



## From biosociality to biosolidarity: the looping effects of finding and forming social networks for body-focused repetitive behaviours

Bridget Bradley

To cite this article: Bridget Bradley (2021): From biosociality to biosolidarity: the looping effects of finding and forming social networks for body-focused repetitive behaviours, *Anthropology & Medicine*, DOI: [10.1080/13648470.2020.1864807](https://doi.org/10.1080/13648470.2020.1864807)

To link to this article: <https://doi.org/10.1080/13648470.2020.1864807>



© 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.



Published online: 22 Feb 2021.



[Submit your article to this journal](#)



Article views: 292



[View related articles](#)



[View Crossmark data](#)

# From biosociality to biosolidarity: the looping effects of finding and forming social networks for body-focused repetitive behaviours

Bridget Bradley

Social Anthropology, University of St Andrews, St Andrews, UK

## ABSTRACT

Anthropological accounts of biosociality reveal the importance of the social relations formed through shared biomedical conditions. In the context of body-focused repetitive behaviours (BFRBs), like compulsive hair pulling (trichotillomania) and skin picking (dermatillomania), biosociality moves people from isolation towards community. After diagnosis, the powerful moment of discovering 'you are not alone' can lead to immense personal transformations, demonstrating the 'looping effects' of diagnosis and biosociality. Yet, biosocial groups do not simply exist, and must first be formed and found and their sustainability requires ongoing work and care from biosocial actors themselves. Biosociality also means different things to different people, often requiring a negotiation between secrecy and disclosure. This article acknowledges the role of stigma in biosociality, differentiating between private and public biosocial experiences. It argues that through biosociality come acts of biosolidarity, where advocacy can improve the visibility and recognition of illness groups. The circular looping effects of biosociality and biosolidarity demonstrate the way that community activism and biosociality reproduce one another. Through reflections from the anthropologist, biosolidarity is considered as a methodological tool that can help scholars to navigate the boundaries between relatedness, sociality and advocacy in the field and beyond.

## ARTICLE HISTORY

Received 30 September 2019

Accepted 3 November 2020

## KEYWORDS

Body-focused repetitive behaviours; biosociality; biosolidarity; diagnosis; looping effects

## Introduction

Sitting behind the computer screen, my nervous excitement was enhanced by the repetitive scrolling through posts, clicking from one to another. Images, videos and text offer familiar sights and reassuring words within this secret and safe space. Facebook became my main online field site, where I attempted to participate and observe within support groups for compulsive hair pulling. Observing felt odd in this context, the potential for lurking made me feel uncomfortable, so I attempted to participate, sharing my own experiences, asking questions, responding to others. New members usually wrote short introductions summarising their journeys, and many of them had stumbled upon the name – trichotillomania

**CONTACT** Bridget Bradley  [bb203@st-andrews.ac.uk](mailto:bb203@st-andrews.ac.uk)  Social Anthropology, University of St Andrews, 71 North Street, St Andrews KY 16 9AJ, UK

© 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

– not long before finding the online group. One step leads to another; a name becomes a community, being alone becomes being together.

I had actually never thought to Google ‘hair pulling disorder’ because I thought I was the only one to do this. But lo and behold, here we are! And I’m so thankful every day I’m not alone and I have support and understanding here (Sophie, Facebook).

For those living with body-focused repetitive behaviours (BFRBs), making contact with other people who share their experiences can be life-changing. Years of silence creates a feeling of being ‘the only one in the world’ who has the ‘weird habit’ of compulsively pulling out hair or picking skin. The process of finding out they are not alone involves the discovery of new kinds of people just like them, from whom they can receive new kinds of care. For many, this process is private, secret, shared only through the online spaces of support groups. For some, the impact of discovering ‘you are not alone’ shatters the isolation and loneliness that came before it and drives them towards new kinds of recognition in solidarity with their newfound community.

This article applies the concept of biosociality to experiences of BFRBs, demonstrating the way that biosocial groups are formed, valued and sustained. Biosociality is the notion that people with shared biological conditions come together to form social networks and was introduced by Rabinow (1996) who considered the implications of new genetics on society. Scholars have since questioned the impact of this concept on the biologization of social life (Franklin 2001; Hacking 2006), with recent endeavours seeking to close the gap between the biological and the social (Seeberg, Meinert, and Roepstorff 2020). In using biosociality to analyse BFRBs, I choose not to delve into the biological or genetic basis of these disorders, and instead I follow those who prioritise lay understandings of biosocial identity formation over scientific (Tiktin 2006). In my view of BFRBs, ‘bio’ is attributed to the legitimacy brought by a biomedical name, but it is also firmly based on the complex and confusing embodied nature of these behaviours. The importance of the body, which appears to have ‘a life of its own’, pulling and picking instinctively, unable to stop – made my interlocutors feel abnormal, ‘like a freak’, and ‘the only one in the world’ with these unusual, inexplicable compulsions. Therefore, the moment of diagnosis can bring a sense of normalcy to these experiences, through the realisation that they are not alone. But diagnosis for BFRBs rarely fits into the dominant medical paradigm of the doctor as expert, instead it frequently takes place within online spaces, supporting the idea that diagnosis is social (Brown, Lyson, and Jenkins 2011). Simply put, BFRB diagnoses are made meaningful through social relations rather than through professional expertise, and these relations can lead to social movements that in turn can alter diagnostic labels.

This article combines frameworks of biosociality (Rabinow 1996) and labelling theory (Hacking 1995) to show how ‘new kinds of people’ (Hacking 2007) come together, care and advocate for one another through their shared experience of illness. Hacking (1995, 1998, 2007) has described the ways in which diagnosis and patient identities emerge ‘hand in hand’ through ‘looping effects’. Through the example of the BFRB community, these looping effects can be followed in real-time, and alongside the new kinds of people that emerge by diagnosis, are new kinds of care, and new ways of being recognised in the public domain.

Biosociality is a popular concept in medical anthropology and has been used to describe experiences of sociality through examples of HIV/AIDS (Tiktin 2006, Marsland 2012), autism spectrum disorders (Silverman 2008; Nadesan 2020), and the Deaf community

(Friedner 2010), to name a few. Biosociality has been described as a way to ‘name the kinds of socialities and identities that are forming around new sites of knowledge’ (Gibbon and Novas 2008, 3), and in this case, that knowledge is gained through diagnosis.

While the organisation of layperson groups lined by disease categories is not new, combining biosociality with theories of labelling allows us to follow the way new patient groups emerge and form social networks surrounding biomedical classification. In particular, this article adds to discussions of how the internet can aide the formation of biosocial groups (Rapp and Ginsburg 2001; Parr 2002; Schaffer, Kuczynski, and Skinner 2008; Meleo-Erwin 2020), and expands the idea that biosociality can lead to patient advocacy (Parr 2002; Novas 2006; Silverman 2008; Nadesan 2020). Furthermore, literature on biosociality has largely been attributed to the *benefits* of sociality, and few scholars have examined its *limits* (Bridges 2011; Meleo-Erwin 2020). I argue that biosociality is not straightforward, not always positive, or inclusive, and consider biosociality as a process. Illness communities do not simply exist but instead come together in various ways that rely on people working together. Often missing from discussions on biosociality are the detailed lived experiences involved in the process of finding and forming communities. Moreover, the potential role of the anthropologist in biosocial relations is rarely considered. In this article, I reflect on my own involvement in building biosociality, and the challenges of attempting to advocate for this community. The development of *biosolidarity* as a concept gives close attention to the activist efforts of biosocial groups, and simultaneously recognises the reproductive power this work can have on biosocial networks. It is hoped that my proposal of biosolidarity as a method will provide useful reference for scholars crossing boundaries of activism in social research.

This article begins by unpacking the relationship between biosociality and diagnosis. Through descriptions of ‘finding out the name’ I show how BFRB experiences support Hacking’s idea that labels create new kinds of people, and new ways of being recognised. Considering the looping effects of biosociality as a process, the uncertainty and frictions involved in this process will be foregrounded. I move on to discuss how biosociality can create new forms of care, resulting from disappointments with medical care. Next, it will become clear how biosociality can lead to biosolidarity, and through the meaningful connections and care networks found in the biosocial group we follow those who are compelled to *do something* with their new BFRB identities. Biosolidarity gives increasing power to looping effects and emphasises the perpetual cycle of looping. Introducing the ‘circle of biosolidarity’ I argue that acts of advocacy increase recognition and visibility of BFRBs, expanding opportunities for people to discover ‘you are not alone’ and subsequently join the biosocial group. I conclude by reflecting on my own role in the biosocial process and consider the potential for biosolidarity as an anthropological method. Biosolidarity is new to the vocabulary of anthropologists, although it is mentioned fleetingly in a few medical articles, without being fully defined (Gaughwin 1995; Burgio and Locatelli 2003). I define biosolidarity as the process through which biosocial actors perform acts of advocacy on behalf of their biosocial community. While I consider this article a major contribution to the development of biosolidarity as a concept, I do not wish to restrict the use of the term to the limits of what I set out in this article, nor do I wish to be the gatekeeper of it. First and foremost, I offer biosolidarity as a framework to make sense of the relationship between the body, sociality and advocacy in the BFRB community, and I encourage future scholars to take it forward in their own ways.

## Methods

This article draws on ethnographic research that took place across multiple sites in the United Kingdom and United States, between 2015 and 2018. The research focused mostly on people living with compulsive hair pulling (trichotillomania, TTM, or trich) and compulsive skin picking (dermatillomania, excoriation disorder, or derma). The project received ethical approval from the University of Edinburgh's School of Social and Political Science Ethics Committee in 2015. The fieldwork process included in-depth, semi-structured interviews with 65 participants: people living with BFRBs (44) family members (11), clinicians (8) and hairdressers (2). Participant observation was conducted at three American conferences run by the TLC Foundation for Body-Focused Repetitive Behaviors (hereafter TLC), in specialist hair salons, and in support groups, both online and in-person. All interviews were audio-recorded and transcribed. Pseudonyms are used for all informants, except BFRB advocates and organisations who wished to be named. A version of discourse analysis (Bryman 2012) was used to analyse interview transcripts and online support group comments, highlighting emerging themes in the data. British participants were initially recruited through online forums, and American participants were recruited through contacts I met at TLC conferences. My own positionality as someone living with BFRBs aided recruitment and access, allowing me to build relationships with my interlocutors based on our shared experience. This insider/outsider positionality was accounted for through critical reflexivity and diary-keeping alongside fieldnotes. I use my personal reflections in this article to show how positionality influenced biosociality and helped me to consider the potential of biosolidarity as a method.

## Diagnosis and biosociality

BFRBs are not easily classified; arguably they are grooming behaviours that have become out of control (Penzel 2003). They are classified as mental disorders, but they have a very physical effect on the body. Simultaneously visible and invisible; this relationship makes them contradictory and complex, and similar in some ways to experiences of self-injury (Chandler 2016), although my interlocutors largely rejected the idea that BFRBs are a form of self-harm. Moreover, individuals will experience unique urges and rituals while pulling and picking that are often subconscious, obsessive and compulsive, supporting to some extent, their inclusion in the category of obsessive, compulsive and related disorders (American Psychiatric Association 2013, hereafter APA).

For invisible conditions, diagnostic technologies can help to make illness visible and offer patients validation through medical tools, for example in video imaging for chronic pain (Rhodes et al. 1999). In the experience of my interlocutors, diagnosis was rarely given by medical experts, and instead took the form of self-diagnosis through online searches. Validation and visibility, also rarely came from the medical domain, and instead were developed through social networks. Literature on BFRBs shows that people will often avoid help-seeking due to shame and embarrassment, but when they do, health professionals usually display limited knowledge of the conditions (Woods et al. 2006; Tucker et al. 2011). Shame has a large impact on daily life, and causes people to hide any physical damage from pulling and picking from peers (Weingarden and Renshaw 2015). This secrecy was described to me in relation to family members and friends, but also in the context of health

professionals, where people were reluctant to show visible damage to doctors, feeling deeply ashamed when they were asked to reveal hair loss or scarring in clinical contexts. Worse still, was the frequency with which health professionals equated the level of visible damage to the level of emotional distress in their patients, often resulting in comments like ‘well you’re not *that* bad’. Because BFRBs are simultaneously visible and invisible, they are not always legitimised through revealing them to others, nor is their severity always measured by levels of visible damage. Instead, BFRBs are recognised through narrative and language, made real through the discovery of a name.

Since the inclusion of trichotillomania in the Diagnostic and Statistical Manual of Mental Disorders (hereafter DSM) psychiatric classifications have struggled to represent BFRBs, and members of the community expressed to me their frustration with the labels provided. At the same time, my interlocutors described feeling reassured by having a medical label, saying that they felt more ‘normal’ as they finally had an explanation for their ‘unusual’ behaviour. This contradicts what Martin (2009) has argued about how a diagnosis of bipolar disorder moves people from ‘rational’ to ‘irrational’, demonstrating that medical labels can have positive connotations as well as negative. For BFRBs, pathological labels are often viewed in a positive light, leading to a reclaiming of diagnostic labels in terms of group identity formation. Of course, labels change over time (Hacking 1995), and so too does the process of finding others with that label. Therefore, labels are not static, unchanging entities nor are they separate from social worlds (Pickersgill 2014).

Despite evidence of hair pulling since the Hippocratic period (Kim 2014), my interlocutors expressed the significance of when BFRBs were officially ‘named’ in the DSM, as moments that validated these behaviours. In my first interview with Hope, a Scottish teacher in her thirties, she said: ‘I grew up in the seventies, when it [trichotillomania] wasn’t even a *thing*’. Researchers working with TLC over the years have aided the movement and improvement of BFRB classifications, successfully lobbying to have skin picking included in the DSM 5 (Stein et al. 2010), and the International Statistical Classification of Disease 11 (Grant and Stein 2014; World Health Organization 2018). BFRBs are a recent example of how a patient community has emerged hand in hand with the labels, with TLC’s founder, Christina Pearson, forming the organisation in 1993, just a few years after trichotillomania was entered in the DSM III-R (American Psychiatric Association 1987). Suggestions made by TLC seemed to influence the classification change that happened in DSM 5 (Stein et al. 2010), moving trichotillomania from ‘impulse-control disorder not elsewhere classified’ into the group of ‘obsessive-compulsive and related disorders’. While the ideal scenario for TLC was to gain full recognition of the term BFRB as its own diagnostic category, the move to OCD was a step in the right direction. In an ongoing effort to reshape the clinical diagnostic categories, TLC now insist on the term ‘body-focused repetitive behavior’, in the hope that it will eventually gain DSM recognition.

When I met Michael in October 2016, he described how he found it difficult to make sense of his own behaviour until he discovered it had a name. Michael experienced the urge to bite and pull hairs from his arms with his teeth. He had always found this combination of biting, pulling and picking confusing, and shameful; being unable to explain it and feeling intensely embarrassed when people witnessed it. He was, in a way, out of place and anomalous. Michael described how he went looking for a Facebook support group and only found groups of women who pulled out their scalp hair. He said, ‘that’s just not me’. Not long before contacting me about my research, Michael discovered the term ‘body-focused repetitive



behaviour'. The new label helped him to feel accepted, he said, 'It was like a family of things, and that included me. That's something I can be a part of, and that feels good'. Perhaps unsurprisingly, the BFRB label was not welcomed by everyone, and during fieldwork I observed some tensions. In 2014, a popular vlogger emphatically rejected the introduction of BFRB on her YouTube channel. The video, entitled 'BFRB Rant' (TrichJournal, YouTube, 2014) complained about 'her disorder' (trichotillomania) being 'lumped together' with skin picking and other BFRBs. In the comments, people with skin picking reacted, saying they welcomed this inclusion due to their historical lack of representation. The opinion that trichotillomania and dermatillomania ought to be separated, was also expressed by a person attending the London support group, who felt that the group should be for hair pullers only. These disputes show how labels can shape people's identities in definitive ways, but they also highlight the tensions between people living with different labels within a biosocial group.

### Diagnostic dead ends

There was a surprising frequency, similarity and vividness of certain narratives I encountered during fieldwork; stories that told me again and again, of the importance of a *name*. The moment of discovering the psychiatric label stood out in the memories of my interlocutors. This revelation was connected to the possibility of relatedness; to discover 'you are not alone':

I googled 'eyelash growth' to find out how long I would have to wait, then I saw the word trichotillomania and Wikipediad it and I remember feeling my heart racing and I suddenly felt really hot and I felt tinglings going down my spine and through my fingers... I realised I wasn't abnormal and that I wasn't alone (Lara, Facebook).

I decided to randomly type 'pulling out eyelashes' into Google and suddenly, hit after hit after hit came up, with the same word, 'trichotillomania'. As I opened each link, the tears rolled down my face. I was crying with such joy, that this *thing* I had done to myself for seventeen years, had a name. I was not alone. (Hope, Facebook).

These examples also show the unexpected-ness of finding other people, where finding the name, to some extent, happened by chance. A few of my interlocutors had discovered the name completely by surprise, stumbling across a newspaper or magazine article. But there was equal shock for those who had typed 'hair pulling' into a search engine and watched it translate into a medical label. Discovering the name opens the door to potential support networks that were previously non-existent, and in line with what Gray (2009) has argued of LGBTQ+ communities, the internet creates added opportunities to find and form networks locally and globally at the same time. After finding the name, BFRB identities emerge through the language of the DSM, bringing the label and the labelled into view through diagnosis. Naming allows people with BFRBs to become visible to one another from online searches, while simultaneously keeping their BFRB hidden in other aspects of life.

Hacking argues that the process of viewing new kinds of people can alter perceptions of those people as individuals (1995, 354) and as we have seen, psychiatric labels can have a positive impact on the sense of self (Rhodes 2010; O'Connor et al. 2018). Before a BFRB diagnosis, the sense of being abnormal reinforces the need for secrecy; and so,

the discovery of a label can alleviate some of these negative feelings. Ironically, the presumed stigma of having the label of a ‘mental disorder’ can actually make people feel less ashamed:

I only discovered that I had trich about a month ago and I was pretty terrified, but so relieved to discover it was what I called a ‘real thing’ rather than something unique that made me disgusting (Olivia, Facebook).

Pulling (starting at age 13) kept me lonely for a very long time. There was no one in my life who understood this thing. I was fifty years old when I found that this actually had a name. It didn’t change the facts, but I knew I was not alone anymore (Marianne, Facebook).

Of course, a BFRB diagnosis can also bring fear and anxiety, as Olivia mentions feeling ‘terrified’, and Marianne says, it still ‘didn’t change the facts’. Diagnosis opens the door to the unknown and brings with it the disappointment of realising that medical labels do not always lead to medical treatment. TLC have helped to progress therapeutic attitudes to BFRBs across the United States, but for my British interlocutors, finding the name rarely led to successful encounters with doctors. Instead, they were often left feeling disappointed with their doctor’s lack of knowledge on the condition:

I found out trich had a name when I was about 15. I was relieved to know I wasn’t alone, but it didn’t really help me in my day-to-day life; I was still bullied at school, I still hated the way I looked and felt, I still couldn’t convince my parents, teachers or doctor to take me seriously (Ruby, Facebook).

When I found out, that it has a name, this moment truly hit me hard. But the moment, when I found out, that there is no guaranteed cure for it – that moment made me... crushed... broken... (Cecile, Facebook).

There is often the expectation that psychiatric labels bring particular kinds of expert care. Rhodes (2010) describes these expectations through the example of an American supermax prisoner with multiple psychological diagnoses, highlighting how a ‘diagnostic dead end’ can bring great frustration and anger. In BFRB experiences, there certainly appeared to be deep disappointment with diagnostic dead ends. Above, Cecile describes feeling ‘broken’ by the realisation that she cannot be cured; for Ruby her diagnosis was somewhat positive, but it did not improve the way people reacted to her hair pulling in everyday life. However, diagnosis is not necessarily a dead end to all kinds of care, as it can lead to valuable care from the biosocial community. Compared to frameworks of medicalisation, the relational aspect of looping effects tells us a great deal about diagnosis, since it is often the process of finding others and forming biosocial connections that makes diagnosis meaningful. In addition, BFRB experiences reveal an irony to medicalisation; that while diagnosis is somewhat dependent on medicalisation to bring people together, it also triggers a necessity to find support beyond the medical sphere. The lack of medical care results in new kinds of people, who must create new forms of care for themselves.

## Biosocial care

When I first met Lou, she was a client at a specialist hair loss salon in London and had been wearing a wig for over a year. We spent time getting to know each other and met frequently



when I was in the city. As time went by, Lou decided to come to the first London support group meeting that I helped to organise in January 2016. Lou was one of fifteen people, and when the time came for her to share her story, she got extremely upset. The group quickly comforted her, offering tissues to dry her tears. The following month, Lou returned to the support group and I was completely amazed to see her without her wig. Her hair was buzzed short, and she looked confident and happy with her new style. Later that year, in October, myself and the support group leader, Dhaya, were running an event in London for BFRB awareness week. We had been sharing updates of the event with the support group members, some of whom came along to join us. Towards the end of the week, Lou emailed me to say she had decided to write an article to help raise awareness. It included a picture of her smiling with her shaved head. In it she wrote:

The thing that has helped me the most has been getting to know other people with BFRBs... it's amazing being able to talk about the frustrations and challenges with people who know exactly what you are going through. I can talk freely about my trich now... I never could have imagined being so open when I was younger, and overcoming the shame associated with this behaviour has been liberating.

The positive experiences of connecting with people who have a shared illness are at the heart of Rabinow (1996) description of biosociality and other scholars' interpretations of it. In the context of HIV disclosure in Tanzania, Marsland (2012) argues that biosociality is not always focused on the body, but instead is formed through the social. But she also argues that forming biosocial groups can occur in less obvious, outward ways. For BFRB networks, biosociality is not defined by public disclosure, and with the help of the internet, sociality can still involve secrecy. Acknowledging public and private forms of biosociality is important, because it reminds us that disclosure is rarely an easy thing to do.

For Rabinow (1996) and Hacking (1995), the processual dynamics of biosociality and looping effects are lacking. The important details of how people find and relate to one another are overlooked, as are the challenges and frustrations involved in these processes. Bridges (2011) has highlighted that not all biosocial groups can coalesce as easily as Rabinow suggests, and points out that people do not always enter these groups willingly. In her ethnography of a New York City hospital, she describes how biosociality brings with it the label of 'high-risk' which has major health implications for pregnant Black women and their children. Similarly, Meleo-Erwin (2020) argues that while shared experiences among post-operative patients of bariatric surgery bring people together, there are also factors that drive people apart and create divisions within their community. Alongside the challenges of disclosure in biosociality, paying attention to the exclusionary or negative aspects of these relations, allows us to see that not all kinds of people involved in the looping effects of labelling become part of a biosocial community. Diagnostic labels can include and exclude different people, and that exclusion from classification can create a sense of not belonging that may cause significant damage to one's sense of self, as we saw earlier with Michael's experience of being left out. Clearly, biosociality is not straightforward and there are multiple factors that influence the formation of a biosocial group. In my attempts to help build the British BFRB community, I encountered some challenges of my own.

In October 2015 I set up the first BFRB support group in Edinburgh, closely followed in January by a London support group which I set up with one of my key informants and friends, Dhaya. From month to month, attendance to these groups fluctuated, but Dhaya

and I were not overly concerned by the low numbers, and we agreed that even if one person turned up the groups would be worth it. As 2016 progressed, I continued with fieldwork, splitting my time between Edinburgh, London and the north of England where some of my interlocutors lived. I began to spend more time in the Manchester area conducting interviews with a few women I was getting to know and visiting a salon in the city for sporadic appointments with clients. In my conversations with these women, I mentioned the support groups, and some of them said they would be keen to attend one if it was closer. After some consideration, I decided to start another group in Manchester. I thought it would be straightforward, since I was regularly in the city anyway. The group started in May and attracted four people, three in June, one person in July and in August no one attended. Feeling defeated, I decided to cancel the group after just a few months. In the work of running these support groups, Dhaya and I encountered numerous challenges, administrative burdens; room hire costs; attendance; balancing expectations; and time management with family commitments. Despite our friendship, the pressure of maintaining these spaces frequently put a strain on our relationship, and we had to keep reminding each other why the groups were worth our efforts.

The support group space is a very particular type of biosocial environment, often framed as harmonious (Martin 2009), and yet support groups remind us that different forms of biosociality require ongoing maintenance and care. Biosociality is fragile, fraught, and is dependent on labour for its ongoing sustainability. However, despite the limits of biosociality, there is an obvious importance of these social networks and the value placed on coming together to share experiences is highlighted in the attempts people make to strengthen biosociality.

### The circle of biosolidarity

Attending the support groups in London, did something powerful for Lou. In these groups, she found people who she could relate to, new kinds of people just like her, that altered her perception of them, and of herself. The impact of these relationships, and her own self-transformation, contributed to her decision to write the article for BFRB awareness week. Importantly, we must acknowledge the enormity of an event like this when compared to the years of secrecy and shame that preceded it. Biosociality was a turning point, a moment that became transformative for Lou, and with that she was inspired to share this experience with others, raising awareness for the community. That is what I mean by biosolidarity.

For many of my interlocutors, biosociality meant connecting with others in ways that preserved secrecy. However, for several people finding out the name and forming social networks inspired them to do something productive. The idea that biosociality can be productive, is put forward by Friedner (2010), who argues that in the Deaf community, productivity is linked specifically to sociality, with diagnosis allowing entry into the Deaf community. Like Friedner, I have shown the clear relationship between diagnosis and biosociality, I also support her argument that the Foucauldian model of biopower (Foucault 1983) does not go far enough to account for these productive forms of community. Power is not unidirectional, but it can operate from below and is influential in the creation of subjects and technologies of care.

This grassroots power and productivity can be seen in the BFRB community, where people decided to re-shape representation for themselves through various acts of advocacy:

promoting BFRBs on social media; writing a blog or a news item; organising an awareness event; fundraising for BFRB organisations; setting up support networks. I understand these to be acts of *biosolidarity*, where the biosocial community works together to change how BFRBs are viewed and understood. Biosolidarity shapes the way BFRBs are seen in the public sphere, and in turn can shape the way people perceive themselves. This visibility subsequently creates more opportunities to connect, and for the community itself to grow and prosper. I have demonstrated elsewhere (Bradley and Ecks 2018) how the low public profile of BFRBs affects family responses to supporting people with trichotillomania. The lack of BFRB attention and accurate representation in the press is mirrored in the limited understanding of health professionals which leads to diagnostic dead ends. Biosolidarity becomes a way to connect labelling, biosociality and care, where people can find the name, find the community and find support.

Our current understanding of biosociality already accounts for patient activism (Parr 2002; Novas 2006; Silverman 2008; Nadesan 2020), and Rabinow himself says biosociality includes patient groups 'lobbying for their disease' (1996, 188). But as this article has demonstrated, biosociality is complex, and the different interpretations, expectations and practices of coming together with shared experiences of illness are deeply nuanced. To say that biosociality as a concept can include forms of patient activism does not do enough to unpack these activist practices, and to some extent suggests that all members of a biosocial group should be able to participate in this action. Developing the new concept of biosolidarity allows us to consider the careful ways that people decide to become involved in activism. It gives us an opportunity to examine the differences between private and public biosociality, acknowledging that stigma plays a key part in disclosure. Following the idea of looping effects, I propose that we think about biosociality and biosolidarity in circularity, and in this way, we can better understand how biosocial relations lead to activism, and how activism leads to biosocial relations.

In comparison to trichotillomania, skin picking has suffered a slow and challenging journey to gain recognition. In relation to diagnosis, it only gained an official psychiatric label in 2013, where it was labelled 'excoriation disorder' (American Psychiatric Association 2013). Despite efforts by TLC, skin picking continues to have a lower profile in the United States in comparison to hair pulling, its recognition in the British context is worse still. However, there is one woman who has worked to increase the visibility of skin picking in extraordinary ways, and her story perfectly symbolises the circle of biosolidarity.

Liz Atkin is an artist who combines her creativity with efforts to share her skin picking story with the world. In the spaces where Liz usually picks her skin (like on the London tube to work), she scribbles drawings on free newspapers, resisting picking by keeping her hands busy, and raises awareness by giving the drawings to strangers, explaining why she draws. Every day Liz gives away about 60 drawings, and very often she meets someone who struggles with skin picking but does not know the behaviour has a name. Through drawing, Liz performs biosolidarity with the BFRB community, extending the opportunities for people to experience biosociality as they discover the name through her. Biosociality and biosolidarity reproduce one other. This 'circle of biosolidarity' was most evident during the 2016 TLC conference in Dallas where Liz had been invited to give the keynote speech. She began:

I've come a long way to be standing in a room of strangers, who have the same understanding of the disorder I've lived with all my life... this quote is really important to me so I'm just gonna read it out: "There is a vitality, a life-force, an energy, a quickening that is translated through you into action. And because there is only one of you in all time, this expression is unique. If you block it, it will never exist through any other medium and it will be lost. The world will not have it. It is not your business to determine how good it is or how valuable or how it compares with other expressions. It is your business to keep it yours clearly and directly and to keep the channel open".

Liz's talk was a powerful overview of how skin picking had dominated her life, and how she managed to turn it around with her art and advocacy. The audience whooped and cheered loudly in response, filling the room with applause. Liz was visibly moved, and clasped her hands to her face, wiping away her tears. When she left the stage, a spontaneous line formed towards Liz, with people queuing patiently to talk to her. She stood for over half an hour talking to each person, hugging them affectionately, many of them in tears as they thanked her for sharing her experience. In the queue that evening was Lauren McKeaney, a first-time attendee to the conference, and a long-term sufferer of skin picking. I had seen Lauren and Liz's interaction in the queue, and I approached Lauren later that evening to talk to her. It was clear that for Lauren, meeting Liz was going to be life-changing.

A few months later, Lauren launched her own non-profit organisation dedicated to skin picking. She called it 'The Picking Me Foundation' and it is the first organisation in the world dedicated to skin picking. Since then, Lauren has travelled across the US to attend mental health conferences, designed care packages for people with skin picking, and worked with clinicians towards improving support for the disorder. The connection between Liz and Lauren is just one example of how biosociality can produce acts of biosolidarity and vice versa. Biosociality and biosolidarity become looping effects: people meet others with shared biosocial experiences, and some are inspired towards acts of biosolidarity. These acts of biosolidarity reach new people who can then become part of the biosocial group, some members of which will go on to advocate – and so the circle continues.

### **Biosolidarity as method**

The process of doing ethnographic research is a deeply subjective experience, as we ask others to share their lives with us. How people respond to this request, is largely influenced by who we are; with our positionality shaping our ability to conduct certain research topics and the direction this research will take. Throughout my research, my positionality both daunted and liberated me. Stating my position as a long-term sufferer of BFRBs provided access to an otherwise very private community and shaped the friendships that I went on to form with my interlocutors. It also felt like a heavy obligation at times, when interviews seemed to turn into counselling sessions, and I realised that many of my interlocutors had no one else to talk to about their problem apart from me.

When my call for research participants was advertised on forums, more people began to contact me directly asking for advice and support. On one occasion, I received a call from a worried mother, who had urgent questions about her four year old daughter who had pulled out most of her hair. She explained that she had spent the last hour calling various mental health helplines. She had tried to reach eight different organisations, and after none

answered her calls, finally she got through to me. We talked for half an hour, and I offered advice about hair pulling tactics for children, pointing her towards TLC and their resources. After the call, I wondered how much information this mother would have been given had she got through to any of those organisations before me. The reality then (and now at the time of writing) is that there are still very few people in the UK who have a deep knowledge about BFRBs, and even fewer who are able to support the many individuals and families struggling with these behaviours on a daily basis. This lack of support was the main reason Dhaya and I chose to set up support groups in the first place, and have continued them to this day (These groups have since moved online during the COVID-19 pandemic, meaning we are now able to serve an even bigger number of people from across the UK who are isolated and in need of support). Being an ‘insider’ meant I was welcomed into the biosocial group without question. Meeting other people ‘just like me’ and hearing their stories inspired me towards acts of biosolidarity as a way of giving something back to them as collaborators. Being able to work closely with my interlocutors to improve BFRB support directly informed my knowledge of biosocial networks. It has shown me the complexities involved in the process of building these relationships, but it has also underscored the power of biosolidarity.

Biosolidarity is at the heart of my efforts as I work with the community to change the way BFRBs, and people living with them, are understood and viewed. Research and writing have an important role to play in assisting communities in this communication and representation. But this work also requires going beyond academic methods and outputs if it is to remain in solidarity with the people with whom we work on the ground. Biosolidarity as a method allows anthropologists to further reflect on the different ways in which we are bound up with our communities, not only through illness, but through our bodies, through relatedness, through our shared embodied experiences in the field. The term highlights the fact that sometimes connecting or relating, to others is not enough, and other practices are required in order for people to be seen and heard. For me, biosolidarity is not only a concept; it is a method of doing research; but it is also a commitment – an ongoing practice that lives on past fieldwork.

## Conclusion

Biosociality and looping effects continue to be useful concepts that help us make sense of how people with experiences of health and illness come together. Combining these theories, alongside the example of body-focused repetitive behaviours, has demonstrated the power that biosocial connections hold in the process of diagnosis, and the transition from isolated suffering to the relief of a shared embodied understanding with others. The experience of finding new kinds of people can positively alter perceptions of the community and the self to create new kinds of care. However, while biosociality has the potential to offer new forms of care through support networks, access to the biosocial community is not always given, and so biosociality can involve feelings of not belonging. Belonging or not, is intimately tied to diagnostic labels, and the frequency with which labels change therefore directly influences the way people find and relate to those who share those labels. Furthermore, this article unpacked the process through which biosocial communities are formed, revealing the challenges and maintenance that is required to shape and sustain biosocial groups. Importantly, biosociality does not have to be obviously social, it can be private and often

allows people to maintain a level of secrecy. As we have seen, for some people biosociality triggers a productive urge to raise awareness on behalf of their biosocial group, and so through acts of biosolidarity the visibility and recognition of a community is increased, so too are the opportunities for others to find and connect with the biosocial group. The circle of biosolidarity keeps the looping effects of biosociality alive through acts of advocacy and everyday activism.

There is much on this topic left unaddressed, and there are issues discussed in this article that may provide a springboard to future conversations within medical anthropology. How might this approach to biosociality and diagnosis further anthropology's understanding of doctor-patient relations, as well as exploring the diverse spaces in which diagnosis occurs? We might also think about the role of families and loved ones in awareness-raising efforts, and the political and economic contexts that increasingly restrict patient advocacy. On biosolidarity, critically reflecting on the issue of privilege is vital, by questioning who is welcomed into a biosocial group, and who is not. When using biosolidarity as a method we ought to consider the politics of representation and the power relations in which anthropologists are bound when they advocate on behalf of communities – even when those communities become their own. What I have done here is the first step in the journey from biosociality to biosolidarity, drawing attention to the efforts involved in finding, forming and reproducing biosocial networks, and offering a new way to critically reflect on our own position in this process.

## Ethical approval

This research was approved by the University of Edinburgh's ethical committee in June 2015.

## Acknowledgements

I would like to thank the people who shared their experiences with me as part of this research. Endless gratitude, love and solidarity go to my fellow BFRB advocates: Dhaya, Liz, Lauren, Jude, Lou and the 'TLC Family'. Thanks to the peer reviewers and colleagues at the University of Edinburgh for their extensive feedback on this manuscript at various stages, especially Stefan Ecks, Alexander Edmonds and Koreen Reece. I am grateful for the funding provided by the University of Edinburgh which supported the fieldwork years of this project, and a grant from the Scottish Funding Council made it possible to complete this manuscript during a pandemic, and provide Open Access.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Funding

The research fieldwork was supported by the University of Edinburgh's School of Social and Political Science Graduate School Scholarship 2015-2017. A grant from the Scottish Funding Council (SFC/AN/08/020) made it possible to complete this manuscript during a pandemic, and also allowed the article to be provided Open Access.



## References

- American Psychiatric Association. 1987. *The Diagnostic and Statistical Manual of Mental Disorders (DSM III-R)*. Revised 3rd ed. Washington, DC: American Psychiatric Association.
- American Psychiatric Association. 2013. *The Diagnostic and Statistical Manual of Mental Disorders (DSM 5)*. 5th ed. Washington, DC: American Psychiatric Association.
- Bradley, B., and S. Ecks. 2018. "Disentangling Family Life and Hair Pulling: Trichotillomania and Relatedness." *Medical Anthropology* 37 (7): 568–581. doi:10.1080/01459740.2018.1476509.
- Bridges, K. 2011. *Reproducing Race: An Ethnography of Pregnancy as a Site of Racialization*. Berkeley: University of California Press.
- Brown, P., M. Lyson, and T. Jenkins. 2011. "From Diagnosis to Social Diagnosis." *Social Science & Medicine* 73 (6): 939–943. doi:10.1016/j.socscimed.2011.05.031.
- Bryman, A. 2012. *Social Research Methods*. 4th ed. Oxford: University Press.
- Burgio, G. R., and F. Locatelli. 2003. "Bioethical Aspects of New Therapeutic Options Involving Haematopoietic Stem Cells (and 'Solidarity' of Donation)." *Blood Transfusion* 3: 202–214.
- Chandler, A. 2016. *Self-Injury, Medicine and Society: Authentic Bodies*. London: Palgrave Macmillan.
- Foucault, M. 1983. *Beyond Structuralism and Hermeneutics*. Chicago: UP.
- Franklin, S. 2001. "Biologization Revisited: Kinship Theory in the Context of the New Biologies." In *Relative Values: Reconfiguring Kinship Studies*, edited by S. Franklin and S. McKinnon, 302–325. Durham, NC: Duke University Press.
- Friedner, M. 2010. "Biopower, Biosociality, and Community Formation: How Biopower is Constitutive of the Deaf Community." *Sign Language Studies* 10 (3): 336–347. doi:10.1353/sls.0.0049.
- Gaughwin, M. 1995. "Poststructuralism and Other 'Species' in Public Health—A 'Darwinian' View." *Australian Journal of Public Health* 19 (4): 430–433. doi:10.1111/j.1753-6405.1995.tb00402.x.
- Gibbon, S., and C. Novas, eds. 2008. *Biosocialities, Genetics and the Social Sciences*. New York: Routledge.
- Grant, J. E., and D. J. Stein. 2014. "Body-Focused Repetitive Behavior Disorders in ICD-11." *Revista Brasileira de Psiquiatria* 36 (suppl 1): 59–64. doi:10.1590/1516-4446-2013-1228.
- Gray, M. L. 2009. *Out in the Country: Youth, Media, and Queer Visibility in Rural America*. New York: University Press.
- Hacking, I. 1995. "The Looping Effects of Human Kinds." In *Causal Cognition: A Multidisciplinary Approach*, edited by D. Sperber, D. Premack, and A. J. Premack, 351–383. Oxford: Oxford University Press.
- Hacking, I. 1998. *Rewriting the Soul: Multiple Personality and the Sciences of Memory*. Princeton, NJ: Princeton University Press.
- Hacking, I. 2006. "Genetics, Biosocial Groups & the Future of Identity." *Daedalus* 135 (4): 81–95.
- Hacking, I. 2007. "Making up People." In *Beyond the Body Proper: Reading the Anthropology of Material Life*, edited by M. Lock and J. Farquhar, 150–163. Durham: Duke University Press.
- Kim, W. B. 2014. "On Trichotillomania and Its Hairy History." *JAMA Dermatology* 150 (11): 1179. doi:10.1001/jamadermatol.2014.2284.
- Marsland, R. 2012. "(Bio)sociality and HIV in Tanzania: Finding a Living to Support a Life." *Medical Anthropology Quarterly* 26 (4): 470–485. doi:10.1111/maq.12002.
- Martin, E. 2009. *Bipolar Expeditions: Mania and Depression in American Culture*. Princeton, NJ: Princeton University Press.
- Meleo-Erwin, Z. C. 2020. "Bariatric Biosociality: Pushed Together, Pulled Apart." *SAGE Open* 10 (1): 215824401989906–215824401989914. doi:10.1177/2158244019899060.
- Nadesan, M. H. 2020. "Autistic Ontologies and the Open Genome." In *Autism 360°*, edited by U. Das, N. Papanephoytou, and T. El-Kour, 43–62. Cambridge, MA: Academic Press.
- Novas, C. 2006. "The Political Economy of Hope: Patients' Organizations, Science and Biovalue." *Biosocieties* 1 (3): 289–305. doi:10.1017/S1745855206003024.
- O'Connor, C., I. Kadianaki, K. Maunder, and F. McNicholas. 2018. "How Does Psychiatric Diagnosis Affect Young People's Self-Concept and Social Identity? A Systematic Review and Synthesis of the

- Qualitative Literature.” *Social Science & Medicine* 212: 94–119. doi:10.1016/j.socscimed.2018.07.011.
- Parr, H. 2002. “New Body-Geographies: The Embodied Spaces of Health and Medical Information on the Internet.” *Environment and Planning D: Society and Space* 20 (1): 73–96. doi:10.1068/d41j.
- Penzel, F. 2003. *The Hair Pulling Problem: A Complete Guide to Trichotillomania*. Oxford: University Press
- Pickersgill, M. D. 2014. “Debating DSM-5: Diagnosis and the Sociology of Critique.” *Journal of Medical Ethics* 40 (8): 1–5.
- Rabinow, P. 1996. “Artificiality and Enlightenment: From Sociobiology to Biosociality.” *Politix* 90 (2): 21–46.
- Rapp, R., and F. D. Ginsburg. 2001. “Enabling Disability: Rewriting Kinship, Reimagining Citizenship.” *Public Culture* 13 (3): 533–556. doi:10.1215/08992363-13-3-533.
- Rhodes, L. A. 2010. “Dreaming of Psychiatric Citizenship: A Case Study of Supermax Confinement.” In *A Reader in Medical Anthropology: Theoretical Trajectories, Emergent Realities*, edited by B. J. Good, M. J. Fischer, S. S. Willen, and M. D. Good. Chichester, UK: Wiley Blackwell.
- Rhodes, L. A., C. A. McPhillips-Tangum, C. Markham, and R. Klenk. 1999. “The Power of the Visible: The Meaning of Diagnostic Tests in Chronic Back Pain.” *Social Science & Medicine* 48 (9): 1189–1203. doi:10.1016/S0277-9536(98)00418-3.
- Schaffer, R., K. Kuczynski, and D. Skinner. 2008. “Producing Genetic Knowledge and Citizenship through the Internet: Mothers, Pediatric Genetics, and Cybermedicine.” *Sociology of Health & Illness* 30 (1): 145–159. doi:10.1111/j.1467-9566.2007.01042.x.
- Seeberg, J., L. Meinert, and A. Roepstorff, eds. 2020. *Biosocial Worlds: Anthropology of Health Environments beyond Determinism*. UCL Press London.
- Silverman, C. 2008. “Brains, Pedigrees, and Promises: Lessons from the Politics of Autism Genetics.” In *Biosocialities, Genetics and the Social Sciences*, edited by S. Gibbon and C. Novas, 48–65. London: Routledge.
- Stein, D. J., J. E. Grant, M. E. Franklin, N. Keuthen, C. Lochner, H. S. Singer, and D. W. Woods. 2010. “Trichotillomania (Hair Pulling Disorder), Skin Picking Disorder, and Stereotypic Movement Disorder: Toward DSM-V.” *Depression and Anxiety* 27 (6): 611–626. doi:10.1002/da.20700.
- Tiktin, M. 2006. “Where Ethics and Politics Meet: The Violence of Humanitarianism in France.” *American Ethnologist* 33 (1): 33–49.
- TrichJournal. 2014. “Trich Awareness Week/BFRB Rant” [YouTube]. 28 September. Accessed February 2019. <https://www.youtube.com/watch?v=3Zzlt1BM1Js>
- Tucker, B. T., D. W. Woods, C. A. Flessner, S. A. Franklin, and M. E. Franklin. 2011. “The Skin Picking Impact Project: Phenomenology, Interference, and Treatment Utilization of Pathological Skin Picking in a Population-Based Sample.” *Journal of Anxiety Disorders* 25 (1): 88–95. doi:10.1016/j.janxdis.2010.08.007.
- Weingarden, H., and K. D. Renshaw. 2015. “Shame in the Obsessive Compulsive Related Disorders: A Conceptual Review.” *Journal of Affective Disorders* 171: 74–84. doi:10.1016/j.jad.2014.09.010.
- Woods, D. W., C. A. Flessner, M. E. Franklin, N. J. Keuthen, R. D. Goodwin, D. J. Stein, and M. R. Walther. 2006. “The Trichotillomania Impact Project (TIP): Exploring Phenomenology, Functional Impairment, and Treatment Utilization.” *The Journal of Clinical Psychiatry* 67 (12): 1877–1888. doi:10.4088/jcp.v67n1207.
- World Health Organization. 2018. *International Statistical Classification of Diseases and Related Health Problems*. 11th Revision. Geneva: World Health Organization.