having ‘valid’/able bodies (cited with Baril and Trevenen, 2015, p. 243).

Baril (2015) extends on this analysis, and points out that there are underlying fears of failing abilities to work at stake. According to Baril (2015), people with BIID are seen as faking disability ‘as a means to exploit the State and obtain resources to which they are not entitled’ (p. 693) a position which also leads the general public to view them as immoral for their plans to purposefully remove a limb or a sense, which could prevent them from working and function-

ing within society. People with BIID are taken as being ‘selfish’ for their requests, and their needs are misinterpreted as being desires to deny their roles in already established social structures. Such an assumption is inaccurate, as many people with impairments and disabilities are able to work or contribute to society, so this notion may speak more to underlying fears around people with BIID deviating from social structures. Millicent, who has spent considerable time grappling with feelings of shame for her needs, shares some of the negative views around finances that she has seen:

... a big statement I see in the online troll community is ‘wanting to be handicapped is ridiculous, there are people who really need it, and you want to take money away from the community’. (Millicent, email interview)

The comments Millicent sees seem to point out a large discrepancy between the opinions of people with BIID, and others who do not understand the condition. Disability and impairment, are to an extent, seen as financially burdensome and to disregard the economic privileges that come being non-disabled seems counterintuitive and immoral to some. The BIID community are under heavy moral scrutiny for their needs, due to their simming practices, which can at times require the use of prosthetics, resources and spaces which are not technically made for them. When people with BIID ‘act out’ or ‘pretend’ to have an impairment, the immoral backlash against them increases monumentally. Adding to these reactions are underlying opinions which situate people with BIID as being sexually aroused by disability, which is seen as fetishistic upsetting to many within the disabled community and general public.

The sick role: An intentional break?

There is a misconception that we [people with BIID] romanticise disability, and would not want to be disabled if only we knew about the reality of what it is all like. But this is false.
(Lux, private-message)

Practitioners and the general public tend to attach moral judgements to people with BIID, speculating that they fake psychological pain to appear impaired, or that they are motivated to acquire the same social gains afforded to the disabled community. These conceptions position people with BIID as immoral for seeking to obtain recognition, attention and resources which are not seen as rightfully theirs. The ‘sick role’ (1951) a concept put forward by Parson is a sociological lens we can use to deconstruct the origins of some of these misconceptions. Parson notes that there are specific roles, practices and behaviours that ‘sick’ individuals are expected to perform when they fall ill so that they can heal, and re-enter society functioning and productive. The sick role provides an unwell individual with distance and a socially sanctioned ‘break’ from their routines and obligations; and in response, the sick person is expected to make a full recovery and take up their previous roles in society.

The feasibility of this model is questioned, however, as it centres on a linear healing trajectory, one which chronic illnesses and disability cannot neatly fit. Parson even notes that these roles are only acceptable for a certain period of time, meaning that individuals who fail to show signs of healing are seen as doing so purposefully. Some interpretations of the sick role interestingly posit that there are innate ‘theatrical implications’ tied to it, hypothesising that instead of complying and healing, ‘a person can perform or take on a role without being intri-

cately bound to it' (Hay-Rollins, 2005. p. 99). What this means is that someone who is sick and expected to perform a set of medical practices to cure disease, may instead just superficially act-out what they are expected to, and re-integrate back into society while still 'sick'. Surgery as treatment for people with BIID can easily be misconstrued as a means to access the sick role, and to obtain the social capital of people who are disabled. Lux, an informant, explains that these sorts of opinions are common online, and that she often needs to reassert that her need for impairment is not one that is borne out of selfish desire or laziness:

Often, people will go ahead and try to tell me that I wouldn't want to be disabled if only I *knew* the reality of it all, but this still doesn't change the fact that I'm in the wrong body
(Lux, private message)

Another subject echoes their experiences with these statements:

...with having BIID, we're *always* questioned about how *real* it all is, and we always get told by others that we're just faking it or doing it [simming] for attention. I just wish it wasn't so hard to get through to people that this is real, and that we don't want to be like this. (Anonymous Tumblr discussant)

When individuals, especially those with long-term chronic illnesses, disabilities or psychological illnesses fail to appear as if they are complying with the sick role, they are seen as 'deviant', or incapable of contributing to society. The 'hidden' nature of their symptoms therefore leaves them vulnerable to stigma and open to scrutiny. To protect themselves from these delegitimising attacks, many will have to spring to their own defence and rationalise their experiences; a process which can become emotionally tiresome. As a result of these opinions and misconceptions, many individuals become disillusioned with the medical systems which

create these unachievable healing timelines. The next section investigates how social ideas about medical healing fails to align with chronic illnesses such as BIID, and how people with non-normative symptoms are commonly seen as ambiguous, or dangerous to the social imaginary.

Liminality: Between blade and skin

The disabled person opens a narcissistic identity wound in the person who is not disabled; he inflicts a threat of physical or psychical death, fear of collapse, and, beyond that, the anxiety of seeing the very borders of the human species explode. And so, the disabled person is inevitably exposed to a discrimination that cannot be shared. (Kristeva and Herman 2010, p. 251)

Not being able to clearly fit into the social categories of ability or disability positions people with BIID as being profoundly ambiguous and ‘liminal’. Building from Van Gennep’s framework on the phases of ritual transformation, anthropologist Victor Turner (1967) focuses on the ritual phase of ‘liminality’, viewing it as a stage of transformation which is full of with multiple potentialities for the ‘initiate’. The individual undergoing transformation is ‘betwixt-and-between’ social categories, and therefore holds immense social power as an ambiguous being. They are not yet able to clearly fit into a category or social role, and have the potential to cause massive disturbances to social order. Turner also explains that being thrust into this state primes individuals to share in their status suspension with their counterparts, guiding them to experience a natural and egalitarian comfort with one another, which he calls ‘communitas’ (p. 99 Turner, 1969, cited in Murphy et al., 1988, p. 237). Douglas (1966) similarly explores the significance of liminality through her observations of social categories,

putting forward that ambiguous traits mark people as uncertain, dangerous or ‘taboo’, and therefore as a potential danger to social order and safety. Jackson (2005) applies both conceptions of liminality to understand why her subjects with Chronic Pain Syndrome are delegitimised and shunned. She explains that individuals with ‘hidden’ symptoms, or traits which are difficult to locate confound ordered systems, and present problems which require an uncomfortable amount of empathy and perspective changing. Jackson (2005) explains:

...sufferers [of Chronic pain] also occupy another kind of liminal space, for their problem relates in complicated and poorly understood ways to mind-body borderlands. In Biomedicine, the mind is itself liminal; the entire mind can be spoken of as a liminal state (p. 234).

Chronic pain, contested conditions and non-normative illnesses like BIID, continuously challenge and fault the logic that biomedicine sustains, forcing sufferers to inhabit liminal places within the social imaginary. Davis (2012) delineates this perspective further, applying this understanding to people with BIID specifically. She explains:

[People with BIID]...queer the categories of ability and disability, desirability and repulsion, health and illness, and mind and body. As such, they are assigned a stigmatised status and become marginalised members of society. Moreover, the perception of transability as a lifestyle choice works to couple this marginalisation with strong moralising judgements (p. 312).

Like the chronically ill, people with BIID are also vulnerable to becoming marginalised based on their symptoms being within the ‘mind-body borderlands’, as Jackson (2005) says. Based on observations and these theories of categorisation, I view the online realm as a liminal

space and dialectical arena for people who are stigmatised, as it offers opportunities for anonymous interactions, unfiltered posting and immediate correspondences. Within these spaces, such as Tumblr or Reddit, community members, or even visitors, are able to engage with a shared space, challenging binarising perceptions around ability and disability. Within this liminal space, users are free to present how they choose, reclaim their identities and deeply discuss and envision their futures with others, allowing them to reconsider their needs and social roles. These spaces give rise to ‘communitas’, fuelling feelings of comradeship to run abundant, which in-turn strengthen social support between members as they revise their roles, expectations and goals with BIID.

The following chapter addresses delegitimizing attacks from the public, which are formulated from misconceptions around the condition. It demonstrates how people with BIID make use of liminal spaces such as forums to refute and deconstruct these attacks, and in the process partake in mutually validating and supportive expressions with other community members. What the next chapter shows is how the liminal space of the internet is used by people with BIID to cope with, and independently treat their delegitimated symptoms through self-taught techniques, label reconstruction and social support given that they are still unsupported by biomedicine and the general public.

CHAPTER 3. CONTESTING LABELS

Addressing why BIID is so staunchly stigmatised pushes us to question widespread cultural values around disability and ability, and how they shape our reactions to the paradox that people with BIID seem to present. Like other people with disabilities, people with BIID are made socially distant on several levels; due to their inability to be clinically recognised, and because of the social connotations of instability and danger attached to them. This ostracisation is multifactorial, varying from context to context, but is underpinned by an overall aversion to non-conventional or ambiguous symptoms. The lack of clear psychiatric legitimisation further charges arguments which position people with BIID as unstable, which delegitimises their experiences. This process of delegitimation invalidates subjective and lived experiences through disconfirming language, belittling actions and overall incredulousness about the validity of experiences. To cope with these structural issues and to validate themselves in the eyes of others, people with BIID engage in relegitimising actions that express their experiences, such as through narrative constructions or the creation of new labels. I use the term ‘delegitimation’ within this section, in the same way that Kleinman (1992) and Ware (1992) do when addressing chronic illness, and also consider it as an intersubjective process between suffering subjects, and others they communicate with.

Resisting labels and delegitimation

There is a sheer persistence to it [BIID]. We keep on trying to out-think everything, but BIID is not something to be simply wished away or controlled. (Lux, email interview)

As discussed in earlier sections, the invisible nature of neurological symptoms tend to position conditions such as BIID and even BDD as socially generated, as opposed to being rooted in biology. Some scholars even express their disbelief about BIID's neurological origins, instead speculating that sufferers align with these labels based on an unconscious desire for the social sympathy afforded to others with impairments (Bruno, 1997; Elliott, 2003; and Kovacs, 2009). As people with physical disabilities continue to be subject to ongoing social stigmatisation, medical invisibility, and structural violence; the desire to produce an impairment comes off as outrageous or even infeasible to some. The commentaries which circulate around people with BIID position them as 'pretenders' and attention-seekers; a misconception which can lead to deep feelings of shame and embarrassment for sufferers (Frey, 2018. p. 108).

Public attacks: 'How could you want this?'

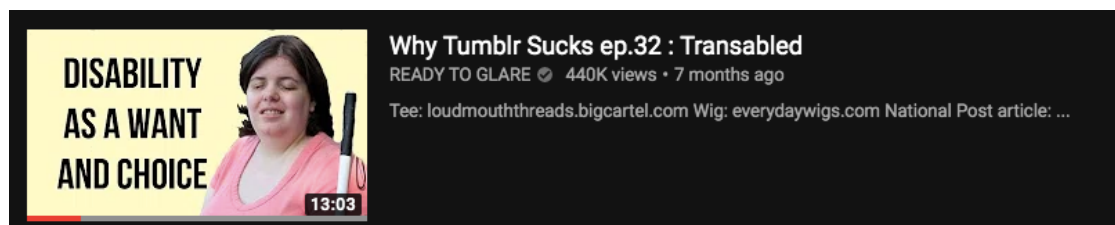


Image 1: Screenshot of YouTube video. Thumbnail Image: Visually impaired person with BIID. Title: 'Disability as a want and choice'. Video Title: 'Why Tumblr Sucks ep. 32: Transabled'.

Stigmatising attitudes from the public frame people with BIID as being wilfully ignorant to the reality of disability. *Image 1* is a screenshot of a YouTube search result on 'BIID', and offers a glimpse into how BIID is seen by the public; as a *want* and a *choice*. Author Wesley Smith (2015) takes up a similar perspective, and also thinks of BIID as a matter of choice. He argues more specifically that people with BIID even seek out surgical interventions not for

treatment, but to enact a sort of ‘self-recreationism’. He explains:

the next stage in radical self-recreationism will be to allow people suffering from the terrible mental illness, body integrity identity disorder (BIID), to have healthy limbs amputated or spinal cords severed to allow an able-bodied sufferer to become the disabled person they know themselves to be... Self-definition is becoming a fundamental right to which all must acquiesce and the medical arts must be applied to effectuate (Smith, 2015).

Here, Smith implies that the patient-centred paradigms shaping Western bioethics are too lenient, and that the physical changes that people with BIID seek to challenge biologically determined qualities. His argument seems to also hint that these radical changes have more to do with producing a superficial shift in identity, which comes from a root place of desire as opposed to being a need. Santinele Martino and Andrejek (2019) point out similarly delegitimizing perspectives through their a thematic content analysis of comments posted to *The National Post*’s article about the ‘transabled’. The remarks surveyed range from being rhetorical and sarcastic, such as ‘What did I just read?’ to being sinister and eugenically orientated such as ‘Why they [people with BIID] are necessary for the gene pool is a mystery’ (pp. 07-09) showcasing the breadth of negative perceptions around the condition.

Santinele Martino and Andrejek point out that these so-called visceral reactions of anger, resentment and disgust are continuous; and act as symbolic boundaries which reframe unfamiliar social phenomena into established values and norms, even though they may not be based on fact. The paper also demonstrates that dominant Western discourse around productivity and morality underscore these perceptions and comments around BIID, and that moral character is judged by one’s ability to conform. With this information in mind, the presence of

trolls—purposefully antagonistic or troublesome commentators—can be better understood and analysed. Many of these negative commentators contribute hateful vitriol to community forums, and even seek out people with BIID to antagonise; actions they deem as necessary, as they see BIID as a fabrication or elaborate ploy for attention. Their agenda, in most cases, is to ‘out’ people with BIID and ‘prove’ that the condition is fake. The following section shows how people with BIID navigate around these attacks (from trolls and other commentators) and manage their emotions with their online communities.

Social support and remoralisation:

Research [online] definitely helped me understand myself better, but it took a lot of searching to do that. Even now, it is still hard to find any information on BIID. In 2006, I managed to find a small Wikipedia page that described it [BIID], and I knew *right away* that was me and everything that I was going through. But I also learned about how taboo the subject is in most areas, so I never really talked about it to anyone else. (Sienna, email interview)

One of the main obstacles to disclosure are ‘looming threats of institutionalisation’, forced psychiatric treatment⁵ and the potential of receiving a misdiagnosis. Digitally mediated spaces therefore become logical choices for people with BIID to use, providing members with a means of combatting the negative effects of stigmatisation through mutual support and a shared identity to come under. While the digital spaces that people with BIID use provide them with solace from these attacks, they are still not immune from being exposed to delegitimising perspectives. The accessibility of forums allows for ‘trolls’ and their hateful vitriol filter into these spaces, where the moral integrity and experiences of sufferers are then prod-

⁵ Informants have mentioned their uneasiness around being required to undergo a procedure called ‘Transcranial magnetic stimulation (TMS)’ a magnetic treatment, which is used mainly on people with depression who have not shown signs of improvement from psychopharmaceuticals or CBT.

ded, questioned and made light of. Davis (2014) notes that in order to manage some of these attacks and protect themselves from feelings of anger, shame or sadness, many members will engage in ‘remoralising’ techniques, which help people to express their needs as valid and authentic. Davis (2014) breaks down these processes through an analysis of posts and narratives from *transability.org*⁶, specifically revealing how people with BIID use narrative representations to subvert misconceptions about their authenticity and moral personhood through ‘mutually verifying exchanges’ (p, 452). Millicent, an informant who has spent a considerable amount of these forums speaks to the positive impact of these mutually verifying exchanges, explaining that comments from trolls and other commentators do not impact her as much, now that she is part of a larger community who can offer advice and support:

So, the comments from able-bodied people shouting on internet platforms...I was scared of them initially, when I was only starting to learn more about BIID. However, now I consider these people to be like any other extremist/misogynist/racist/anti-gay/Trump supporter type of person who just roams the internet looking for an argument... I don’t read their posts anymore, and I also don’t care about what they have to say. There are so many people who don’t even understand basic human decency, so I’m not going to try and hope that they’ll empathise with what people with BIID are going through. (Millicent, email interview)

Millicent demonstrates that the harsher the comments community members receive are, the easier it is for them to later rationalise them as projections of a sender’s poor social skills or lack of empathy. Through replying with comments such as, ‘They are just nasty people with no empathy’, ‘they don’t even understand human decency’ and ‘this person is trying to trigger

⁶Transability.org is a now archived support forum, for people with BIID to use. The forum was also open to others who were ‘Wannabes’ or ‘Pretenders’, remaining active for almost a decade.

us, why bother responding?’ members are able to gradually re-position their attackers as emotionally immature and unworthy of their attention:

I’ve now learned that the main goal of these internet trolls is to make people with BIID feel bad and ashamed of ourselves, and to ultimately stop us for being so weird. (Millicent, email interview)

Other members agree with this sentiment and reaffirm that these outside users do not seek to engage in meaningful dialogue and, instead, aim to police. Members swiftly learn to work around these attacks and focus instead on managing their safety and wellbeing. Community members are aware that their symptoms are hard to grasp, and use this knowledge to affirm their images. However, it is also important to note that not every act of delegitimation is intentional or from someone who does not have knowledge about chronic illness or pain. Millicent explains that sometimes, people with physical disabilities will visit these forums to make sense of BIID, and to engage in a dialogue which is informed by their lived experiences:

Another recurring theme is from disabled people. They can come on to the online forums, and then they express their firm disbelief on our online platforms, usually saying something like, ‘I have been through so much, and it is *really* horrible, why on earth would you want this [disability]!?’ So we just try to educate them on how BIID is not about a want, but a need. (Millicent, email interview)

Attempts at relegitimation are softer in these instances, and work to present the BIID community as empathetic, rational and potential allies to other disabled communities. As one anonymous subject explains, ‘A lot of people with BIID *already* have a chronic illness or disability of some sort— disability does not necessarily protect you from having BIID’. An attempt at showing how alike the two communities are may help to educate others about the

needs of people with BIID, and demonstrate that the condition is not social fabrication but a need to be correctly embodied.

Connections: BIID is not about disability

Familiarity and a sense of acceptance characterise the bonds shared between group members within these digitally-mediated settings. The fluid, open and public discussions occurring within these forum-like spaces openly display intensely private experiences, helping users to reflect on their own personal emotions and histories, while remaining open to receiving social support from others. What is expected from them, though, is mutual care and support. When I first joined these forums to get to know the community better, I was initially taken-aback by the mix of conversations I saw, and their variations in intensity:

Amputee_Earl:⁷ DBK [double-below-knee amputee] and new member here! Has anyone tried binding their legs? any suggestions on how to start?

BIIDsyndy: I don't think that I can live with my leg anymore. I just want it gone, and I will do anything at this stage. I'm not looking for advice, I just don't know where else to go.

Karolyn_Kat: GUYS!! I finally got a [wheel]chair to use around the house, yay! :D

Digital spaces like Tumblr and Reddit provide a glimpse into the concerns of community members, and though these arenas leave discussants vulnerable to the likes of voyeurs and internet trolls, users still offer unwavering support to one another. Millicent explains how despite being intimidated by using forums at first, she now seems them as pivotal in helping her

⁷ These are pseudonyms

understand herself and her needs. ‘I was learning about the experiences of people with disability before I knew about BIID being a thing’, she began. ‘These people were all so open and honest with each other and about how it [disability] dramatically changed their lives, and yet there I was, sitting on the sofa, trying my absolute best *not* to feel my legs???’ The disability forums were in the realm of what Millicent was experiencing, but the social, physical and emotional differences between her and other people with disabilities were unbalanced. She was left feeling conflicted after leaving these spaces, and did not know how to manage her symptoms, let alone speak about them. She only regained her sense of momentum and hope after she found BIID specific spaces to join:

It has all required some self-exploring on my part... But that is where talking to people online on BIID specific forums has helped. The conversations and posts have all helped me to better come to terms with what exactly BIID is, how it manifests in me, what I can do to have more control over it and how not to feel ashamed about it. (Millicent, email interview)

It seems that through joining and interacting with these flexible spaces is something of prime importance for people with BIID, and that the social input of others who can empathise is significant. Millicent in this example was able to re-address her symptoms and life trajectory with BIID, discovering that she could still obtain mutual support, care and new knowledge on how to manage her dysphoria, despite the lack of medicalisation around BIID. Joining these forums provided her with a deepened sense of community and social support; which she was not able to find in other disability forums. The difference between the two communities seems lie in their perceptions of impairment and disability, and what they mean for each individual on an existential level. Impairment for people with BIID is not seen as ‘disabling’ or a

disruption, and their need to acquire an impairment fits in with their correct selves. Through joining BIID specific spaces, people like Millicent are able to reaffirm that their needs are not experienced in isolation, and are also not cause for stigmatisation.

Lux's advocacy

We [people with BIID] *know all about* the multiple neuromas, phantom limb pains and other neuropathic and physical pain that other people with disabilities and amputations have. If we desire an amputation, then we already know about stump revisions and skin infections, and about the recurring revisions of limb sockets that people frequently need when they have to get prosthetics. We also know about the hard times, like when it [a prosthetic] can still not fit right, despite all of the trials and measurements people go through. Regardless of how much we know, it does not take away our need to change our bodies, and it does not take away the joy of finally being in our correct body. (Lux, private message)

Digitally mediated spaces like Tumblr and Reddit provide individuals with BIID the chance to firmly express their point of view without repercussion. Lux is a community member who actively engages in conversations, and seeks to educate others about the 'reality of BIID' through her anecdotes and comments. Like Millicent, Lux has also come to understand that her BIID and need for impairment is not intentional through continuous discussions with others with disabilities and BIID. Based on this knowledge, she now works to help verify the label of BIID on structural and interpersonal levels through continuously engaging with visitors and outside commentators. Knowing that she has a form of BIID that is more physically intense than her counterparts, she is driven to speak about her experiences to help other members understand what they are going through. The incongruency that Lux experiences manifests as a desire for complete paralysis from the neck down—starting at the C4—C5 sec-

tion of her spine—which would make her a person with tetraplegia. When I began speaking to Lux, I was initially taken aback by the breadth of knowledge she had about anatomy, medicine, surgery and rehabilitation. Her understanding of the human body was impressive, and her descriptions were rich. She explained that to produce her embodiment, she would need an invasive surgery, and paralysis at this extent would make her permanently reliant on a mechanical ventilator. If this surgical intervention is made, her lung capacity would reduce, impacting her ability to speak and breathe without assistance. She was extremely knowledgeable about the surgical intervention she desires, and was adamant about this point being acknowledged by others. ‘A common misconception about people with BIID is that we know nothing about disability, or about chronic illness’. It took many hours of independent research before Lux accepted that achieving her needed embodiment is not something feasible. Despite her extensive understandings of the changes she would have to make, her perpetual bodily discomfort fails to diminish. ‘I’ve tried to convince myself to get on with life. I want to manage to live with my able body. It should even be easier for me, without all of the other issues of ableism’. Understandably, Lux finds little consolation in ‘wishing’ away or suppressing her dysphoria. She is wracked with conflicting feelings based on her reflections on the damaging impacts of ableism, which she says she will likely also experience if she became impaired.

Accepting that she will not be likely to produce her correct embodiment fuels her desire to advocate for the acceptance and proper understanding of BIID for others with more ‘achievable’ embodiments. While she accepts that she will not be able to bring out her needed paralysis, she still engages with the online community she is a part of, and seeks to educate others about BIID. Her drive to continue engaging with the community is based on her desire to cor-

rect misconceptions and to provide a sense of hope to people within the community who is yet to feel validated. She explains that ‘BIID is about needing to be in the right body, *a body that is considered to be disabled by everyone else in society*’, and that this understanding is pivotal in depicting their needs.

‘It was hard for me to reach out to others at first’.

The provision of social support and digital spaces can be seen through Persephone's account and experience in joining these groups and speaking to others. Persephone is a young trans woman who desires a right below-the-elbow amputation, and a double below-the-knee amputation. She laboriously conceals her legs from view, avoids her reflection, and wears long non-constricting clothes. She also puts on compression socks and sits with weighted blankets, tips for managing her dysphoria which she picked up directly from online forums. Persephone explains that her understanding about the origins of her dysphoria was minimal and vague through-out her life, until after she one day discovered a set of digital artworks with characters with BIID. As she read the descriptions underneath these images, she was assured that she was not alone in experiencing this mismatch. According to Persephone, these were the first other people she had ever seen or heard of, who were also split-away from their real selves; something that she acknowledges she would not have discovered if it were not for the internet. As a naturally introverted person, disclosing her easily stigmatised symptoms to others was not easy for her. Persephone knew that if she ever wanted to manage her dysphoria, she would have to learn more about it from others:

It was hard for me to reach out to others at first. I am not very good at talking to other people, and discussing something so personal made it a lot more difficult for me. The talking has been

getting a bit easier, though. After I found out about this disorder, I started searching online to learn more about it, and eventually I found that BIID forum (Persephone, email interview)

Persephone speaks highly of these communities, explaining how they helped her to understand that her needs are valid and shared and provided her with techniques to cope with her dysphoria, given that she has had trouble speaking to medical professionals about her symptoms and everything she experiences :

They [other group members] showed me a lot of different methods that they use to deal with their BIID. They mostly helped me feel less alone. There are so many people online that are incredibly hateful when someone starts talking about this disorder, so having a place where people not only are kind when talking about it, but also understand what it is like to live with on a daily basis is really nice. (Persephone, email interview)

Now that she is comfortable with speaking about herself and her symptoms, she feels much more hopeful about one day receiving treatment, though she knows that this will be difficult without a diagnostic label to work with:

I'm hoping to see someone that has experience with trans people because of the similarities between gender dysphoria and BIID. I want them to help me figure out more ways to deal with my legs. I wish I could find someone that would just amputate my legs so I wouldn't have to deal with them anymore, but I doubt that's going to happen anytime soon (Persephone, email interview)

Given that there are no medicalised labels given to BIID, people with the condition, like Persephone, have to independently seek out ways to deal with their dysphoria. The accessibility of online spaces provides her with the chance to engage with others who are empathetic,

which ultimately helps her to feel ‘less alone’. While there are still many unaddressed pains in Persephone’s life, the online community clearly serves as an educational and social platform, which helps her to independently manage her dysphoria without resorting to amputation or another sort of invasive intervention.

Medicalisation: Trying to align with biomedical values

I remember being particularly relieved when I found neurological papers. I stumbled across information from a study that revealed that there might be a link between abnormalities in the parietal lobe and disorders of this nature. (Verity, email interview)

People with BIID continually have their authenticity questioned, and have to work incredibly hard to prove their experiences as legitimate. This challenge is partly due to misconceptions around the condition, and the understandable trouble they experience when trying to express their symptoms to others. One avenue for validation is through ‘medicalisation’, a process where human pain and sickness is labelled and turned into diagnosable and treatable phenomena by biomedical professionals. Being recognised through a unifying and verified diagnostic label is a shared goal for people with BIID, who view this specific form of medical recognition as essential to their treatment and gaining social acceptance. To express these needs for verification and unison, many community members continue to utilise online forums and digital spaces to advocate about their needs. As Persephone explains:

I don’t know what kind of advice or help I’m looking for. Just something to help deal with the stress this disorder causes, I guess. A big reason I want to talk to someone is so I can help with the research around this disorder, and help others to get a better understanding of it. I’m

hoping once we have a better understanding of it, we can figure out the best way to treat it.
(Persephone, email interview)

BIID is poorly understood and understudied, which often leaves people with the condition confused on what steps to take to treatment, and how their symptoms will affect them in the long-term. While social support within forums can provide a sense of companionship and ease troubling feelings, it is not a substitute for the ethnomedical systems that people with BIID depend on. As Persephone says, she wants to 'figure out the best way to treat it'. Medicalisation and biomedical recognition become the best avenues for these explanations and help to come about. Medical validation is so sought after that people living with BIID will align with psychiatric frameworks, despite feeling that their symptoms are not caused by any underlying mental illness. Subjects demonstrate their willingness to adhere to incorrect systems, seeing it as being a part of a higher struggle for social and personal acceptance (Davis, 2014). My informants repeatedly mention the DSM, and how important the inclusion of BIID is for them and the community, as it gives them a tool to refer to and use to defend themselves against delegitimizing attacks or comments from others. The potential of sharing a diagnostic label assures people with BIID that they are not alone in experiencing their internal disparities, while also providing descriptions of their immaterial feelings, allowing them to understand themselves and come under the protection of biomedicine, where they will be treated with systemic and evidence-based care. However, given that BIID was not included in the latest version of the DSM (DSM-V), many people with BIID are now disillusioned, and worry excessively about how they are supposed to seek help without these structural and medical bodies to assist them.

Wanderers: Updating the ‘digital map’ with the community

If I did not have BIID, I would finally be able to focus on *me*, and all of the other problems in my life. I could take a break from constantly worrying about my legs, and I would just be happier overall. (Persephone, email interview)

Having a community to engage with allows for a shared goals and trajectories to be cultivated between members. Through building a stronger label to resonate with, community members find a means of expression, and are able to protect themselves from the negative connotations attached to their previous labels. Specific examples of this identity construction can be seen on Tumblr, a micro-blogging platform filled with images, discussions, question boxes and ‘tags’, which users attach to their content. In Tumblr, I observed many posts tagged within the BIID community, many of which centred on the desire to be seen, heard and understood by others:

xMimi99: I just want people to know about how it [BIID] makes me feel. If I could control it, believe me, I would not have it at all. (Tumblr, text post)

Dysphoria-Witch—: I’m too afraid to tell my therapist, because she might just shame me and say something like, ‘don’t you know how many amputees would *love* to have their limbs back????’ (Tumblr, text post)

Princess—Foxglove: Help. Should we just make a private chat together? I’m getting so sick and tired of having to explain my dysphoria. I hate living like this, and I’m honestly too scared to speak to anyone else, because I know they are going to point out all of my other professional diagnoses, and my self-dx [self diagnosis] and say that it’s all fake and for attention. (Tumblr, text post)

Community members, like those depicted above, evidently use these forums as venting spaces. Like other online users, these members use these spaces to seek support, and to determine if others empathise with them. Community forums and sites like these provide a sense of connection, helping people with BIID to organise their responses to troubling issues, such as intensified dysphoria or fear of disclosure. The posts above are emotionally based and structured around a need for social support during potentially frightening and upsetting situations. In a notable discussion, a group of users with BIID had decided to address some of their issues with being incorrectly labelled or referred to, and revised their shared concept of the ‘digital map’, in the hopes of clearing up misconceptions around what they are experiencing. The discussion addressed the importance of neurological data in verifying their experiences and their desire to not be shunned as irrational or attention-seeking. To represent their community as valid and worthy of biomedical attention, these users borrowed the recognisable parts of neurological understandings and constructed a metaphor which synthesises their experiences to it. The term ‘*wanderers*’, was generated and chosen by members as the best new way to represent BIID. To be clear, there were other options thrown around in this tumblr discussion about new names, such as, ‘*the lost-ones*’ and ‘*limb-shifters*’, but ultimately, ‘*wanderers*’ became the leading contender. There were two reasons for the desire for a new label for themselves. The first was to provide an alternative for outdated terminology such as ‘transability’ and ‘wannabes’, as the community sees these names as being incorrect and calls back to a shaky history of medical misunderstandings. The second reason was so that their experiences of being incorrectly embodied can be understood more accurately by others. As one user explains:

Calling ourselves ‘wanderers’ works perfectly, because we are lost in our *own* body, and we cannot find our way unless we change ourselves to match this map. I think that this term works better than the old ones anyway, because it really just gets the point of being mismatched across to others. We are essentially trapped *and* lost inside of ourselves all at the same time. We’re trying to not get lost *within* our own maps as we wander the world.
(Anonymous discussant, Tumblr)

The basis for this metaphor correlates with neurological theory, and community members see an opportunity to align with this understanding in order to medically validate themselves. According to de Vignemont (2010) the body schema and body image is a ‘sensorimotor representation of the body’, which functions through a relationship between action and perception. De Vignemont explains that ‘no successful action is possible without a representation of one’s bodily parameters, such as the size and the strength of one’s limbs’ (p. 200) ultimately signifying that the internal map and external body are inextricably linked. Ruptures and mismatches between either can therefore cause significant pain on physical, emotional, mental and existential levels. By aligning with this neurological concept, community members also show that their pain is something that is deep and rooted in a mismatch which is out of their control. Community members who are experiencing difficulties in expressing themselves and validating their experiences to practitioners and the general public can align with the meanings used by the wanderers, and express their dysphoria to others without fear of mischaracterising the community or not knowing how to describe their shared experiences.

When community members engage with these mutually assuring and creative processes, they claim their symptoms and bodies as valid and integral to their personhood. In doing so, users are able to utilise these spaces to collectively envision and construct what Hunt (2000) calls,

a ‘changed self’, meaning that the disruption an illness would typically present becomes enmeshed with their evolving life-stories, instead of disrupting them (p. 101). Aligning with biomedical understandings also allows for community members to reclaim a sense of agency and power over their labels and representation, and demonstrates their ability to fit in with medicalised understandings; a strategic move which validates them. The ultimate agenda here is to demonstrate that there is a shared ‘root’ cause to BIID, and that the biomedical system should acknowledge it to reduce pain and suffering. In doing so, people with BIID may access treatment and medical assistance which work with understandings of their body, which cannot be provided by community members or independently.

The next chapter, ‘phenomenological perspectives’, while more focused on individual and closer relationships, similarly demonstrates the importance of social support in the management of BIID’s challenging symptoms. The accounts presented here show how people with BIID manage their dysphoria intersubjectively and through creative engagements with others and their own environments.

CHAPTER 4. PHENOMENOLOGICAL PERSPECTIVES

I think it is essential to gain more understandings about BIID... Because whatever it is that I am feeling and experiencing every day, it is really not fun for me at all. And it [BIID] has a massive impact on my life. At times it can be agony to deal with. It truly is something that hinders my daily life, my work, my relationship and all of my free time. It impacts everything in life that you can imagine. (Persephone, email interview)

Many informants feel as if they cannot communicate with medical practitioners and those around them, due to their inability to point out where their dysphoria comes from. Compared to ailments with readily observable traits, the deeply embodied nature of the neurological map means that external validation through biomedical measures, such as X-Ray's, pain questionnaires and blood tests are likely to fail in producing tangible evidence for people with BIID to use in their defence. In contrast to previous chapters which show how people with BIID externalise otherwise incommunicable pain through narratives and relegitimising actions within community spaces, this next chapter focuses more closely on how disclosure and continued engagements with the environment are used to manage troubling symptoms. This chapter looks into the anecdotes of three informants—Sienna, Millicent and Verity—to highlight how BIID is embodied and intersubjectively managed through disclosure, co-constructive narratives and simming practices. I lastly present a description from Verity, with the final aim of depicting what BIID feels like from an immediate and embodied perspective, showing that it does not come from a place of loss, but instead is based on a yearning to feel complete.

Embodiment and Intersubjectivity

‘Embodiment’ is a phenomenological term used to describe how people experience their own bodies, and perceive their lived experiences in relation to their social environments. While the concept of embodiment is widely used by social scientists, embodiment in anthropology has its own distinct usages, which primarily work to ‘collapse mind-body dualisms’, and to question distinctions between subject-object relationships (Csordas, 1990. p, 5). Csordas (1990) in ‘embodiment as a paradigm for anthropology’ argues that embodiment should be

used as a *consistent methodological approach* to represent the human body as being not an object, but as a vital subject and the ‘existential ground of culture’, (p. 5) a perspective which re-centres lived experiences as key to understanding the continuous relationships between individuals and their cultures. Jones (2011) also engages with the methodological approach of embodiment, and discusses how it can be used in contemporary bioethics to humanise representations of people with illnesses. She affirms that the use of the ‘anthropological gaze’, which is focused on lived experiences ‘enlivens’ how people are personified; which positively influences how practitioners and stakeholders extend care to others. The main thrust of Jones’ argument lies in her assertion that embodiment ‘grounds human behaviour by asking not only the *what*, but the *how* and *why* of people’s actions and beliefs’ (Jones, 2011, p. 73), orienting questions I also sought to answer when I closely spoke with my informants about BIID and simming. In contrast to the delegitimizing perspectives and the biomedical hyper focus on centring on a singular aspect of disease, the paradigm of embodiment considers experience from a holistic view and offers insight into the needs of people with BIID.

Wieseler (2018) points out a large gap in the literature around BIID, arguing that philosophical and psychological studies into the condition fail to focus on the first hand accounts of sufferers. She argues that this lack of focus leaves the needs of people with BIID as vulnerable to being altered and re-situated into dominant narrative tropes; which have patterns of positioning impairments and illnesses as trials which can, and supposedly *should* be overcome. Wieseler specifically notes that amputee-based narratives—which tend to focus on themes of loss and struggle—are consistently used to reframe experiences of BIID, which she cautions as inaccurate and rudimentary, given that not all people with BIID seek out amputations. Elaborating on this limitation, she explains:

The medical and social models of disability *do not address experience* and fail to provide a means for understanding what *people with BIID are seeking, which cannot be captured within the terms of impairment and disability*. (p. 102)

To remedy these shortcomings, Wieseler also advocates for an embodied approach, specifically a ‘modified’ version of Merleau-Ponty’s concept of ‘*Being-in-the-World*’, which aims to situate the lived experiences and subjectivities of people as being both ‘embodied and intersubjective’ (p. 83). Merleau-Ponty’s phenomenology is significant to the study of BIID, due to his dynamic analysis of the experiences of people with Phantom Limb Pain; the phenomena of still being aware of a part of the body which is no longer there. Based on his analysis of the Phantom Limb phenomena, he argues that human beings have a deep conception of the self which can outlast accident or illness, showing that subjectivity is intertwined with, and expressed through the body within the environment it has become familiar with. He explains:

To have a phantom arm is to remain open to all the actions of which the arm alone is capable; it is to retain the practical field which one enjoyed before mutilation. The body is the vehicle of being in the world, and having a body is, for a living creature, to be involved in a definite environment, to identify oneself with certain projects and be continually committed to them. (Merleau-Ponty 1962. pp, 81–82)

While people with BIID do not technically experience phantom limb pain from amputations or limb loss, this perspective may still help us understand why an existing limb, or sense, may be an incredibly wrong fit for a person. The following accounts to show how BIID is a part of my informants subjectivities, and falls outside of the conceptions of ‘impairment’ and ‘dis-

ability' and that their feelings and actions act as coping and meaning-making tools for them and those around them.

Simming: Integrating the internal body-map to the environment

The incorporation of an artificial limb into the phenomenal boundaries of the body enables some users to achieve corporeal knowledge, that is, a form of phenomenological understanding that is usually achieved with an anatomical limb (Murray, 2008, p. 121).

Simming is perhaps one of the most controversial parts of BIID, save for the radical surgeries or body modifications that some obtain. There are accusations of immorality and selfishness tied into simming, as it on the surface appears to depict people without disabilities as using prosthetics or resources which are not 'rightfully theirs'. However, discussions with informants show that simming is a deep and intersubjective process, which allows for people with BIID to fit their correct inner map into their environments, as opposed to being a mimetic practice. It can therefore be seen as a form of emotional and physical treatment for people with BIID, and taken as further indication of the deeply embodied nature of the condition. The significance of tools and prosthetics is not an unexplored phenomena for people who have experienced limb loss or damage. Rybarczyk and Behel (2008) in their examination of limb loss and body image, point out the significance of prosthetics in building a positive body image for amputees, arguing that prosthetics act as extensions of someone's body into the environment, maintaining a sense of bodily integrity. Sienna and Millicent demonstrate that simming practices, rather than being performative or based on desires for financial gain or disability, are deeply personal meaning-making activities which also reaffirm a positive body image for them. These two accounts depict two different simming practices: the first is based

on textual role-play and the second is more tacit, involving a shared environment. Both instances of simming occur after disclosure, and within the safety of close romantic relationships, which highlights the importance of social acceptance in facilitating positive body image and symptom management. These accounts show that instead of being superficial actions or mimicry, simming is an attempt to cope with the uncomfortable and deeply dysphoric experience of BIID, through allowing an individual to express themselves and make sense of their environment.

Sienna: ‘It took away a lot of the discomfort from real life’.

Years ago, on a night out for dinner with her family, Sienna was served by a young female waitress, who was a below-the-elbow amputee. Although she cannot remember the first time she became aware of her BIID, she points-out this interaction as crucial to her accepting her body image later in life. Sienna is now twenty-nine years old and speaks confidently about becoming her true self, as well as her desires for a lower-elbow amputation on her left arm, and double above-the-knee amputations for her legs.

Sienna engaged in secretive research as a teenager on forums like many others when she was first becoming more aware of her symptoms. However, her search was disrupted when she was caught by her aunt. When trying to explain her dysphoria, she was told that it was a ‘phase to grow out of’ and quickly became recluse. During her senior year of high school, she discovered a newfound form of social support after meeting her girlfriend, who also had BIID. When I asked if having a partner with BIID was beneficial or helpful for her, Sienna

confirmed:

It definitely was a positive. It took away so much discomfort from our real lives. We would essentially role play over text about our perfect world, one where we both looked and felt exactly as we should, even though we knew this wasn't real-life, or going to be happening anytime soon. (Sienna, email interview)

Through building trust within a close relationship, her and her girlfriend were able to focus on maintaining their images as 'regular high school students', while also navigating the emerging challenges of BIID. Given that they were able to relate closely with one another, both Sienna and her girlfriend were able to clearly speak about their perspectives and experiences without fear of judgement. The term 'role-play' was significant here, and I was curious to learn about how these activities specifically helped them both:

Well, my partner and I would usually start by talking about how we thought we should look. We would first figure out where our brains map of the body stopped. For her [Sienna's girlfriend], she wouldn't have her right leg from the hip down. And for me, it was both of my legs from above the knee, and my left arm from below the elbow. (Sienna, private message)

Although role-playing helped both Sienna and her girlfriend to conceptualise their needs and what they were seeking, the roller-coaster of emotions that came with being incorrectly embodied and keeping their dysphoria hidden took its toll:

I mean it [the relationship] had its ups and downs, of course. We would both have our 'flare-ups'⁸ together. But what ultimately drew us apart were the realistic goals and expectations

⁸ A 'flare-up' refers to periods where pain and symptoms exacerbate, causing additional stress. These flare-ups can occur randomly, after an environmental trigger or because of another underlying stressor.

attached to our correct embodiments. (Sienna, private message)

The reality of developing deep muscle pain and weakness, potential heart failure and multiple infections are unavoidable risks that come with the illegal and unregulated surgeries people with BIID are presented with; facts that Sienna and her girlfriend both acknowledge. With these dangers taken into account, they decided to compromise and re-imagine what sorts of treatments to seek:

If we even found someone willing to operate on us, the risks of our amputations would be too high. After reaching these conclusions, we could only really just continue to talk about it instead. For my girlfriend, just missing her leg from below the knee would be *acceptable* if it all came down to it, if we couldn't get the surgery that we want. And for me, just losing the tips of my fingers on my hand would be enough for me to deal with my BIID.

Together, they were able to define their ideal bodies through role-playing (which externalised their maps) and imagine realistic and hopeful treatment plans. While their roleplaying did not diminish their feelings of mismatch, it gave them a practical means of dealing with the stress of not being able to inhabit their correct bodies. It also acted as a proxy or means for them both to examine their inner maps and to reach new conclusions about reasonable treatments to request. Simming or roleplaying in this instance allowed for Sienna and her girlfriend to also avoid stigma and to work out alternative means to coping with their dysphoria outside of radical surgical interventions. By acknowledging the risks and danger associated with their correct embodiments and the surgeries required to bring them about, both Sienna and her girlfriend were also subtly able to conform to biomedical standards, and reconsider meaningful ways to manage their feelings. Given that Sienna had already had an unpleasant experience

with disclosure, exploring and learning how to articulate what she is feeling within a close relationship was a logical choice, made to protect their confidentiality and to minimise potential backlash. We can additionally see that instead of being an activity which was based on mere wish-fulfilment or desire for disability, this simming activity helped both Sienna and her partner to manage their emotions, learn about their bodies and internal map and to temporarily maintain a sense of normalcy.

Millicent: ‘A princess in a wheelchair’

I think if you would have to put a label on it, I guess I would call it partially paralysed? (Millicent, email interview)

Like Sienna and her partner, Millicent engages with simming activities to manage her BIID and to maintain a sense of correctness. Millicent is a thirty-eight-year-old woman who desires partial paralysis from the waist down, and to become a full-time wheelchair user. Although she does not know the precise medical names for her ‘cut off’ zone, she notes that her internal map fades at the ‘L1—L2’ level of her spine, rendering this space as intangible and foreign. Millicent became aware of her BIID as a child, and would even have recurring dreams of herself as a ‘princess in a wheelchair’, after figuring out that paralysis was the best fit for her body. However, in her waking life, she would cope with her feelings of external and internal mismatch by imagining herself as using a wheelchair whenever she would sit or move. Coming into adulthood, she found that simply envisioning her correct embodiment became a less helpful way of managing her dysphoria, only making it feel more obvious and apparent. Now, in her thirties, Millicent’s physical feelings of pain in her lower extremities continue, which are at times, ‘comparable to a persistent burning feeling’. These flame-like sensations render

her legs as a definite, ‘no-touch area’ that she is always aware of. Millicent also asserts that her feet and lower body feel as if they are at a great distance to her, describing them as ‘numb’, and always ‘a second behind the rest of her’, a gap which continues even when she is stationary:

Standing up. Very unpleasant. I avoid it when I can, and if I have to, I usually just lock my knees and lean against something else. It does not hurt me; it just feels very wrong... every step I take, my mind says something like, ‘uh, don’t do that’. (Millicent, email interview)

While Millicent has breaks between her physical flare-ups, it is her constant awareness of the spaces in her internal map which troubles her the most:

The metaphor I used to describe it was to compare it with when you have something stuck in your teeth; it does not hurt most of the time, but it is annoying because it is *always* there... So imagine that you have got something stuck and you know it is not going to kill you, but it is annoying, and since you do not have a toothpick, there is no way to make it stop. (Millicent, email interview)

These perceivable spaces within her internal map make her legs feel deeply wrong, driving her to concentrate on not using them. She also makes an effort to not pay attention to the sensory feedback they provide her. These are all crucial coping methods for Millicent, but tasks that are incredibly difficult to keep up, given she has a job that requires her to be alert and continuously active for safety reasons. Adding to her discomfort is her awareness of ableism, and the systemic discrimination of the disabled community. She becomes especially aware of this reality when she is walking, or exploring environments without a wheelchair to use, as feelings of melancholy start to weigh heavily on her:

I have this thing where everywhere I walk, I actually imagine myself to be rolling in a wheelchair instead. Everywhere. I think this is the most tiring part of BIID for me, as it constantly makes me feel sad that I am not able to move around like that. Living in ____ also makes me upset, because there is pretty much nowhere that is accessible for wheelchair users. (Millicent, email interview)

Having struggled with an awareness of her incorrect embodiment from a young age, Millicent was driven to learn about what was socially acceptable, to others to avoid attracting unwanted attention to herself. She recalls pivotal ‘shame moments’ as playing a role in her later understandings of disability:

I think I always realised that it [BIID] was not something I should talk about with others. I was quite young when I had my first ‘shame moment’. I had made a new friend who told me that her younger sibling had to use a wheelchair. My reaction at the time was to say, ‘Oh cool!’ This sparked questions and drew attention to me, and my friend just said that it was a ‘weird’ thing for me to say. I can just remember the absolute *embarrassment* I felt for saying that about someone who *needed* a wheelchair, in comparison to me *wanting* one to use. (Millicent, email interview)

The concepts of *need* and *want* greatly contributed to Millicent’s initial understanding of disability. This ‘shame moment’ she spoke of cemented the fact that disability is seen as taboo or undesirable, and balancing this social norm with her feelings of dysphoria became difficult. This ‘shame moment’ eventually led to her deciding to keep her true self hidden, which exacerbated the severity of her later flare-ups, which then lead to overwhelming feelings of fear.

Millicent only experienced a positive turn with disclosure when she entered a new romantic relationship, and was able to find a way to be her correct self within her environment:

I just blurted out the truth to her [Millicent's girlfriend] one night. She was *so* supportive and listened to me the whole time as I explained everything. I was really nervous about telling her at first, but she was so amazing, and listened to me the whole time. This led to many changes around the home later, to accommodate everything. I first asked her if I could try sitting down in a regular chair. It felt strange with her there for the first minute or so, but it got better. Now it is completely fine and doesn't feel awkward at all. Since having the first *real* honest conversation with my girlfriend some time ago, there have been changes around the house that have been *amazing*. She told me that she is open to helping me work towards managing my BIID, and she has been doing just that.

After disclosing her BIID to her girlfriend and making adjustments to her home, Millicent's self-esteem and confidence grew exponentially:

[Simming] at home was probably the first time in my life where I was able to do something 'normal' in a way that feels normal for my body. I can now do things like sitting down for longer periods of time. And I feel *so* much better not moving my legs for as long as possible. I can sit down more, or even reposition my legs with my hands, if that makes me feel better. The most amazing thing is being able to cook at home, when I'm sitting at my desk chair. I absolutely love cooking. But it was always agony to deal with the physical side of it. (Millicent, email interview)

She reaffirms that while her body schema or internal map, is invisible and intangible, she can represent her correct self through simming and engaging with her home environment. If we apply Merleau-Ponty's concept of 'being-in-the-world' to Millicent's example, we can see

how BIID is a deep yearning for normalcy and completeness, which manifests as an engagement through the *definite environment*, *continuous commitment* and *familiar projects*. Interpreting Millicent's simming as integral to her expression and correct embodiment—as opposed to being performative—demonstrates how the needs of people with BIID are not borne out of desires to be impaired or disabled, but instead come from a need to live in a way that is ‘normal’ for them. Disclosure and simming are therefore ways which help people with BIID adapt to their environments, providing them with a sense of continuity as they attempt to independently balance their feelings of dysphoria. This holistic understanding demonstrates that achieving a sense of normalcy is key for people with BIID, and the desire of limb loss as secondary to this. Based on these accounts from both Sienna and Millicent, we can see that needs for drastic bodily changes are not driven by feelings of ‘loss’, as previous amputee-based narratives would posit, but instead come from a need to correct the self. Simming is the mode they use to converge their inner selves to the outer environment, which is not constructed for them.

Explanatory Models, Illness Narratives and Metaphors

In addition to the community interactions presented in earlier chapters, the dysphoria BIID presents is also managed through the use of personal narratives and co-constructed metaphors. The following section focuses more intensely on the creation of illness narratives and their significance in helping people with BIID maintain emotional stability in times of uncertainty. All experiences of illness are informed by cultural and shared understandings of disease aetiology, progression and treatment trajectories; and explanatory models reflect these understandings. Illness narratives similarly carry culturally meaningful themes, and these

themes are used by individuals when they seek to find balance in their lives. Kleinman (1988) explains the personal significance of narratives further:

Patients order their experience of illness... as personal narratives. The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings (p. 49).

The concept of intersubjectivity—referring to how knowledge is produced with others—is particularly important here. As narratives and metaphors are created through ongoing dialogues between people and others around them, studying these descriptions from people delineates and clarifies what people feel, shedding insight into what they are seeking and how they envision their futures. With these understandings in mind, I wish to introduce accounts from my informant Verity, demonstrating how her experience of BIID was set on a positive trajectory, due to the influence of social support and co-constructive narrative processes between her and loved ones.

Verity's intersubjective metaphor: 'The arm thing'

Verity is a young woman whose right arm fails to belong, noting that this disparity starts an inch below her right elbow. Verity became aware of this issue when she was just six years old, in the school playground during recess. 'Something felt wrong in that area... and I just had to acknowledge that the feelings I had toward my arm were not normal at all. But no one else spoke about it'. During puberty, a time where the symptoms of BIID are already thought to increase and become much more challenging to manage (Frey, 2018), Verity was faced

with an onslaught of physical discomfort, at the same time as other turbulent life-events. Her first confession about her BIID spilled out ‘in the wake of a few more revelations’ about her personal life, and was met with mixed emotions. ‘There were some things happening at the time. I saw a lot go on. But the worst part was when this traumatic event happened, and I had to finally speak to my mother about it:’

When I told her about what had happened, my mother cried. And she told me that she loved me. She then asked if there was anything else she needed to know. That’s when I told her that my arm wasn’t right, and I had been wanting to cut it off since I was young. Telling her seemed like the natural thing to do at the time, as we were already being open and honest with each other. She asked me if I wanted to cut it off right then, and I told her ‘no’. We then stopped talking about it. (Verity, email interview)

‘That’s me, mum, remember?’

Verity’s pivotal breakthrough and disclosure was years later. It was a casual afternoon, and she was sitting on the couch with her mother, enjoying the latest episode of a medical drama. Verity’s attention was suddenly absorbed when a man appeared on screen, asking for an amputation for his foot. The patient, who appeared to be in his late-thirties, assured incredulous hospital staff that he was ‘*not* crazy’, and that he needed immediate help. Accompanying the patient at first, was lively and mischievous instrumental melodies playing as he spoke, ceasing only when a doctor replied to or questioned him. The patient had discussions with many professionals, while intermittently stomping his troublesome-foot. The nurses with his in-take file were baffled by his healthy medical record, and were even more taken aback by his occupation as a banker. He was eventually prescribed regular dosages of ‘anti-anxiety medication’

(which was likely an SSRI⁹) to treat his severe case of Body Dysmorphic Disorder, which lead him to re-assert that he needed ‘*surgery*, not pills’. The episode reached its climax when the man stole a mechanical saw from another patient in the emergency ward, taking matters into his own hands. There was blood splattered on nearby medical tools and chaos in the ward as doctors frantically raced to save his leg. He received his amputation, and was later shown musing with the doctors on whether or not what he did was, ‘crazy’. It was then, back in her living room, that Verity interjected, ‘That’s me, mum, remember? It’s a thing; I’m not the only one!’

Image removed due to copyright

Image 2. *Two hands held together in an embrace, one with amputated digits*: This is an image from a biographical book about BIID, apotemnophilia and extreme body-modification, addressing the intersection between sexuality, identity and disability. This text was recommended to me by informants who thought it was helpful, and representative of their needs (by Chris Panatier, for ‘*Headcheese*’ by Jess Hagemann, 2018).

⁹ An SSRI is a ‘Selective Serotonin Re-Uptake Inhibitor’ prescribed to treat depressive symptoms, and disorders such as major depressive syndrome, post-traumatic stress disorder and obsessive compulsive disorder. SSRIs are a pharmaceutical staple for many, and often a core part of treatment plans which also involve ongoing CBT therapy.

‘The way she chose to act after that, I have forever praised her for’.

Turning the television off, her now concerned mother took hold of Verity’s right arm and reminded her that she ‘loves her very much’. Verity’s mother asked her how long she had been feeling this way about her arm, gently stroking her thumb over it, listening to her explain that she has been feeling this way since she was six. She re-clasped Verity’s arm, cradling it this time, and explained, ‘It’s a prosthetic. I’ve spent lots of time and money creating it, to make sure that it feels just right for you.’

She would move her thumb gently and then ask me how the *synthesised nerve endings* were going. I explained to her that I could *feel* the nerve endings, and her touch—But my *soul did not extend all the way* into the prosthetic—even though it was fully functioning. (Verity, email interview)

The importance of narrative and embracement

The onset of illness can severely disrupt an individual’s life trajectory, directing people who are chronically ill and sick to feel lost and confused about how and why they are experiencing what they do; and how they can manage in future. People, therefore, generate illness narratives to maintain a sense of continuity in these times of ambiguity, imbuing these narratives with coherent cultural themes, metaphors and characters which resonate with and comfort them best (Hunt, 2000. p, 90). Illness narratives are also malleable and open to change, meaning that they can accommodate the tumultuous physical and social disruptions that an illness can cause, transforming uncomfortable events—such as the onset of sickness or a diagnosis—into empowering and significant moments in life. ‘I still think back to this moment’, Verity said, ‘and I use it as a coping mechanism for when things get tough’. Given that BIID

is so understudied, Verity had no other way to express what she was feeling and chose disclosure as her main mode for asking for help and gaining social support for her symptoms, which she also recognised as worrying. As Verity explains earlier, her *soul* does not extend all the way through her arm, and as a result, she is disconnected to it. This gap is a reality that cannot be changed without a targeted medical intervention of some sort, though emotional intercessions can help her to manage the pain it causes. The above interaction between Verity and her mother is a prime example of intersubjective narrative work, and shows how a worrying revelation was transformed into one with a positive trajectory and outcome. To clarify, the arm prosthetic Verity's mother spoke of is not a literal device which was made and fitted to her, but it is instead a metaphoric tool which was constructed to help reframe a troubling way of relating to the body. Verity's mother offered up the metaphor as a symbolic gesture to communicate her unwavering support for Verity, and to attempt to turn this event into one with a logical and emotionally meaningful timeline. The prosthetic was therefore generated as a creative explanation to answer the *why* and *how* questions about Verity's experience with dysphoria. As Verity also recognised this metaphor as a meaning-making tool, she was able to alter it to communicate her feelings and embodied perceptions. Through intersubjectively constructing this metaphor and past timeline together, Verity and her mother were able to retry discussing BIID, and to reach a mutual understanding about the situation. In doing so Verity was able to clarify her perspective and recognise that her arm is a part of her identity, as opposed to a rupture or burden.

Reaching out: Listening to people with BIID

In 2011, neurological papers examining the relationship between BIID, the parietal lobe and proprioception began to circulate, absorbing Verity's attention. Scientific papers were recognising her symptoms as potentially neurological and based within the body; providing solid explanations as to why she, and many others were experiencing their dysphoria. Two years later in 2013, the fifth edition of the DSM was due to be released, and there were debates on whether or not BIID was going to be included. This was an emotionally charged time for Verity and the online community, as the 'holy bible of mental disorders', was about to determine what conditions were revised and added to, or stricken from the psychiatric record.

When BIID was not included in this edition, DSM-V, Verity and the online community saw it as a symbolic door-slam; venting their pain, frustration, confusion and fear about the decision together. Many at the time were relying on receiving a medical label to affix to their symptoms, and not being able to fit into the biomedical system caused a great amount of turmoil and disenchantment for community members. 'I know for sure I was not alone before the DSM-V was published. I can remember the depression I had in the wind up to its publishing, and whether or not BIID would be included'. After this period of grieving, Verity resumed her research about BIID, where she came across the contact details of Dr Morgan¹⁰, a professional who was advocating for BIID's medicalisation. With new hope, she introduced herself, and asked for advice on what steps she could take to receive treatment, in light of the DSM's disappointing revelations. This professional recommended the help of a general practitioner

¹⁰ Dr Morgan, Dr Wolfe and Dr White are pseudonyms.

(GP) who could help provide Verity with a referral to see Dr Wolfe, a psychiatrist specialising in working with patients with gender dysphoria and body dysmorphia. The appointments went extremely well, and like Lux from the previous chapter, Verity found she was even taking on the role of being an educator or advocate for the condition:

He [Dr Wolfe] laughed a little when we discussed the sexual aspects of BIID, and I had to promptly inform him that *I do not* fetishise it [her arm], experience any arousal over it, and to be perfectly blunt, am uncomfortable with others doing so. He then joked that that had rendered a fair portion of what he had read useless, and that he would learn more about BIID. (Verity, email interview)

The interactions Verity had with these medical professionals put many of the fears she, and many others, had about treatment seeking to rest. In moments which could have been exceptionally uncomfortable—such as when Dr Wolfe joked about the fetishistic connotations around BIID—Verity was able to diffuse tension, and immediately correct any misconceptions. In doing so, she proved herself to be a ‘valid’ and ‘authentic’ patient, and even encouraged this practitioner to do more research about BIID. Social support from both the community and her mother helped Verity to come to firmly understand her needs, and to express them without restraint. Verity added ‘This doctor was *great*’. ‘He actually had promised to do even *more* research about BIID for me, and he went ahead and did *exactly* that’.

‘Isolate further than that’

Given that biomedicine has not yet accurately expressed the needs of what people with BIID are seeking, many sufferers have to engage in creative and involved ways of expressing their symptoms. In some cases, the internal rupture that BIID presents is expressed through labels and descriptions, and in many others simming or pretending becomes the most accurate way to demonstrate what BIID feels like. When I first asked Verity about what BIID felt like for her, she paused and admitted that her symptoms are hard to articulate, given that there is not much to compare it against. Like the wanderers who were introduced before, Verity had also come up with her own way of expressing her relationship with her inner map. ‘Here is an exercise I share with my friends and family who ask me about it. I would like to share it with you if I may.’

I first ask them to take a quiet moment, perhaps with their eyes closed, ruminating on their body and the room. I ask them to note sensory information—a draft, the pressure of their clothes. Then I ask them to isolate further than that—to their innate sense of bodily positioning.

I thanked Verity for her response, assuring her that anything she sends is helpful. Next, I found a quiet space and tried the exercise alone. I wondered how well I would be able to get in touch with this sense of bodily positioning, and if maybe I would learn something new about *my* map. I also felt apprehensive, because this exercise was going to be my first physical try at participant-observation with BIID, meaning that I was placing a new reliance on my own body to reveal something about another’s perspective. After a few minutes of silence and slow, mindful thinking, I noticed an abrupt mental block at the final step of ‘isolation’ Verity mentioned. I feel no separation in any part of my body. I was still aware of my surroundings.

The carpet I was laying on was rough on my skin, and the air around me was cold. I kept my eyes shut for as long as I could, mentally envisioning my disconnected body, limb to limb; but I still could not sever myself away from a feeling of being whole. I was shocked at how simple I thought the exercise was going to be, and was also admittedly embarrassed at myself for thinking so. However, I was now also grateful, as I finally gained some insight into how complex BIID is.

Verity explains that ruminating questions from those around her are common. When her close friends and family attempt the visualisation for themselves, they ultimately still fail to relate to her internal rupture. In these moments, she clearly explains that BIID is simply a ‘physical and sensory feedback for a part that is not recognised as innately apparent’, and that it is this ‘constant disparity’ which perpetuates her discomfort. Like Sienna and Millicent, Verity’s experience of BIID is also not situated in a feeling of, ‘loss’ but is one that is instead characterised by a deep sense of incorrectness. Social support, disclosure and mutually verifying experiences, however, help her to manage this disparity and to cope with her feelings outside of biomedical help. ‘I’ve actually told a few more people now’, she wrote in our final correspondence:

I think you’ll be pleased to know that I do not really see my arm thing as something that is *taboo* anymore. I’m not even sure if it’s still BIID. I am quite over being ashamed of it at this stage of life, and I am actually very used to the odd reactions I receive from others, which I also completely understand. And as for my family, their incredulousness over it soon morphed into acceptance, and we now just call it, ‘the arm thing’. (Verity, email interview)

CHAPTER 5. CONCLUSIONS

If the human condition frames medicine and not the other way around, then our age calls not for a more exact, but a humbler medicine. (Reynolds, 2018, p. 5)

The pervasive stigma and cultural anxieties which impact not just people with BIID, but many other people with disabilities, are core to this thesis. As a neurological condition without an immediately observable dimension, BIID is contested and seen as a ‘matter out of place’, as Douglas (1966) would say. This thesis was driven by a desire to demystify BIID and misconceptions around the condition. This research has humbled me, and also yielded insights into what it means to be incorrectly embodied. Based on ongoing and attuned conversations with my informants, I was able to address orienting questions regarding the explanatory models people with BIID, how online communities provide social support for this uniquely stigmatised, and finally, how a phenomenological approach can enrich representations of BIID.

I firstly uncovered that biomedical and neoliberal culture heavily influences how people with BIID present their symptoms and decide on how to seek help, and that their explanatory models are also shaped by biomedical understandings which prioritise a focus on disease and physical explanations for illness. What this specifically means is that people with BIID will place their trust in biomedicine to offer explanations to why they experience their dysphoria, and seek answer from it on how to alleviate their pain. This reliance has however lead for many to have their experiences scrutinised and not taken seriously by practitioners. Current treatments from biomedical practitioners are too risky for many of my informants, and dis-

cussing their symptoms is seen as too risky. To deal with this discrepancy, people with BIID turn to online communities to discuss their pain, and to find other non-invasive ways to maintain a steady feeling of consistency (such as through simming). These online communities provide social support for people with BIID, and function as hubs for learning about and educating others on their needs and symptoms, given that people with BIID are misrepresented in media accounts or medical literature.

Phenomenological approaches (introduced in Chapter 4) reveal that BIID is not a desire for *disability*, but it is instead a constant awareness of being incorrectly embodied, accompanied with a desire to correct this. Informants expressed that while the correct body map is not tangible at first, it is made perceivable through behaviours and visible actions—such as simming—and carefully constructed narratives. These actions and behaviours are often taken as evidence for perceived immorality or deviancy, but my informants instead indicate that these practices are ways for them to engage with the environment, self-treat and maintain a sense of normalcy or continuity in their lives. As shown, part of the distress that people with BIID experience comes directly from having to keep their true embodiments concealed, while not being able to be recognised by medical systems which are supposedly meant to deliver surgical interventions to people who are suffering. The use of online forums and simming are shown to not be performative practices or attempts at ‘self recreationism’, but are instead examples of how people with BIID and their communities manage their dysphoria, while managing the lack of biomedical attention and social validation afforded to them.

Directions for future studies

Due to the rarity and controversial reputation of BIID, the research had a small sample size, and non-digital interviews and observations were not feasible at this point. Future studies should consider expanding sample sizes, engaging in face-to-face interviews and carrying out simming observations to further enrich understandings of BIID. A qualitative and explanatory approach should be used in these studies, to further explore salient and emerging questions around experience and identity. The research highlights the integral role romantic partnerships (and other close relationships) play in facilitating positive body image and coping methods. These findings can be incorporated into future studies on intersubjectivity, disclosure and body image, so that the effects of the social environment on embodiment can be explored further. The sample has different demographic characteristics from previous studies, specifically demonstrating that some people with BIID also identify as trans, which should be recognised in future discussions, as this challenges arguments which have placed both identities in contention with each other, contributing to a more intersectional understanding of BIID.

Final reflections

My informants have taught me that the journey of BIID does not end with a revelation, but starts from one instead. People with BIID already *know* about their correct selves, and much of the turmoil they experience stems from an inability to be correctly recognised and acknowledged within their social worlds; due to stigma, unfair representations or misunderstandings about disability. Coming in to fieldwork, I had to leave aside any biased preconceptions I had about BIID and disability; and engage in continuous and attuned listening with my informants, which has taught me to consider each case of BIID as unique and shaped by various factors. I learned that BIID carries different meanings for each individual, and not all of

them are negative. For Millicent, BIID has meant navigating around the judgements of others but arriving to find growth and progress through sharing her needs. For Persephone, it has meant carrying a long-held secret and finding unwavering support within the digital world. For Lux, it has been a continuous self-reflection, and a chance to share her understandings with her counterparts. For Sienna, it has been a lifelong learning and unlearning process. For Verity, it has been a constant disparity and search for truth. What they all have in common is a unique bodily experience, and a desire to be understood.

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Appendix I of this thesis has been removed as it may contain sensitive/confidential content

APPENDIX II. Participant Information Consent Form

I, *(participant's name)* have read *(or, where appropriate, have had read to me)* and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research, knowing that I can withdraw from further participation in the research at any time without consequence. I have been given a copy of this form to keep.

Participant's Name:
(Block letters)

Participant's Signature: _____ Date:

Investigator's Name:
(Block letters)

Investigator's Signature: _____ Date:

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Your data may be used for future projects. If you do not wish to have your data used please indicate your choice through ticking one of the options below:

Yes, I consent to having my data used in future projects ☐

Or

No, I do not wish to have my data used in future projects ☐

(INVESTIGATOR'S [OR PARTICIPANT'S] COPY)