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Exploring the Discourses of Compulsive Hair-Pulling: A Body-Mapping Study

by

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B.Sc., University of Guelph, 2012

THESIS

Submitted to the Faculty of Social Work

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Research Abstract

Compulsive hair-pulling (which is sometimes diagnosed as the OCD-Related Disorder, Body-Focused Repetitive Behaviour, "Trichotillomania") is an understudied experience that has significant social and emotional impacts on the women that it affects. This study focused on the meanings that are derived from the interactions that women with compulsive hair-pulling experience with social discourses surrounding mental illness, physical appearance, and behaviour. Guided by relativist ontology and the co-creation of understanding between researcher and participants, this qualitative exploration was guided by anti-oppressive practice and used an arts-based research method called Body-Map Storytelling. In group format, four women were invited to describe their knowledge, experiences, and journey visually on a life-sized tracing of their own body over five consecutive weekly sessions. The end result of these sessions was a life-sized depiction of each person's visual telling of their story, which had been co-created within the context of guided facilitation through the sessions. The visual data and the participants' personal narratives of creating the body maps were analyzed thematically. The participants shared contrasting experiences of wanting to be both visible and invisible, feeling whole and fragmented, and building oneself up and breaking oneself down. They shared the impacts of compulsive hair-pulling on the pressure that they feel; from self and others, around self-disclosure, to meet social expectations and how they resist this pressure. Participants shared the impacts of being labelled and how they accept, reject and resist labels. The final theme arising from analysis was that of self-guardianship. These findings add to current knowledge on compulsive hair-pulling, mental illness stigma and visual research methodologies as an example of a study guided by anti-oppressive theory conducted by a researcher who herself shares the identity of compulsive hair-puller with the research participants.

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Chapter One: Introduction

Defining Terms

Compulsive Hair-Pulling (CHP): The behaviour or act of one pulling hair out of their body compulsively. This can be associated with the diagnosis of the Obsessive-Compulsive (OCD)-Related Disorder Trichotillomania.

Compulsive Hair-Puller / Hair-Puller: A person who pulls out their hair compulsively. This term is used, as well as the term Compulsive Hair-Pulling (CHP) in this report to refer to people who pull out their hair compulsively. Please note that all people who pull their hair out compulsively may not refer to themselves as hair-pullers.

Trichotillomania (TTM): An OCD-Related Disorder listed in the Diagnostic and Statistical Manual of the American Psychological Association (5th Edition) (DSM-V). Trichotillomania and Hair-Pulling Disorder are two names for the same diagnosis.

Body-Focused Repetitive Behaviour (BFRB): A general term for a group of related experiences labelled as OCD-Related Disorders by the DSM-V that include (but are not limited to) examples such as Trichotillomania or Hair-Pulling Disorder, Skin-Picking Disorder, and Nail-Biting Disorder.

Introducing the Research Issue

People who pull out their hair compulsively often suffer from feelings of shame and isolation due in part to perceptions that few others share or understand their experience. A search of existing literature on Trichotillomania and compulsive hair-pulling yields generous results in the fields of psychiatry, psychology and health sciences. The majority of this literature employs quantitative methods and adopts a medical lens through which findings are evaluated and applied to the development of treatment options. Comparatively, less literature in the fields of social work or social science is available on this topic. Among these fields of study, qualitative research that centres lived experiences is scarce, even more so among Canadian populations.

Marked shame, embarrassment and isolation are among the many psychosocial issues that individuals living with compulsive hair-pulling face (Casati, 2010) and estimates of its prevalence rates are highly varied. It is generally agreed upon that prevalence rates, estimated to be between 0.6% and 3.4% of the United States population (Canadian data is missing from the literature) may be underestimated due to limited research and knowledge of the disorder and the tendency of individuals to hide their conditions (Dixon, 2016). In addition to there being no known etiology, current research identifies no distinct guidelines for its treatment (Dixon, 2016). In contrast to the modest presence of compulsive hair-pulling on academic and medical radars, and its “silenced” (Dixon, 2016) position, the difficulty often described by individuals living with it is emotionally and socially significant.

In his (2010) book, Bob Mullaly details the contributions of discourse to the operation of power in society. Mullaly cites Leonard’s (1997) explanation that "discourses are linguistic systems of statements through which we speak of ourselves and our social world" (2010, p.123) and highlights that language is not inherently neutral and carries with it sets of assumptions,

curated realities, vested interests and ideological positions. When we see language as part of larger discourses, we may begin to attend to the particularly-constructed versions of reality that are reflected linguistically, and we may also begin to question the organization of knowledge that renders certain pieces invisible (Mullaly, 2010). Mullaly names discourses as a key component of Anti-Oppressive ideology, as they are "delivery systems" (2010, p.115) for the interests of dominant groups which maintain the production of class, race, gender and other inequities. Discourses are carried by language, enacted by all participants of society and move through social worlds in ways carved through legacies of social organization influenced by capitalism, sanism and patriarchy. A discourse is "a framework of thought, meaning and action" (p. 41) in which knowledge, reality or truth is created and maintained through reflecting the rules which decide how language is used and framed (Thompson, 1999 in Mullaly, 2010).

These descriptions create a picture of discourse as insidious and harmful, though this picture is not complete. The idea of a discourse is in itself assists the development of anti-oppressive practice as it brings to light the nature of conflict present in language and the way ourselves and our social world are spoken of. Paying attention to social discourses creates opportunity for invisible assumptions and ideologies to be revealed (Mullaly, 2010).

Development of the Research Question

It's a problem because society tells us it's a problem.

- Anonymous BFRB Support Group Attendee, October 2016

I had seen from my personal experience of living with hair-pulling, attending and facilitating peer support groups and facilitating information workshops for clinicians that much of the difficulty of living with compulsive hair-pulling (and other BFRBs) is manifested at the level of interpersonal encounters. For example, a well-intentioned family physician prescribed a

swimming cap to one of my hair-pulling peers, to assist them in reducing the amount of hair they pulled out while they were in bed at night. I am asked relatively regularly by strangers whether I have cancer. Difficult interactions also occur intra-personally, with ourselves. The topics of shame, helplessness, worthlessness and guilt are regularly explored in the support group that I facilitate. I first envisioned an exploration of the specific labelling of compulsive hair-pulling as a ‘problem’ after reading Melissa Marie Dixon’s 2016 PhD dissertation. She asked what the effect on hair-pullers might be of others’ conceptualizing of hair-pulling behaviour as a problem, after noting this as a consistent theme among her study’s participants. The naming of their behaviour as a problem was often accompanied by “the message that something was wrong with the hair-puller” (p.116) and Dixon connected the problem conceptualization to the need to find (an often-medicalized) solution:

Now, hair pulling was a problem, but for whom? Hair pullers utilized TTM as a means of coping, relief, validation, and for self-care in relationships. When hair pulling was conceptualized as a problem, this led to a type of problem solving that was often entrenched in the medical model (p.170).

Dixon (2016) presented a strong case for the investigation of others’ conceptualizations of hair-pulling behaviour, especially considering that the idea that hair-pulling is ‘wrong’ often originates outside of the person pulling out their hair. I was drawn to this concept, admittedly, because the concept of highlighting this source of stigma felt like a way to solve a piece of the difficulty that I had experienced as part of the community. I decided to expand the scope of this study to inquire regarding all social discourses that hair-pullers themselves perceive to experience, to avoid the potentially reductive dichotomy of ‘problem’ and ‘solution’.

This study aims to centre the voices of people who pull out their hair and the meanings they derive from their interactions with what the world around them has to say about their hair-pulling by asking: What are the meanings that people with compulsive hair-pulling derive from their experiences with social discourses around mental illness, physical appearance and behaviour?

This development of the research question was guided by three themes. These are:

1. Discourse and Self

How do people with compulsive hair-pulling see themselves as affected by social discourses surrounding their status as people with CHP?

What effects of stigma on their lives, sense of self and personhood do individuals with CHP themselves perceive?

2. Discourse and Others

What perceptions do people with CHP have of how they are regarded by others and by themselves?

What social messages do people with CHP receive from others and what meanings do they draw from these messages?

3. Changing the Discourse

What recommendations may individuals with CHP have for social change with regard to their experience?

Guiding Epistemological Perspective

The constructivist worldview, guided by Anti-Oppressive Practice (AOP) and supported by literature on Labelling Theory, will inform the epistemological orientation of this inquiry.

The study's foci are to develop deeper understanding of certain individual meaning and the stories behind their development. This is a key tenet of social constructivist belief (Creswell, 2014) which accommodates the needs of the study's qualitative design in multiple ways. Firstly, constructivism attends my own position as researcher sharing the experience of compulsive hair-pulling with the research participants. This allows for the integration of personal values into the study framework and interpretation of results (Creswell, 2014). Secondly, constructivism supports collaborative co-created data (Creswell, 2014). An especially important issue when practicing AOP as a method is to attend to power differential between researcher and participants. Thirdly, constructivist knowledge claims take into account the context of participants (Creswell, 2014), which is a key component of AOP's acknowledgment of societal processes that contribute to individual experiences of oppression (Mullaly, 2010). Through the constructivist lens, the proposed study aims to further develop understandings of the ways in which individuals and society mutually shape each other with respect to the knowledge that oppression is experienced differently by different people (Mullaly, 2010). This research, as seen through the constructivist worldview, is rooted in the acceptance of multiple truths (representing relativist ontology) and the co-creation of understanding between researcher and participants (representing subjectivist epistemology) (Mayan, 2009).

Chapter Two: Review of Literature

The Current State of Literature

What is revealed in research literature regarding what the (North American) social world has to say about people who pull out their hair compulsively? To support a thorough understanding of this study's research objective, literature searches on the topics of appearance, behaviour, stigma, hair loss, hair-pulling, and Trichotillomania were completed using the search database ProQuest.

The characteristics of the returns in these searches demonstrate that the topic of social discourse is under-studied in the fields of social stigma and compulsive hair-pulling research. The search criteria "hair loss", "appearance" and "stigma" yielded numerous sources investigating the experiences of women with genetic alopecia, an auto-immune disorder characterized by hair loss resulting from the body's immune system compromising hair production by hair follicles on the body (Dua, 2011), or alopecia resulting from chemotherapy treatment. The topic of compulsive hair-pulling does not fit itself well into one category of stigmatization. The "dual stigma" (Kelley, 2005) of both violating mental health norms and appearance norms blurs any clear construction of "appearance" and "behaviour" as was tasked in this study's research objective. In the case of compulsive hair-pulling, physical appearance *is caused by* behaviour. Literature investigating norms and stigmatization of intersecting appearance and behaviour is populated mainly by research exploring intellectual disability (Rasdale, Warman & Phalen, 2018; Scior, Connolly & Williams, 2013) and mental illnesses with 'visible' symptoms (Brohan et al, 2012; Penn, Kohlmaier & Colligan, 2000; Rusch, 2014; Scior et al (2013); Shilling, 2003). Marcks, Woods and Ridosko's (2005) work is the only study with the objective of exploring stigma as experienced by people who pull out their hair.

Research on compulsive hair-pulling and Trichotillomania clearly agrees upon the psychological and emotional difficulties that hair-pullers experience. Minimally present in the literature, however, is focused attention paid to the sources of these difficulties which may be located in society, *beyond* the individual. Gaps in research knowledge do not invite a solid base for understanding the topic of study. As such, the following review of literature draws from various sources to cultivate a closer understanding. Adopting an Anti-Oppressive perspective in the field of mental health includes rejecting individualistic reasoning, challenging current cultures of the moralization of social problems and attending to the avoidance of reproducing inequality of treatment representative of larger society that oppresses people with mental illness (Mullaly, 2010). The present review will refer consistently to Anti-Oppressive Practice (AOP) and will evaluate current literature through this lens.

The literature review is composed of three sections. Section One contains literature investigating social norms of appearance focused on women and hair. Section Two contains literature exploring social norms of behavior focused on people's actions and the connections of behaviour to mental illness. Section Three explores the work of researchers who have investigated stigma and mental illness, with a specific focus on Trichotillomania.

Section One: Physical Appearance: The Way We Look

The basic visual presence (or absence) of a physiological trait, hair, may be ascribed multiple values when observed and considered. Missing hair is much more than just that, and we, as participants in society, are tasked with considering "what is natural about a body" and "what a body is" (Shilling, 2003, p.185). This is especially true if the body that is missing hair is a woman's body. Multiple authors make statements in their work about the status of women who are experiencing loss of their hair. For example, "We do not live in a society where women's hair

loss is socially acceptable" (Dua, 2011, p.14); "Women are more likely to be encouraged to cover hair loss after chemotherapy than men" (Hilton et al, 2008, p.579) and "In our culture, women's hair is used as an indicator of personality, attractiveness, sexuality and femininity." (Münstedt, Manthey, Sachsse & Vahrson, 1997, p.140). Buchanan (2016) cited a primary difficulty for women with alopecia being the societal views of bald women, that, "...societally, bald women are viewed as less attractive and/or appealing as a prospective mate" (p.15). A grim and unfortunate reality is presented for women who live with hair loss. A 2010 study by Trüeb et al found that 47% of female cancer patients consider hair loss to be the most traumatic aspect of chemotherapy (in Zannini, 2012). People who pull out their hair cite negative self-image as a particularly difficult aspect of living with their disorder (Casati, Toner & Yu, 2000). In a 2000 study by Townsley-Stemberger, Thomas, Mansueto & Carter, 87% of those with the disorder reported feeling unattractive.

Although these authors are citing societal and cultural reasons for their findings that women with hair loss experience psychological difficulty (Tucker, 2009), focused exploration into these reasons, including their mechanisms, operations and connections to power and oppression are scarcely offered, if present at all. The burden of managing the impacts of hair loss continues to rest solely on the women who experience it because, seemingly, although they cannot control it, they are left to negotiate with it. This calls into focus the notion of bodily control and societal stigma when considering the relative absence of compulsive hair-pulling in hair loss literature. Synnot's 1981 article discusses "negative attitudes to baldness" (p.23) in society, detailing the symbolic nature of, for example, a monk's tonsure (a hairstyle in which the crown of the head is shaved) as a rejection of the values of the popular social world. The significant difference between Synnot's monk's tonsure as a rejection of societal values, and a

compulsive hair-puller's bald crown is that the monk's hair is intended to be this way. Yet, there exists the lingering assumption that a person with hair loss or some variation of baldness is intentionally rejecting society. Synnot (1981) continued to state that perhaps, the appearance of baldness inspires a "reciprocal rejection" (p.23) in that both the bald person and the social world find themselves at odds with each other.

Priya Dua's (2011) PhD dissertation investigated the experiences of women with temporary hair loss, alopecia and thinning hair. The experiences of women who lose hair because they pull it out was not included in the author's definition of "hair loss". This finding represents a pattern existing among hair loss literature, that the qualitative exploration of loss of hair due to genetic factors such as alopecia, or environmental factors such as chemotherapy appears to be attended to more commonly than hair loss due to Body-Focused Repetitive Behaviours. Due to the behavioural connection in the case of compulsive hair-pulling, could social stigma be operating in such a way that subtly shifts the cause of the hair loss further into the norm of being the 'fault' of women who pull their hair out? Could this shift result in the partitioning of hair loss research into 'physical' and 'mental' causes? These questions are the small beginnings of an inquiry beyond the scope of the current review. They do provide generous direction, however, to the exploration of social discourses that impact the creation and maintenance of knowledge and ideology surrounding how people appear and how they are regarded in the literature.

Differing – or deviating – from norms judged to be acceptable in the realms of appearance and hair, and how these presentations interact with experiences of stigmatization is a key aspect of this review. Münstedt et al claimed that the “The presence or absence of hair allows other people to judge a person differently.” (1997, p.140), conceptualizing a person's appearance, or their deviation from certain accepted norms of appearance, as an invitation for others to be

allowed to form judgements. In a departure from investigations of hair loss, though not from investigations of 'deviant' hair, I would like to discuss the 1997 work of Heckert and Best who conducted interviews with redheads to explore their experiences of stigmatization using symbolic interactionist theory. The concept of deviance and how it is approached by Labelling Theory is featured heavily in their work. In their discussion of attractiveness, the relative nature of what is considered attractive was presented at forefront.

What is physical attractiveness? Who are the physically attractive? Perhaps, as in the case of art (Gillespie and Perry, 1973 p.49) the crucial aspect of these questions is the meaning a public attaches to the definition of attractiveness since there can be no conclusive or satisfactory response (p.4).

In this reading, it could be said that a norm of attractiveness is that *there is no norm of attractiveness*. And yet, the ongoing difficulty that women with hair loss experience due to social constructions of deviance carried by stigmatization continues.

Goffman (1963) defined stigma as "an attribute that is deeply discrediting" (p.3) to the individual, based on the connections between such attributes and the stereotypes that accompany those attributes." What is discrediting about the attribute of hair loss in the case of compulsive hair-pulling? In which ways are people who compulsively pull their hair out discredited? He outlined three major types of stigma: bodily disfigurements, "blemishes of individual character" (including concrete examples such as addiction or mental disorder), and "group affiliation" (including racial, national and religious origin) (1964, p.4). This returns us to the aforementioned "dual stigma" of body-focused repetitive behaviours - violation of norms of both mental health and physical appearance (Kelley, 2005).

Synnot's statement in 1981 that “hair is a physiological phenomenon but, it is also a social one” (p.31) continues to endure 37 years later. This is further rendered in the idea that “the body physical and the body social are symbolically one” (p.31). It is puzzling to see a pattern in the literature, then, that supports the separation of physical and mental causes for loss of hair when considering the impacts that this appearance has on the women who live with it. Women's hair is a site of particular social significance. This is highlighted when hair appears different than is expected by social norms of attractiveness, bodily control and health. These norms are impactful for women who experience hair loss, and particularly so for women who pull out their hair because the circumstances of the hair loss carry certain signatures of deviance.

Section Two: Behaviour: The Reason for the Way We Look

Behavior and appearance are inherently inter-related and teasing out a black-and-white picture of either without the influence of the other is not possible. The task of exploring social discourses around appearance and behavior is made complicated by the nature of the experience of compulsive hair-pulling, which may render a person appearing as deviant from both appearance and behavior norms. A key aspect of mental health stigma is the visibility of a stigmatized attribute. This visibility, discussed by Brohan et al (2012), factors into how the attribute contributes to a person's social identity. In their investigation of people's disclosure of mental illness in the workplace, Brohan et al. discussed how the “relative concealability of mental health problems means that these differences are often unobservable” (p.2) and as such, people with these difficulties have some choice in whether to make their mental illness known.

Concealability of appearance and behaviour in compulsive hair-pulling is well-covered topic in BFRB literature. Many people with BFRBs feel they must hide their appearance, and that they have no choice but to attempt to appear (physically and appear to behave) within

accepted norms (Kelley, 2005). Participants across studies exploring experiences of TTM (Casati 2010; Dixon, 2016; Kelley, 2005) share their concealment strategies. For example, concealing physical appearance with hair pieces, head coverings, makeup or hair styling as well as concealing the cause of the hair loss, through explanations that it is due to medical conditions such as thyroid dysfunction, alopecia or cancer which they may not actually have (Casati, 2010; Dixon, 2016; Kelley, 2005;). In the past I, too, as a person who pulls out her hair compulsively have employed every aforementioned concealment technique to account for my hair loss. At a hairstyling appointment I blamed a bald spot on having given a piggy-back ride to a child who tugged too hard on my ponytail. This is a form of impression or identity management, as explored by Kelley (2005) which is a way that people manage their self-presentation. Another aspect of identity management is “preventative telling” (Link et al., 1989) wherein a person with a stigmatized condition controls information which could influence others’ perceptions of them by disclosing their condition. People with TTM shared in two studies that disclosing their condition increased feelings of self-worth and contributed to educating others; however, these disclosures resulted in increased negative social perceptions by peers (Casati, Toner & Yu, 2000; Marcks et al, 2005). A clue toward the appearance-behaviour stigma connection could be found in the subject of attributions. Panek and Jüngers found in their US-based 2008 study that intellectual disability due to genetic causes was perceived most positively, and disability resulting from a person's actions (the example they gave was brain damage caused by drinking cleaning fluid as a child) was perceived the most negatively. Their study (and no studies to date), as cited by Scior et al (2013), did not explore further into the impact of labelling on people's causal beliefs. These findings suggest that stigmatization increases when a difference can be attributed to a person's actions.

Compulsive hair-pullers often increase their social distance from others through avoidance behaviours - avoiding allowing their hair to be seen, avoiding situations where their concealment may be compromised, avoiding physical closeness, and avoiding sharing their experience (Marcks et al, 2005). Marcks et al. offer that: “More than 20% of people with TTM qualify for a diagnosis of body dysmorphic disorder and nearly 80% have concerns about their body image” (2005, p.300). However, the authors do not provide an explanation as to why this statistic could be, beyond individual psychological difficulty or where this altered self-perception's roots originate from. Boudjouk, Woods, Miltenberger & Long (2000) state that: "Persons with TTM are viewed as less socially acceptable than those without the disorder" (p.34). Perhaps a link between norms of behaviour, appearance and self-image lies in the concept of self-stigma, meaning that "individuals agree with public stereotypes and internalize them, leading to low self-esteem and demoralization" (Rusch, 2014, p.1). A participant quote in Kelley's (2005) study illustrates the complex connection between low self-esteem (self-stigma), what others think (public stigma) and behavior:

So it's almost like you have two sets of problems—one that you're making yourself look bad, so there's that, and two, the fact that you're doing it to yourself, so I think there's a certain—where people think, 'Oh my god, what is wrong with her?' (p.1)

Paying attention to the attributions that this participant makes of their behaviour shows that their understanding of the “problems” leads them to conclude that they are the cause of “what’s wrong” with them. The visibility (and resulting impact) of hair loss as a stigmatized attribute is often modulated by how concealed the attribute is. Concealability of both the hair loss and the reason for it feature heavily in discussions of social and self-perception in studies of compulsive

hair-pulling. Public and self-perceptions may lead to causal judgements of compulsive hair pulling, intensified by attributions that hair pulling behaviour renders people at 'fault' for their difference.

Section Three: Mental Illness: Stigmatization and Labeling

Link and Phelan (2001) explore conceptual variations of the definition of stigma that have surfaced since Erving Goffman's (1961) seminal book and propose a foundational concept which is often referenced in sociological research. Their inquiry acknowledges two aspects of stigma research that have informed the direction, design and implementation of my work. The first being that the majority of researchers in the area of stigma have not experienced it in the way the people in their studies do, further reinforcing the need for research conducted by in-group members. Secondly, they identify that most research focuses on the individual experiences of stigma, pointing towards a need for research exploring the social and economic sources of such experiences. Link and Phelan (2001) make reference to the effect of discourse on the separations of "us" from "them" on directing action and influencing understandings of illness, for example. The attribution of socially constructed differences to individuals versus society informs prejudice and discrimination (Link and Phelan, 2001). The outcomes of this discrimination include marginalization of individuals deemed guilty of 'being different' or 'having a problem'. Arboleda-Florez (2012) links stigmatizing discourse with power, noting that the presence of power generates the process of stigmatization and the creation of social inequities. The element of power comes into sharp focus for people who pull out their hair when they seek support from health practitioners and when they encounter academic or research knowledge about them that reflects dominant knowledges and discourses which may not represent their experiences.

Many people with TTM report that their first experience having their behaviour labelled as a problem occurred during interactions with health professionals (Dixon, 2016). Corrigan's (2002, 2012) investigations into the concept of "self-stigma" directly references the subscription of the general public (including mental health professionals) to stereotypes regarding mental illness, termed as "public stigma" (Corrigan, 2002). The previously-mentioned 'dual stigma' concept as explored by Kelley (2015) is reflected in the examination of the phenomenon of greater public disapproval of psychiatric disabilities in comparison to related physical illnesses.

Dixon (2016) identifies a notable lack of qualitative research on the subject of Trichotillomania and her PhD dissertation is the only study that includes people's own conceptualizations and meanings of their experience. This study, using a constructivist approach and grounded, narrative method, proposed the novel area of investigation of whether the labeling of TTM as a 'problem' affects peoples' conceptualizations of their behaviour. Casati et al (2000) conducted mixed-methods and narrative (2010) inquiry into the psychosocial impacts of living with TTM in the fields of psychiatry and counseling psychology, respectively. While attending to the meanings that individuals draw from their experiences, her two studies are not in alignment with an Anti-Oppressive approach overall. This is due primarily to examples of oppressive, individualistic language in the discussion of findings and failing to link individual experiences of oppression to greater societal systems. Examples of this language include the author choosing the interview question "when was the last time you had a normal relationship with your hair?" (Casati, 2010, p.52). The choice of the word "normal" reflects dominant societal norms of normality and abnormality and ignores the individual's own concept of this experience. Hersperger (2012) employed a mixed-methods approach in the field of psychology, incorporating both descriptive statistics analysis and grounded theory to investigate individuals'

own elaborations of the psychosocial impact of living with TTM. This study is one of two within this review which recruited individuals based on their self-description of living with hair pulling behaviour as opposed to Casati et al (2000), Casati (2010) and Dixon (2016) which required a formal diagnosis of TTM according to the DSM-IV to be eligible.

Hersperger's (2012) inquiry, though anti-oppressive in its recruitment, demonstrated oppressive ideology similarly to Casati (2010) and Casati et al (2000) by holding interviews exclusively on the phone on the basis of assuming that individuals with TTM would be too ashamed to meet the interviewer in person. This decision draws power away from the participants by removing their choice, and is based on prejudicial attitudes which ascribe the association of shame by some people with TTM to the entire participant pool. Anti-oppressive research aims to clearly address power differentials between researchers and participants by recognizing that participants hold expertise in their experience, which was not demonstrated in this study.

Kelley's (2015) sociological inquiry adopted a grounded theory approach and possesses a unique angle of engagement as the author self-identifies as living with TTM. She incorporated significant self-reflexive analysis in her inquiry and set a positive example for the field as a novel exploration of the hair pulling community by an in-group member. Kelley (2015) identifies the interconnections between stigma, labeling and TTM and refers to the experience of dual stigmatization people with TTM experience; that of mental illness, and that of not appearing a certain way.

Corrigan's (2002, 2012) research examined people's belief of their inherent value and how it is affected by prejudice related to mental illness. In recognizing that stigma is intimately connected with the labels placed upon persons of 'difference', Thoits (2012) employed a

quantitative approach to investigate people's own experience of acceptance, rejection or deflection of the label of 'mentally ill' and investigated deflection as a method of coping with stigma. Their findings show higher positive affect and lower psychological distress among individuals who believed that they were not mentally ill and deflected this label (Thoits, 2012). Thoits' analyses spotlight the effects of labels on individuals' self-perceptions and connect these findings to the experience of stigma; however, these analyses fail to account for societal oppression among factors contributing to stigmatization of individuals. Since Goffman's (1961) work, research into understandings of stigma and its linkages to discrimination, marginalization and prejudice has included investigations of power (Arboleda-Florez, 2012), discourse (Link and Phelan, 2001) and self-stigma (Corrigan, 2002). Stigma is named in research studies on Trichotillomania (Casati, 2010; Dixon, 2016, Hersperger, 2012), yet is only the research focus itself in one piece of work (Kelley, 2005).

Scior et al (2013) note that terms "mark" or "attribute" are associated with early definitions of stigma. These words centre on the individual on the receiving-end of stigmatization (Coffman, 1963). Link and Phelan's (2001) deliberate shift to the term "label" was a linguistic move that spotlights those doing the labelling. Only certain differences have sufficient saliency to warrant a label, and saliency changes over time. Scior et al also note that not all differences are salient enough to warrant a label, and this saliency is not static (2013). Thomas Scheff (1999) proposed that labeling theory, developed in 1966, is a counter-discourse to dominant medical biopsychological models. Building upon this theory and examining Modified Labeling Theory, Link's (1987, 1989) work details the impact of "officially labeling" people with mental illness through contact with mental health professionals, and its connections to lowered self-concept (1987). Wright (2011) investigated the link between the use of

psychiatric terms to label mental health problems in young people and its resulting effects on stigmatization and clearly defined the need to distinguish between the effects of labels on the individual versus on the mental health issue being examined. Wright notes the level of complexity of stigma as a contributor to lack of consensus among scholars in this area regarding the effects of labeling (2011). Although it was the first study to examine labeling and stigma of mental illness, importantly, Wright's (2011) inquiry used quantitative methods, leaving out the opportunity to capture rich narratives of the individuals on the receiving-end of stigmatization.

A theme among existing literature on compulsive hair pulling is the lack of research which centres and explores what peoples' experience means to them, pays attention to the effect of discourse, and makes connections between mental illness stigma and labelling. These gaps have informed the development of my research study. I began my approach to this work as a hair-puller who felt that most of the literature on this subject did not reflect my personal meanings around my experiences. Through reviewing extant literature through an Anti-Oppressive lens, the need was reinforced further to conduct research from this perspective to avoid repeating oppressive societal norms, to de-centre the individual from being morally responsible for their own illness and to reject attributing the results of societal oppression to the individual (Mullaly, 2010). The subject of labeling is especially pertinent when considering the entrenchment of this practice among medical practitioners, family and society, who often push individuals to stop their behaviour even in the paradoxical reality that no true 'cure' exists. Hair (and the circumstances surrounding its presence on women's heads) has been described as a site of social significance, where broad norms surrounding behaviour and appearance intersect. Ideas of belonging, deviance and difference are further realized within the context that compulsive hair-pulling is incontrollable, without definite 'cure', and is categorized as a mental illness. When

I originally sought out to design a study investigating the social dimensions of compulsive hair-pulling, I was drawn to the simple idea that by defining this experience as a 'problem', this experience then became a 'problem'. The literature clearly provides complexity and depth to the subject. To search for a singular spot to land upon and name as the 'problem', would be to reduce this multi-dimensional exploration. As such, an approach that honours difference, offers flexibility of meaning and is in line with Anti-Oppressive ideology is well suited to support the investigation of this research topic.

Chapter Three: Methodology

Arts-Based Research Methods

The objective of this study was to investigate the meanings that women with experience of compulsive hair-pulling have of their interactions with social discourses around appearance, behaviour and mental illness. I set out to answer this question by using a data collection method called Body-Map Storytelling (BSMT). Four women participants attended five consecutive weekly group sessions in Toronto which were facilitated by me and a co-facilitator. These sessions occurred from October 16th to November 13th 2017.

The decision to use the arts-based method Body-Map Storytelling came about in conversation with mentors during the early stages of designing the present study. The desire to do research *with* the participants, whom I share the identity of compulsive hair-puller with, strongly encouraged me to explore methodologies that: went beyond conversation in interview format, would offer a unique experience of participating in a group setting, and provide them with a personalized tangible product of their work. Beyond these aspects, arts-based research (ABR) offers an outlet for expression of meaning beyond words alone by combining verbal and non-verbal communication interactions. In his 2004 book, Graeme Sullivan offers four tenets of conceptualizing art practice as research, two of which are presented below, which I interpret as poising ABR as aligned with principles of anti-oppressive practice.

Firstly, “Visual arts knowledge is transformative” (Sullivan, 2004, p.41). The social nature of meaning-making in interpretation of visual information renders this knowledge as inherently mutable, always changing and constantly negotiated between artist and viewer (Sullivan, 2004). This seats visual data firmly within an anti-oppressive position of creating dialogue and engaging with multiplicity of encounters and representations of experiences as

discussed by Barone and Eisner, 1997 (as cited in Sullivan, 2004). In Sandra Weber (2008) asserted that “images can be more accessible than most forms of academic discourse” (p.46), that they “can be used to capture the hard-to-put-into-words” (p.44) and that they “encourage embodied knowledge” (p.46). Anti-oppressive practice is concerned with the distribution of power in research relationships, including the relationships between researcher-participant, artist-viewer as well as the ways that the researcher disseminates knowledge. The translation of knowledge in research is also a site where power dynamics may operate. The arts as a non-traditional means of academic knowledge translation may result in the findings more effectively reaching the community and intended audience, those who may benefit most from the research (Fraser & al Sayah, 2011). Visual data generation in arts-based research reduces disparities in power distribution across these relationships due to its collaborative and accessible nature. Pelander et al (2007) share that research participants in arts-based projects have increased control over the production of knowledge and may experience the benefits of creative art creation that supports identification of feelings which may not be easily accessed verbally (as cited in Fraser & al Sayah, 2011). Boydell (2012) notes therapeutic benefits for participants such as accessing deeper emotions, space for reflection, gathering of new insights and experiences of empowerment in addition to building self-esteem, collaboration and creativity. An added benefit of reduced power disparities between researcher and participants is the possibility of increased participant trust in the research process itself and a felt sense of community among participants who engage in group projects (Boydell et al, 2012).

Secondly, “Visual arts knowledge is constructivist” (Sullivan, 2004, p.33). Sullivan sees art as produced through the integration of theory and practice, where the definition of the word ‘meaning’ is not singularly influenced by a single context (2004). Rather, following MacLachlan

and Reid's (1994) stance that the word "context" itself is unsatisfactory due to its tendency to make static the dialectical nature of text-context relations, Sullivan sees meaning-making as "negotiated as interpretations are formed" (p.51). The "realm of shared symbolically-mediated meanings" as described by Parson (1995, in Sullivan, 2004. p.67), locates meaning outside of a specific form, and rather interacting within social discourse and relations. This makes room for intersubjectivity in the research framework, a key design consideration of the current study. I am a researcher who shares experience with the participants related to the research topic. I sought a framework of inquiry that saw my intersubjectivity and interactivity, the way I encounter and represent my experience as a peer, as "assets rather than liabilities" (Sullivan, 2004, p.53). The assets of these dimensions are further carried into the research design and my interpretation of the data through reflexivity and self-critique. In this way, the visual product is seen as more than a static product or item delivering a certain contextualized meaning. It is seen as the starting-off point for the generation and construction of multiple meanings. Sullivan sums this concept up in the statement:

The interpretation of visual data is not so much about trying to describe visual content. Rather, the task of the researcher is to understand how those who make images – artists and other visual communicators – and those who interpret images – construct their meanings as they present them in visual form(p.194).

Van Leeuwen (2001) describes that images such as photographs "[pass] through a number of 'moments' and its passage through each moment contributes to the meanings which it has and may have." (p. 114). This interpretation highlights how images are made, distributed and consumed in a social manner. To Van Leeuwen, analysis of visual images must consider the social history, social life and the ways that images are regarded. These points are echoed by

Weber that “images can make us pay attention to things in new ways”, that they are “likely to be memorable”, that they “can enhance empathetic understanding” (Knowles & Cole, 2008, p.45). These sentiments all carry with them the notion and importance of human engagement and cognitive experiencing of the visual material, of the humanity present in visual communication. My own research into literature on arts-based research and visual analysis has allowed me a greater understanding and appreciation for the capacity of visual data to evoke reaction, response and reflection in viewers. Van Leeuwen (2001) names an important dimension of humanity to consider, our “sensuous, pleasure-seeking interest in looking at and feeling ‘the world’ including the media we have put in it” (p.33).

This heavy leaning on collaborative meaning-making in itself embodies anti-oppressive practice by distributing the responsibility of interpretation among co-creators and acknowledging the presence of multiple interlocking social and discourse-related contexts. Gwyther (2009) characterizes arts-based inquiry as “collaborative, respectful and transformative” (p.110), reflected in its capacity to carry anti-oppressive theory and, more importantly, translate this stance into practice. Researchers and participants are no different from each other in terms of the basic benefits that ABR has to offer. This blurring of lines between ‘researcher’ and ‘researched’ lends to co-creation, participatory inquiry and action toward social justice (Knowles & Cole, 2008).

Body-Map Storytelling

Body-mapping, also known as Body-Map Storytelling, as a current research methodology was first incepted for therapeutic and advocacy work in countries in Africa in the early 2000’s (Solomon, 2008). The Life Long Project, developed by the Aids and Society Research Unit (ASRU) in South Africa during 2001 to 2003, incorporated peoples’ representations of their

bodies artistically in sharing their stories of living with HIV (Wienand, 2006). This project built upon the ASRU's prior work, the Memory Work project and Memory Box project (started in the late 1990's in Uganda and South Africa, respectively) (Solomon, 2008; Weinand, 2006). Body-map storytelling has been used in multiple countries and research contexts, notably in health research such as HIV (MacGregor, 2009; Orchard, Smith, Michelow, Salters & Hogg, 2014; Stevens & Le Roux, 2011; Van de Riet & Hough, 2005), social determinants of health in migration (Davy, Magalhães, Mandich & Galheigo, 2014; Espinoza-Tapia & Segovia, 2015; Gastaldo, Carrasco & Magalhães, 2012; Sweet & Escalante, 2015), chronic illness and pain (Quijano, 2016; Skop, 2015), sexual health (Chenhall, Davison, Fitz, Pearse & Senior, 2013; MacGregor, 2009; Senior, Helmer, Chenhall & Burbank, 2014) and sexuality (Murasaki & Galheigo, 2016).

Jane Solomon created a facilitation guide for body-map storytelling as a therapeutic tool in 2008. Gastaldo, Carrasco and Magalhães (2012) built upon Solomon's facilitation framework to adapt BMST as a one-on-one research method to explore immigration experiences of undocumented migrant workers in Canada. Skop (2016) built upon Gastaldo et al's guide to adapt it as a tool to investigate the healthcare experiences of people with the chronic illness fibromyalgia in a group body mapping setting. Gastaldo (2012), Solomon (2008) and Skop's (2016) facilitation guide resources are the three resources that I referred to when developing my facilitation guide.

The ability of this research methodology to visually depict an embodied experience among social, political and economic axes is a strong draw for a person wanting to do research with a population of people that find themselves in some way on the margins of 'normality'. Gastaldo et al quoted Gaunlett & Holzwarth (2006) in their facilitation guide: "people think

about things differently when making something, using their hands” (pg.11) which stood out to me as a person who compulsively pulls my hair out, using my hands. My years of experience with this behavior and its associated psychological, physical and social impacts have been carved into my body and particularly, my hands. I see the act of holding a pencil, paintbrush or pen, and using hands to tell a story by creating a body map, a work of art, as an emancipatory, liberating and intrinsically freeing departure from the ways that people with mental difficulties are so often requested to give up their knowledge for research.

Empowerment in Research

Body-mapping offers participants who are part of a silenced or marginalized community an experience of empowerment. In this study, participants were offered resources to connect with community and a support network specific to compulsive hair-pulling, which reduces isolation and feeling alone in their experience in addition to connecting with others who also live with compulsive hair-pulling. The potential benefits of participation in this research study outweighed the potential risks through effortful minimization of potential social and psychological harm to participants. By adopting an anti-oppressive approach, this research aimed to avoid reproducing dominant ideologies and discourses, which directly influence participant experiences in the study.

Grant Larson (2008) offers seven principles of anti-oppressive practice in mental health work. Larson’s (2008) principles were each considered in the design and implementation of the research activities with participants and included: “inviting service users to be full participants in all aspects of mental health service” (p. 44); “using language and discourse that is respectful, egalitarian and empowering” (p.45); “actively deconstruct the medical model with service users...” (p.46); “establishing just working relationships” (p.47); “promoting education” (p.49);

“embracing cultural diversity and strengths perspectives” (p.50); and “promoting principles of social justice” (p.51). This study’s intentional incorporation of anti-oppressive considerations prevents inequalities of larger society from being reproduced, rejects the moralization and individualization of social problems, and upholds that the pursuit of professional respect is not gained at others’ expense (Mullaly, 2010) within the context of this research work and the dissemination of its findings.

Developing the Methodology

In this study, body mapping was done in a group format. Designing and planning the sessions to be in group format had both economical and anti-oppressive rationales. For the scale of this project, one five-week period of data collection where all participants gathered together weekly was logistically more feasible than arranging five separate two-hour sessions for each participant to participate in body-mapping one-on-one. Offering women the opportunity to create their body maps with other women who live with compulsive hair-pulling was important to me from personal experience as a hair-pulling researcher who has facilitated peer support groups for BFRBs. This is also echoed in compulsive hair-pulling literature which has found that many people who pull their hair out feel isolated (Marcks et al, 2015). This was the first time that body-mapping was being used with participants who live with compulsive hair-pulling. Ensuring that the content of the body-mapping sessions was focused as much as possible on the needs, interests and concerns of the population was of paramount importance to me. To achieve this, I turned to my role as a peer support leader for the Canadian BFRB Support Network. I founded and facilitate an open-format peer support group for people that live with Body-Focused Repetitive Behaviours in Waterloo-Wellington. I have recorded anonymous meeting minutes of

the group for the four years that it has been running and these minutes are publicly available¹. I read through the entirety of the document to draw out recurring discussions from the meetings that were related to my research questions, and I generated a list of questions that investigated these discussions.

I organized the questions into coherent, overarching themes that formed a narrative that session exercises could be developed with and coupled to. These themes were: internal processes (what people think of their own behaviour), external processes (what people perceive as social attitudes and values of their behaviour), interrelations (how people are impacted by these external attitudes) and moving forward (recommendations for change and goals).

Each theme was then compared to the body-mapping facilitation guides developed by Gastaldo, Skop and Solomon. During this development phase, I met with Dr. Denise Gastaldo and Dr. Michelle Skop to further refine my session plan design, prepare for session facilitation and for mentorship on my own facilitation. The result of this process was a five-session facilitation plan that incorporated the key elements of body-mapping seen in previous literature, with distinctive session elements relevant to the scope and purpose of my study and the interests of my community (Appendix A). Appendix B contains a flowchart visualizing how each session exercise is linked to greater themes, objectives and the research question.

Rooting the session exercises and questions in the themes from the support group was a way for me to ensure that the session content was centered not just on my perspective and interests alone. This step felt crucial to me as a way to honour the curiosity, knowledge and resistance of this community of people with BFRBs that I am a part of. This also increased my confidence in my work, feeling more of a representative of a greater collective of minds rather

¹ https://docs.google.com/document/d/1_wzWfIC0mnTpEBdESMYwPVqVJ9J8-Uw0VP4a74WcZl0/edit?usp=sharing

than a lone researcher "going in" and imposing my desire for inquiry on the subject matter. This step turned "my" journey into "our" journey, symbolically.

In the final stage of developing my facilitation guide, I tested the guide content by creating my own body map. This allowed me to experience each exercise and session first-hand, and to edit the content to account for pacing and practicality. In the first session with the four women, I presented my own body map as an example. Creating and sharing my own map served multiple functions. The most salient function to me was to decrease the power differential between myself and the participants. It was important to me to build trust. I intended to bring my humanity and the 'real me' into the sessions to create true relationship and dialogue in the room and worked toward this by being vulnerable and sharing my story with the group. Another function of sharing my map was to demonstrate what the certain session exercises could look like and how responses to the questions and prompts could be communicated visually. Some of the women had expressed to me that they were not totally confident in their artistic abilities. Showing participants that no particular artistic talent was required functioned to perhaps ease any anxiety about performing to any certain standard artistically. Body-map storytelling is a co-creative and generative data creation process influenced by all who work together (Skop, 2016). Cross-pollination, sharing and reflection of ideas is expected within the group context.

Session Facilitation

Body mapping group sessions occurred weekly over a period of five weeks in October 2017 to November 2017. Each session was two hours long and was facilitated by myself primarily, with a co-facilitator, one of my peers from my Master of Social Work degree cohort, Sarah Erwin. The purpose of co-facilitation was overall to ensure efficient and effective management of the experience for all involved. Sarah was instrumental in ensuring that sessions

began on-time as considerable set-up and take-down was required, in ensuring that participants were supported practically and emotionally in their creation efforts and in aiding data collection through her own field note-taking. Sarah was also available to me in the form of ongoing debriefing which I found very helpful in processing my own emotions and reactions to the content of the sessions. The location of the sessions was The 519 Community Centre, a non-profit, City of Toronto agency located at 519 Church Street in Toronto. The 519 generously donated the space at no cost. Participants were compensated for any travel costs associated with getting to and from the sessions and were each compensated \$50 at the outset of the initial session for participation. Each session was audio-recorded and I transcribed these audio recordings. I used a single audio recorder to capture discussions with individuals and group discussions around, and explanations of, the work going into the body maps. Sarah and I both took detailed field notes. I included self-reflection pre- and post-session, recorded my own observations, reactions and details of nonverbal information throughout each session. Sarah and I compared our field notes weekly. Each week, participants arrived at the session and received the daily session agenda. This agenda laid out the content of the forthcoming session. All people involved participated in a quick pre-brief at the beginning of each body mapping session where I would introduce the content and exercises of the week. This also gave participants time to reflect on their process or to ask questions about the content before starting their creation for the day. High-resolution photographs of the body maps were taken.

Sampling

Purposive and convenience sampling were used to recruit participants. I invited people to participate in the research through the internet. My advertising poster and brief recruitment letter was distributed through the social media pages and website of the Canadian BFRB Support Network (www.canadianBFRB.org). The advertising materials were distributed via email to peer

support group leaders affiliated with the Canadian BFRB Support Network across Ontario. I also used the social media platform Facebook to post my advertising materials on the Facebook groups called "Trichotillomania Hope" and "Trichotillomania Acceptance". Please see Appendix C for the advertising poster. The rationale for recruitment through the internet is seated in the strong presence of online support and education community for people who live with BFRBs. Many people do not openly disclose their experience with compulsive hair-pulling. I am a member of the two Facebook groups which have 3564 members and 1392 members, respectively. Interested people were directed to respond to the contact information posted.

Over a two-month period from August to September 2017, approximately fifteen interested people contacted me. Due to scheduling or geographical limitations, only four people were able to commit to the five in-person sessions of body mapping. The only inclusion criteria required of a person to be involved in this study was that participants were sixteen years of age or older and live with either a self- or professionally-disclosed experience of pulling one's hair out compulsively. A diagnosis of "Trichotillomania" or "compulsive hair-pulling (CHP)" or a "BFRB" was not required. The inclusion criteria is a point of particular salience for me as a researcher upholding principles of Anti-Oppression and as a person who lives with CHP. Due to marked experiences of shame and not wanting to disclose, lack of public knowledge and lack of health professionals' knowledge of this experience, many individuals who pull their hair out compulsively are not diagnosed (Dixon, 2016). Requiring a formal diagnosis would exclude people from lending their voice to this research exploration and would constitute organizational silencing of a community that already is profoundly without voice. The classification of TTM as a diagnosis of mental illness is a point of ongoing controversy (Casati, 2010) and by widening the scope of eligibility criteria, individuals who have not received diagnosis are able to

participate. From an Anti-Opressive standpoint, this widening of eligibility attends to the societal oppression of hair-pullers who are marginalized by a lack of medical and public knowledge which would result in reduced likelihood of their behaviour being formally recognized. I believe it significant to note that two of the research participants in this study had not disclosed their experience to a health professional and had not received diagnoses. I have been deeply impacted by, and am deeply grateful for, the contributions of these women to this research and cannot envision the possibility of this work without them. Study participants Violet and Laura (pseudonyms) were instrumental in this work and their experience is no less valid because a professional has not described it with a diagnosis.

Participants who had confirmed their interest and availability were sent a detailed information letter. Participants still interested then participated in brief screening interviews (see participant screening interview form in Appendix D) during which I gathered brief demographic information and confirmed participant attendance at all five body mapping sessions. During the screening interview, participants were asked to self-disclose their age, gender identity, race and/or ethnicity, and “any other things about you that you think are relevant as a person living with compulsive hair pulling”. The purpose of collecting minimal demographic information in self-report format was to follow an anti-oppressive framework by reducing power differential between myself as the “researcher” and the women as “participants”. Participants were sent the informed consent form (Appendix E) for their review prior to the first session.

Ethical Considerations

Psychological risks associated with participating in the study included the possibility that recalling stories and memories of marginalization and oppression may be distressing for participants. The activity of having one’s body traced, or tracing another’s body, onto the large

sheets of paper may be uncomfortable for some participants. Participants were asked to share their experiences of compulsive hair-pulling in group sessions, which may have been out of the ordinary for those who do not openly disclose or share this information with others.

Participants who did not feel comfortable having their body traced, or tracing another's body onto large sheets could opt to modify this activity to suit their comfort, by tracing one of the co-facilitator's bodies onto their sheet of paper as their representative. One participant chose to draw a generic outline of a body rather than trace themselves or another person. In the final session of body-mapping, participants were invited to alter or remove items from their body maps that they did not want included in their data and re-confirmed their consent for their data and quotes to be used in the research report. Up to one month following the body mapping sessions, participants could discontinue their involvement in the study and their data, personal information and connection to the study would be terminated if they desired.

Including opportunities for debriefing and offering participants connections to community resources for counseling and psychological support mitigated psychological risk associated with participating. If a participant felt that they needed a person to talk with during or immediately after a body-mapping session, both facilitators were trained active listeners available for support.

The Research Participants

Laura is a 34 year-old white woman who does not have a formal diagnosis of Trichotillomania.



Figure 1. Laura's body map.

Kay is a 30 year-old white woman who does not have a formal diagnosis of Trichotillomania.



Figure 2. Kay's body map.

Maggie is a 24 year-old Sri Lankan woman who has a formal diagnosis of Trichotillomania.



Figure 3. Maggie's body map.

All four participants lived in the Greater Toronto Area. In addition to the four participants, the group was facilitated by me, Julia, a 28 year-old white woman formally diagnosed with Trichotillomania and co-facilitated by Sarah, a 30 year-old white woman who does not have experience of compulsive hair-pulling. I include myself and the session co-facilitator Sarah in the context of the participants because in the sessions, all in the room contributed to the generation of data and, due to the public and interpretive space created, all contributed to data analysis and my assessment of the data.

Data Analysis in Visual Methodology

Coding strategy.

I transcribed the audio recordings of each two-hour body mapping session. Upon completion of the body maps, I took high-resolution photographs of the full maps and of details on the maps. I created a set of analysis guidelines using material from Skop (2016) and Braun & Clarke (2006) to guide my analysis.

The analysis guidelines I created consisted of a checklist-style document that was designed to assist me through the stages of data analysis. The document divided the process into five steps from familiarizing myself with the data to defining and evaluating themes. I closely followed Braun and Clarke's (2006) material which included guidance regarding coding process, search strategy for theme generation and criteria for strong thematic analysis.



Figure 5: The author taking high-resolution pictures of the body maps.

Phase one: Familiarizing with the data.

The first phase of my analysis consisted of becoming familiar with the data. In this phase, I visually examined each body map individually and took notes on my reaction to it, possible patterns and emergent ideas and themes. I called this my 'first impression'. I captured the body-level and emotion-level initial impact that viewing each map had on me. I recognize that this was not my first encounter with the map; however, it was the first encounter in a setting that was set up as a space for intentional and analytic viewing. I continued to familiarize myself with the data by reading and re-reading the audio transcripts of the mapping sessions. This assisted me to generate full-bodied and rich conceptualizations of each participant's rendering of their work in as close proximity as possible to their intended meaning by ensuring my visual experience with each map was aided by the artists' narrative descriptions.

Phase two: Organizing the data.

I created tables for each participant which organized the visual and narrative data present in their maps and audio transcripts according to the exercises that were completed in the session (please refer to Appendix F for an example section of Laura’s participant data table). These tables were designed to capture, in text format, all aspects of the data that was created. My decision to organize participant data into table format was guided by the analysis methods of Espinoza-Tapia & Segovia (2015). They first organized data from participant body maps into tables containing narrative, graphic and projective aspects of the data before examining links between these three aspects and used a deductive approach to continue analysis (Gastaldo, Rivas-Quarneti & Magalhães, 2018). To ensure that my understanding of the data, and translation from visual to text data was appropriate and correct, I sent each participant the data table that I had created with their data and gave them an opportunity to provide feedback electronically or in-person. This allowed the artists to confirm that my organization of their work aligned with their intention in creating it, or to correct the organization if needed.

Below is a sample of Kay’s data table showing the way I organized data from a particular body-mapping exercise (Self Portrait: Face) and shows both the graphic data (my verbal description of what I see on the body map) and narrative data (transcribed from the audio recording) associated with that particular body-mapping exercise.

| Exercise | Participant Data | |
|-----------------------------------|---|---|
| | Graphic: Researcher (J.M.) Description of Body Map | Narrative: Transcript Quotes |
| <i>Self Portrait: Face</i> | Eyes covered by scarf (“blindfold”) Writing: “Why don’t you just stop??” over scarf covering eyes Scarf ends flowing away from head over left shoulder One scarf end: red writing: “done, isolated, one, only, unsure, suffocating, suffering, stop, what if, | <u>Blindfold:</u> K: “I’m blind in dealing with this disorder. I’m not knowing what I’m doing” “The blindfold represents good things and bad.” “I feel overwhelmed by thoughts.” “So, um, another thing is I covered my eyes. Mostly because I didn’t want to |

| | | |
|--|--|--|
| | <p>scared, be seen, vulnerable, running, stop, fight or flight, unsure, sad, last, fear”</p> <p>Other scarf end: black writing: “community, love, respect, patience, acceptance, you’re not alone here, my passion, my heart, the love and light in my eye, my people, my gift, to listen and stand up”</p> <p>Mouth: lips closed, neutral</p> | <p>draw eyes (laughs) also because I wanted to be able to show like some type of feeling that I don’t know where to go and I don’t know what to do, and I feel blind and I feel lost. Even before I knew where we were going with this, the biggest thing I’ve heard my entire life is “Why don’t you just stop?” and that is like one of the most frustrating things that I could probably write an entire book about, just those words. So that was like a huge deal, when I feel like, it’s a block.”</p> <p>“So, on my little scarf thingy that covering my eyes, one side is the bad things that I feel or that this hair thing makes me feel. So like, scared, vulnerable, feeling like fight-or-flight, all these bad things. And then I have this other one that’s all the good things. So I feel like, you know, it’s my passion, this Trich has become my life. But in a good way, so everything I do with CBSN is really good. That’s why I feel that what my job sucks the life out of me but CBSN fills up the gaps.”</p> |
|--|--|--|

Including narrative and visual data in this round of coding and treating the extracts as individual pieces of data was an intentional choice. The implication of this choice is that a piece of visual data (for example in Kay's map, the words "why don't you just stop?" written over scarf covering her eyes) and a piece of narrative data from the audio transcript (Kay saying "the biggest thing I've ever heard my entire life is "Why don't you just stop?") are treated as separate items rather than one item. I felt it necessary to treat artists' visual rendering and the way that they speak about it as separate pieces of data. The narrative data's main function is to verify that my interpretation of a visual item is true to the artist's intention. In the later analysis stages when themes began to emerge, separating these types of extracts was helpful as a quote from a participant could be linked thematically to other visual extracts.

The information in the data tables was coded by hand. I used different colours of pencil crayon to define each code, one table at a time to ensure that I remained immersed in each participant's data. I first used themes that Dr. Michelle Skop used as guiding themes in her 2015 study (Skop, 2015). These are: colour, discourse and themes, type of representation, size, repetition and location. I organized the data from each table under of these themes. Organizing the data extracts along this framework allowed for maps to be compared to each other and for me to begin to consider any emergent patterns in the data.

Phase three: Open coding.



Figure 6. Open coding exercise for Laura's body map.

I returned to the body maps and my 'initial impression' (generated during Phase One). I used an open coding strategy to capture any element of the map that was related to the three research themes of the project: Discourse and Self, Discourse and Others and Changing the Discourse (as outlined in Appendix B). Please see Appendix G for an example of a list of open codes generated for Laura's data. I linked any visual data extract with accompanying narrative

data to ensure that my coding of the visual extract was grounded in the artist's intention for that item. I then wrote a descriptive statement incorporating visual elements with artist intention for each element of the map that was captured in the open coding. An example of this process is depicted below:

Visual Data:

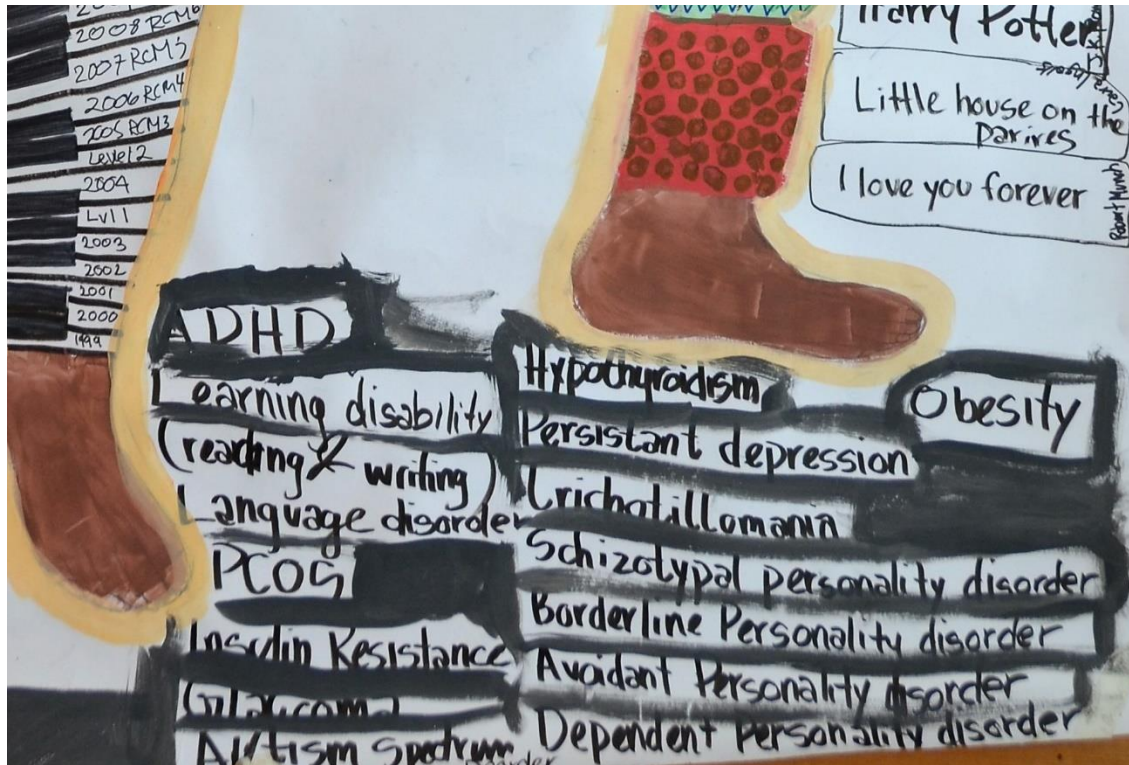


Figure 7. Bottom-right corner of Maggie's body map.

My Note for Open Coding: "Rejecting Diagnoses"

Participant's Audio-Recorded Narrative Data:

I'm stomping on my diagnoses into the garbage. I was like "okay it's all interlocking and I'm walking all over it" because it's all BS. Because, like, they gave me a bunch of personality disorders. And on Thursday I went to my doctor's office and he was like "ok your therapist sent me this fax", and he diagnosed me with Autism in 15 minutes. I'm like, who does that? So. I don't think any of the diagnosis is real. I know there are some

things that do impact me a lot. But, I'm more than that. I have so many other things going on.

Researcher's Descriptive Statement:

The diagnoses Maggie has been given by health professionals are represented in black and white, below her body, in a cluster or pile. They are separate from her body, they are not colourful or multi-dimensional. They are flat and black and white. She has depicted herself stepping on them.

This descriptive process was repeated for any visual item that had been marked in open coding as being related to the three research themes which were: Discourse and Self, Discourse and Others, and Changing the Discourse.

Phase four: Thematic analysis.

I analyzed the lists of open codes for the four participants thematically across maps. I underlined codes in different colours according to emergent themes. The previously-generated descriptive statements for the elements of each participant's map were then organized according to these emergent themes. I created a thematic map which incorporated all emergent themes from open coding. This initial map was complex and included multiple inter-relationships between themes. This thematic map was not sufficiently grounded in the data as it represented an attempt by me the researcher to force themes to follow a flow that was not rooted in what the data was actually representing. This thematic map was also an example of me analyzing the data rather than simply reporting it.

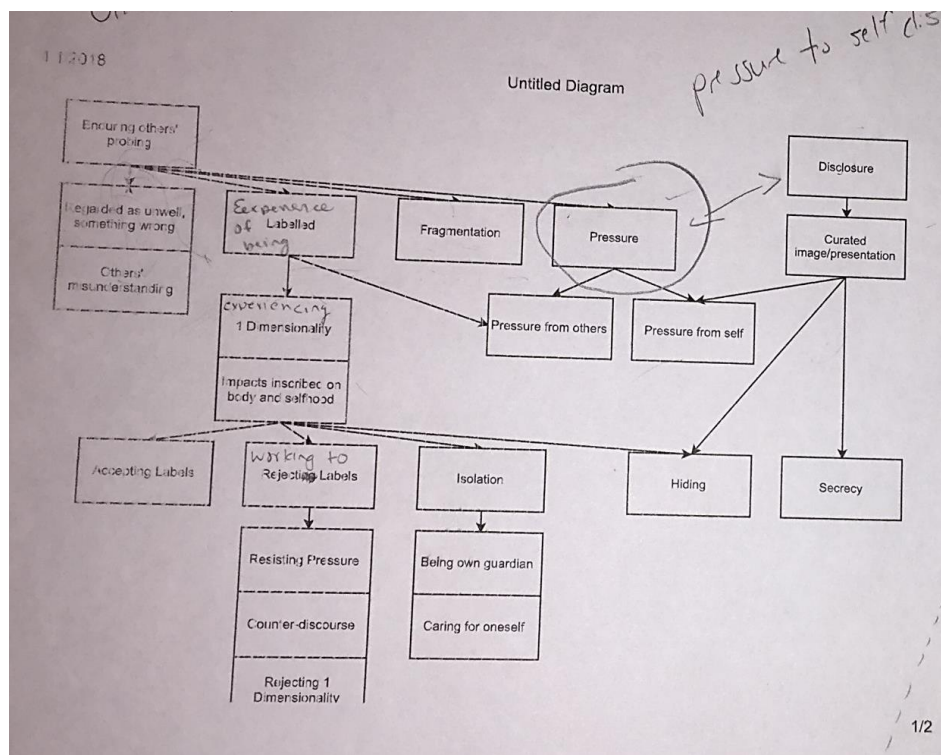


Figure 8. First candidate thematic map.

I refined this candidate map, guided by theme evaluation parameters of Bran and Clarke (2006) including: collapsing sub-themes into each other, ensuring that all aspects of each theme cohered around the central idea and ensuring that each theme was clearly distinct from other themes. This resulted in the second candidate thematic map.

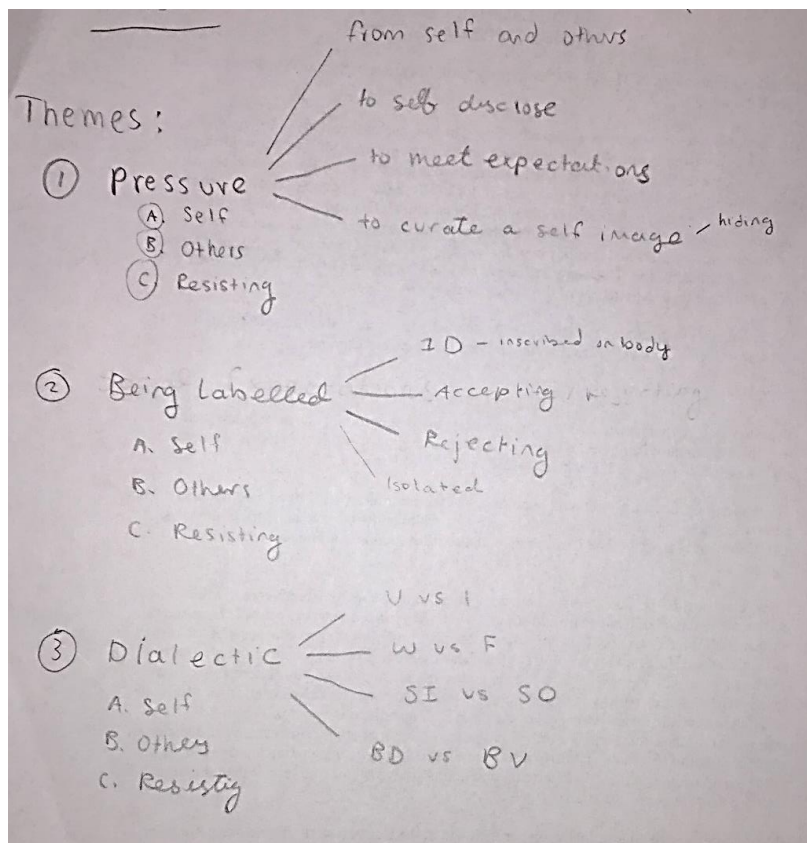


Figure 9. Second candidate thematic map.

After further refinement of themes, including renaming 'Dialectic' to 'Contrasting Experiences', the final thematic map emerged. The Findings section is framed around this final map. This final thematic map follows a less complex organization than the original map, stays closer to the data (and the participants' voices), incorporates the candidate themes that had been generated originally in Phase Three, and provides further depth and richness to the narratives of the themes that had emerged in open coding.

In summary, I first organized data semantically, based purely upon visual analysis methods using Skop's (2016) visual analysis framework in Phase Two of analysis. I returned to the data in Phase Three and used a more latent approach which was guided by the research question in an open-coding format. Looking at the data in two different ways (semantic approach

and latent approach) created a form of triangulation which contributed to the validity of emergent themes during thematic analysis in Phase Four.

Chapter Four: Findings

Finding One: Contrasting Experiences of Compulsive Hair-Pullers

Section One: Wholeness and Fragmentation

Section Two: Built Up and Broken Down

Section Three: Visibility and Invisibility

Finding Two: Impacts of the Social World on Compulsive Hair-Pullers

Section One: Experiencing Pressure

Section Two: Experiencing Labelling

Section Three: Self-Guardianship

Finding One: Contrasting Experiences of Compulsive Hair-Pullers

The first finding of this study is that participants' data showed a pattern of three themes of contrast. This finding was originally described as being "contradicting experiences". This term did not fit the data completely and the word "contrasting" was found to be better suited to describe the finding. The first two themes of contrast, Wholeness and Fragmentation and Built-Up and Broken Down were compiled through data that was found within each body map. In these two themes, data was compared within maps. For example, a data extract in Kay's map would be analyzed in comparison to another data extract in Kay's map. In the third theme, Visibility and Invisibility, data was compared within maps and across maps. In addition to comparing data extracts among the same body map, data extracts concerning similar content were compared across Kay, Violet and Laura's body maps. Each theme captures examples of data that shows the participants' depicting of contrasts in their experience.

Section one: Wholeness and fragmentation.

All four participants show examples of co-occurring experiences of being and feeling wholeness in their self-representation, and of being and feeling broken into parts. Wholeness, whole selves, full selfhood and full self-representation is depicted alongside representations of fragmentation; partial selfhood, parts-of-self, and fragmented selfhood in experience. Participants have shown and spoken of grappling with the ways that their experience of being a compulsive hair-puller is an experience of being reduced, or fragmented, and not indicative of them as a whole person.

An example of a participant's portrayal of an experience of being fragmented is Maggie's choice of depicting the mental illness diagnoses she has received from health professionals. She

portrays these diagnoses as a dark, black pile outside of her body, which she is seen stepping on into the garbage. She describes her body map figure as “walking all over it because it’s all BS”. The diagnoses are located in the bottom-right corner of her body map, outside of her body, underneath her foot. Of her experience with receiving these diagnoses, she shared that:

He [her therapist] diagnosed me with Autism in 15 minutes. And I’m like, who does that? So. I don’t think any of the diagnosis is real. I know there are some things that do impact me a lot. But I’m more than that.

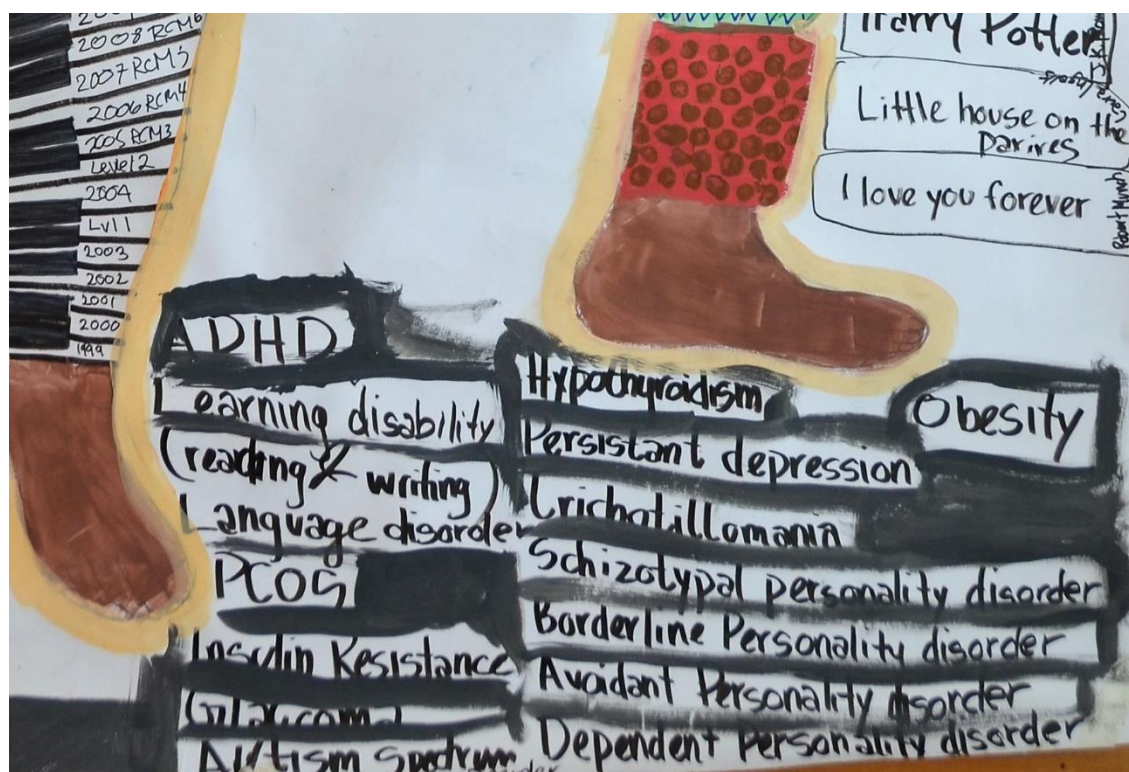


Figure 10. Maggie’s feet stomping on her diagnoses.

Maggie depicts her resisting of diagnosis and the pathologizing of these parts of her by stamping them into a garbage can. Maggie doesn't count them as "real" parts of her. This exemplifies the contrast between wholeness and fragmentation by showing that Maggie sees herself as a whole

person separately from her diagnoses, and she simultaneously acknowledges that the diagnoses are part of her experience and identity.

Another example of a participant displaying engagement with their whole self and with parts of their self is seen in Violet's representation of "turtle mapping" throughout her whole body. Repetition of black dashes connecting varied symbolic items throughout her limbs and torso creates a sense of cohesion and connection (wholeness) amongst these multiple different parts (fragments) of her identity and experience. In addition to this "turtle map" in her body, another example of the theme of wholeness and fragmentation is Violet's choice to depict a "lighter side" and a "stormy side" on her body map. This demonstrates tension, of being stuck-between, and experiencing these aspects (fragments) of life simultaneously. She shared that "I'm going to do like a stormy side and a light side. So all the things that bug me on this side. And I'm also doing, like, the turtle's journey. Because it's swimming, right. So I'm just figuring it out." In this quote, Violet connects the experience of "swimming" to the turtle's journey, (echoed in her choice of personal slogan, "swim at your own pace" which is depicted within the image of a turtle in her chest) and of navigating through different parts of experience.



Figure 11. Violet's torso showing her 'turtle mapping' and personal symbol (turtle) and slogan ("swim at your own pace").

An example of a depiction of fragmentation is captured overtly in Laura’s visual representation of two distinct body figures occupying her one body map, each carrying a unique portrait of her experience. The distinct splitting of portraits portrays a dramatic sense of the body and self being fragmented. The theme of wholeness and fragmentation is also portrayed in Laura’s personal slogan, “Hiraeth”, a Welsh word without a literal translation in English, but what Laura describes as:

...a longing for your homeland. But not just the land, the like, the people, the culture. And even though I’m not Welsh myself, it kind of, the idea of the longing’s part of it. Kind of sums up something for me.



Figure 12. Laura’s personal slogan “Hiraeth”

In this quote, Laura describes a sense of wanting to feel connection to a part of her heritage and seeking a more whole, fuller sense of identity and self. She described her connection to the word hiraeth as “...feeling a desire to stay connected to that side of myself.”

She continued to say, “I don’t know what it’s got to do with hair pulling [laughs] but it just felt like the right thing to put there. I really like that word”. Her use of the visual depiction of dual figures and her choice of personal slogan “hiraeth” exemplify the theme wholeness and fragmentation as ways of capturing a sense of fracturing of self and engagement with connections that would create a fuller sense of identity.

Laura’s choice to include two figures in her body map is an example of demonstrating wholeness and fragmentation. She shared, “I’ve thought there’s always this conflict where I try to observe myself as this confident person” and named shame as a key factor in wanting to hide aspects of herself away. In the first group session, Laura traced the tall standing figure. She returned to the second session expressing that:

It didn’t feel like the first one [outline] was honest. I really like last week, but it’s really not the truth. It’s just a little bit of a lie. I’m not like that all of the time...Last week, I just wanted to focus on the strong, the positive. And this week I just went right to the doom. Angry, sad. And that felt a bit more honest. Right now.



Figure 13. Laura’s depiction of two figures.

Laura discussed the two different pieces of her experience and chose to depict them as co-occurring on her body map.

Fragmentation is represented by Kay in her depiction of a scarf wrapped around her eyes, with its two ends blowing away from her head. Although they originate from the same object, the ends of the scarf contrast each other.



Figure 14. Kay's scarf.

On one end in cursive, red writing along the inner edge of the scarf, Kay wrote the words “Done, isolated, one, only, unsure, suffocating, suffering, stop, what if, scared, be seen, vulnerable, running, stop, fight or flight, unsure, sad, last, fear”. On the other end of the scarf, in cursive, black writing, Kay wrote “Community, love, respect, patience, acceptance, you’re not alone here, my passion, my heart, the love and light in my eyes, my people, my gift, to listen and stand up”. The scarf is a single object representing her feelings of blindness and not knowing what to do and is depicted as simultaneously having both “bad things” and “good things”. These

feelings are connected to the phrase she has chosen on the scarf over her eyes: “Why don’t you just stop?”. She explained that:

One side is the bad things that I feel or that this hair thing makes me feel. So like, scared, vulnerable, feeling like fight-or-flight, all these bad things. And then I have this other one that’s all the good things.

Kay acknowledges that the experience of “this hair thing” has resulted in both positive and negative experiences. This is an example of the theme wholeness and fragmentation because it represents a co-occurring engagement with her whole experience of hair pulling and parts of the experience.

Section two: Built-up and broken down.

Three of the participants have depicted this second theme of contrasting experiences. In this theme, the term “broken down” means experiences of feeling weak, ashamed, and experiencing difficulty. The term “built-up” means experiences of feeling strong, proud and joyful. These contrasting experiences are depicted as occurring simultaneously on the body maps.

This theme is exemplified by Kay’s depicting of herself as a hero who is also blinded by uncertainty. The built-up part of herself, depicted with her bright red cape, is representative of being strong for herself and the community of people with BFRBs. She shared that:

It’s ok to remind myself that I do a lot. It’s ok to feel like a hero. One thing I want everyone to know is that you can do it. Some days I do have my moments where I don’t feel like I can do anything. I’m always a cheerleader for other people but I’m really hard on myself.

In this quote, Kay alludes to experiences of difficulty within the hero (or “cheerleader”) role. This represents a contrast in the experience of being built-up, which Kay has shared comes with experiences of being broken down (“being hard on [herself]”). Present on her head is also the scarf that is blinding her. Kay shared that one end of the scarf represents “good things” that have come from her experience as a hair-puller. This portrayal of, in my words, a ‘blinded hero’ represents a contradiction of experience in being both built-up and broken down.

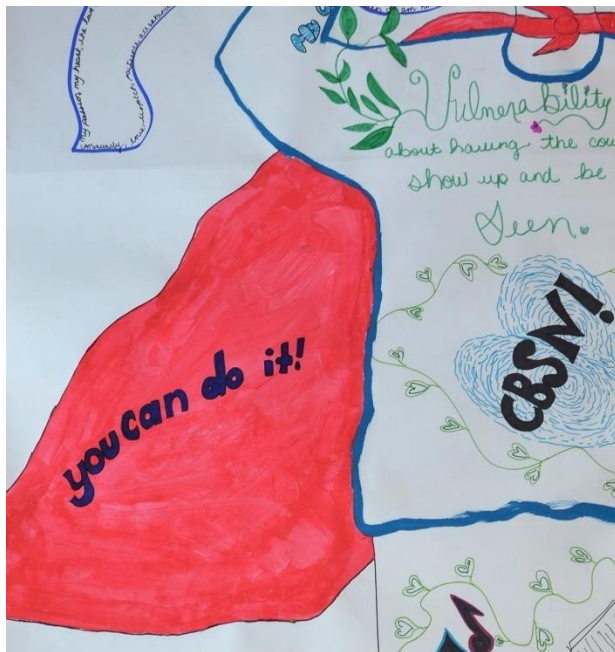


Figure 15. Kay’s cape.

An example of this theme is seen in Violet’s depictions of messages from others. She drew red hearts containing loving messages from her husband, directly beside her ear, between her and negative messages from others portrayed in black arrows. She shared that, “It’s more outer strength than inner strength at this point. So I put it by my ear, so it shows that I am listening”. The theme of built-up and broken down is rendered in how Violet listens to the

affirming and supportive words of those that care for her which build her up as well as the negative messages of others which break her down.



Figure 16. Violet's depiction of messages from others.

This theme is exemplified in Laura's map through black circular scribbles taking up the majority of the space in her standing figure's chest. This is an example of the simultaneous experience of being built-up and being broken down. She explained her choice to portray the tall, proud figure as containing confusion and self-doubt:

A lot of the time I looked at these questions and I thought "oh my god, I don't know, I don't know". What do I do to support myself? I don't know. When did I start this? Where does it come from? I can't remember how old I was when I started. I can't remember why, what was happening. So that's also why I've got a lot of cloudiness inside because I just feel that it's been quite hard to think about the answers to all these things. It's not

clear to me. And I've always thought that I'm really self-aware but I guess there's things that I find a bit mysterious.

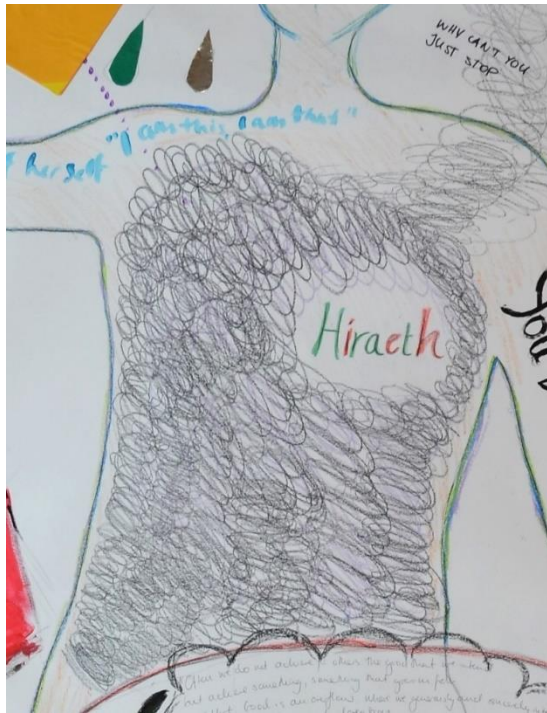


Figure 17. Laura's torso containing black scribbles

This example of being broken down is contrasted by Laura's choice to include items that help her to cope and to build herself up. These items are bright purple, red and gold running shoes, a bright red book (representing writing and journaling), a bright red and yellow envelope (representing connection to a best friend), the bold black cat tattoo, and metallic raindrop shapes. These offer a counter-visual and depictions of being built up to the dark cloudiness of Laura's depicted confusion and feeling of being broken down. Laura shared that engaging with her physical self is a part of taking care of herself, even though she acknowledges that these practices represent a 'double-edged sword', another contrast of co-occurring experiences:

Things that help me cope is always a little bit of a double-edged sword. Exercise always makes me feel better, reading and writing, you know, kind of scholarship. And, up here this [rain drops] represents, when I'm feeling in the zone that I just can't stop pulling, running my hand in water or putting oils, or gels on it will kind of soothe it and calm it down. But, on the other hand, like I had a therapist who was like 'you're just giving yourself another sensation. You know you want to feel something there'.

In this quote, Laura has described how this concept of a “double-edged sword” plays out in her building-up practices and in a way, contribute to the contrasting experience of being broken-down. She also shared:

Reading, I love so much but that can be a time when I pull. And the running as well, I so love, it's relaxing and it makes me feel better. On the other hand, I get competitive with myself, the joy went out of it.



Figure 18. Laura's coping.

While she enjoys the experience of reading, she presents this practice with the word “but” and connects reading to times of pulling out her hair.

Section Three: Visibility and invisibility.

All participants shared depictions of engaging with their experiences of visibility as a person with compulsive hair-pulling. The finding of contrast is represented in depictions of being fully visible, open, exposed or seen, as well as being invisible, hidden, or not seen. In this theme of contrast, the theme of Laura, Kay and Violet’s workplaces emerged and data was compared across these three maps in addition to data being explored within each map.

In the body-mapping exercise “Self-Portrait”, participants were prompted to consider how they would like to portray their hair on their body map. All four participants shared that the visual presentation of their hair is strongly connected to their concepts of being seen and being visible. This is exemplified for Maggie on her body map in the second, smaller figure to the left side of Maggie’s body. This figure was originally meant to be a depiction of her wig. As she continued to work on her map, she decided that this image would become a representation of her past self and a past relationship with self-medication. She shared that “I started off with me holding the wig and how the wig is like another pill I take to seem normal”. Maggie connected the wig, a tool that alters visibility (of hair loss), to what it means to be “normal” to her. The theme of contrast between being visible and invisible is depicted in how Maggie chooses to present herself as a hair-puller. She could be ‘invisible’ as a hair-puller (and “normal”) if she wears a wig. The way Maggie chose to depict her head on her body map is a representation of her desire to grow her hair to what is pictured. She said that “I want to get there”.



Figure 19. Maggie's two heads.

Kay's hair is portrayed as it would appear during a time when her hands are interacting with her hair and/or pulling it out. Her hairpiece which covers the majority of the crown of her head is seen being held by one hand while the other interacts with her hair behind her head. Including the hairpiece in her hair portrait is a part of representing important connections to her that surround feelings of 'normality'. She shared that, "When a hairpiece works, it's a modicum of normality, a good feeling". These feelings are linked to fear of exposure and feelings inadequacy surrounding her work, depicted in a large cloud shape to the right of her body on her map.

I wish I could get more comfortable with my hair. I'm scared that people will think I'm 'less than' at work. I don't want people to see me as less mentally competent. Every time I have to tell someone about my hair, it's like I'm coming out, all the time. I feel fear of, say, co-workers finding out.

Kay discussed the difficulty of finding a reliable hairpiece and the disappointment associated with the possibility of it failing, which to her would result in her needing to wear a wig. She stated that “I can’t go back to wearing a wig. I can’t go back to work magically with a full head of hair” and “I want to be seen at work, but I don’t want to be seen because of my hair”. The visual appearance of her head is important to her, especially in her workplace. The contrast of visibility and invisibility play out in this example through Kay’s discussion of ‘appearing’ at work in a certain way (ie. With a full head of hair by wearing a wig after having only a hairpiece previously). Kay verbalized her experience of tension between wanting to be seen, but not wanting to be seen.

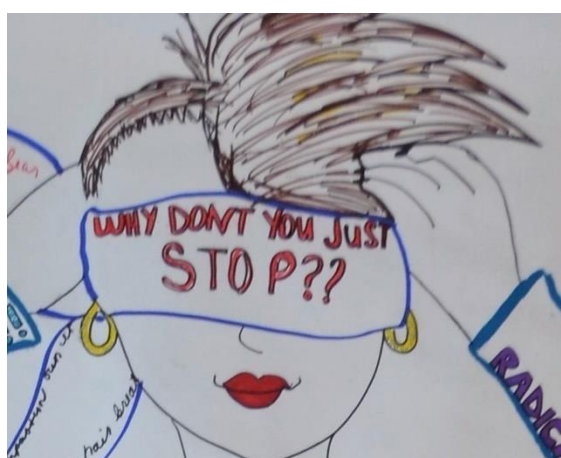


Figure 20. Kay hair detail.

Kay’s thoughts resonated with Laura, who has experienced frustration and difficulty with hairpieces and the impact of this difficulty on her work. She shared, in conversation during a session that “I lied to my colleagues. I was like, I can’t come to work because, it was literally hanging off my head. I absolutely hate lying to my boss”. To Kay and Laura, showing visible hair loss in their work environments is not an option to them. These women portray a consistent message that if they were to be ‘out’ at work, the rest of them would become invisible, and their

identity as someone with hair loss would take over. This represents an example of the interplay between the contrast of being seen and not being seen. Laura shared:

At my work, everyone is very passionate and focused on the work... there just isn't room for it [being open]. Like, it's a non-profit, and there's a lot of corporate partners, and it's a very corporate environment...and I'm just not going to explain why I have a shaved head.

Laura shared that visibility in her workplace is not an option and she kept her hair-pulling invisible by not attending work on a day her hairpiece was not working properly. Laura shared that she feels this way despite having colleagues who allow themselves to 'be seen' as living with a mental health-related difficulty:

The weirdest thing is, like, a lot of people I worked with had experienced some kind of mental health issue, and a lot of people were very open about it. Oh yeah, amazing colleagues. And it's so inspiring. But I have never told anyone, about this.

The word "open" (ie. her coworkers were "very open" about their mental health) is implied to be connected to the words "visible", "out", and "seen". In her workplace, although her co-workers have chosen to be visible, Laura chooses to keep her hair-pulling invisible. Laura's two body figures convey a narrative of a dual embodiment regarding being 'seen'. Laura explains this:

I'm standing up. I've thought there's always this conflict where I try to observe myself as this confident person. And the other thing about my hair-pulling, is that I've always been really, really good at hiding it. And then a few months ago I couldn't hide it any more, so I paid some money to stick something on top of my head. There's always these parts of

myself that are really hidden, and I think about them every day and I don't talk about them with anybody. Or maybe, like, a couple of people.

Laura connects the experience of confidence to her experience of hair-pulling. The tall, proud, confident figure in the body map has a head with hair, where the hair-pulling is invisible. The crouched, hidden figure has a head without hair, where the hair-pulling is visible.

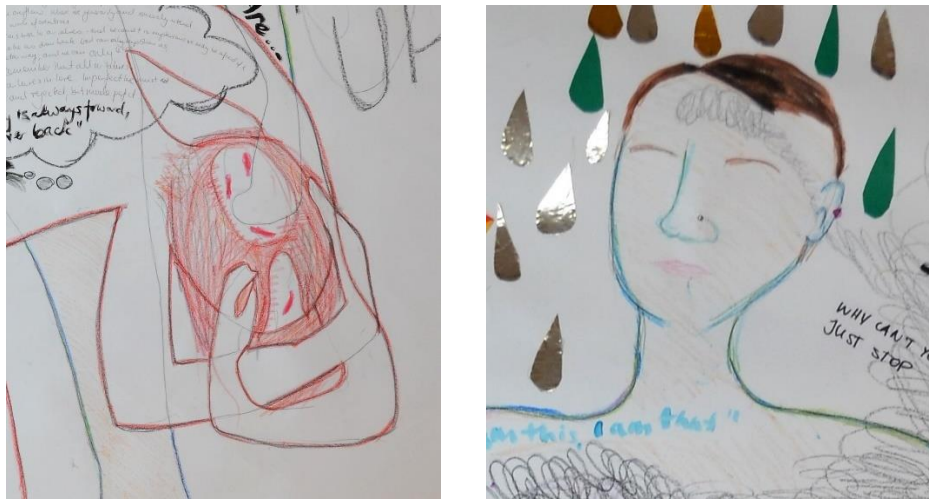


Figure 21. Laura's two heads.

For Laura, Kay and Maggie, having a part of their self be invisible and not seen is their reality. Laura linked this reality to shame in the following quote:

So that's why there's this kind of ghostly person who's like, crouching down and if you take away all the cover-up that's essentially...the bald patches and red marks because I pick my skin as well and it bleeds. For me, it's a lot about shame. And hiding things away.

Laura explained that the crouched figure is exposed, without "cover-up", and with the physical impacts of her hair-pulling visible. The perception that the corporate environment could see Kay as "less mentally competent" and would demand an explanation for Laura's shaved head

are two examples of reasons that being seen at work is not perceived as accessible to these two women, and examples of how the theme of contrasting experiences is rendered at the level of visibility for these participants.

Comparing across body maps, Violet's experiences of visibility and being seen at work are different than what Kay and Laura offered. She shared that she allows her head and hair to be visible as they are at work and that "I don't hide it at work". In her working environment, her identity as someone with hair that appears to be thin or have sparse areas is considered a part of her whole self. She stated "I guess I'm lucky because of where I work. Like, with disabilities, it's kind of like, everybody is their own person". In this quote, she connects her sense of personhood to her visibility as a hair-puller. Visibility to Violet is also rendered at the level of verbal encounters, when someone may inquire about her hair's thinning areas, in addition to encounters where people could visually see her appearance:

I don't care if anyone were to ask me, if clients were asking me if there were problems with my hair. Co-workers, I don't really mind it. Like I had one client who asked me about my hair and I said somebody pulled it, I didn't say it was me, and he asked "did it hurt" and I said sometimes, and he genuinely looked concerned. And that was it, he dropped it, so I'm lucky that way. And I had one co-worker the other day, she thought my hair was thinning and when I explained it she was like "ohh". Because I just came back from mat leave, and I had thicker hair and now I have thinner hair.

Violet's hair's appearance in her body map mirrors the minimal impact that interactions about her appearance or behavior have on her. Violet says, "My hair, just looks like me". The only portrayal of Violet's hair-pulling-related behavior can be seen along the sleeve of her shirt, which is depicted as frayed.

I do have my hand closed, holding technically my sweater. I actually started pulling fabrics before pulling my hair and it evolved from there. So I also made sure to put raggedy fabrics at the end, cause that's actually how it starts.



Figure 22. Violet shirt hem detail and head detail.

Being visible, to Violet, includes being open to co-workers and clients' questions and comments about her appearance in her work environment. This is an example of contrast between participants. Violet's experience contrasts the experiences that Kay and Laura reported in that she did not share any instances of feeling the need to be invisible.

Finding one, *Contrasting Experiences*, is populated by three categories of participant stories. Firstly, *Wholeness and Fragmentation* explores participants' simultaneous experiences of recognizing the wholeness of their identities as well as the ways in which their selfhood is fractured into multiple parts. Secondly, *Broken Down and Built-Up* explores how participants shared the ways that they feel both strong and weak, for example, Kay's rendition of herself as a 'blinded hero'. Finally, *Visibility and Invisibility* explored participants' engagement with being

visible as hair-pullers through their interactions with tools such as hairpieces or wigs, their experiences in their workplaces and their experiences with being 'out' as hair-pullers. These three categories each approached the over-arching finding of contrasting experiences from a different angle of the concept of co-occurrences, simultaneity and both-ness of experience.

Finding Two: Impacts of the Social World on Compulsive Hair-Pullers

The second finding of this study is centered around participants' social experiences of social pressure, interactions with labels and being labelled, and experiences of self-guardianship. The concept of social pressure consists of participants' reporting of feeling persuaded, required or being desired to behave in certain ways. The concept of labelling consists of participants sharing the words that they encounter which describe their experiences, and whether these words are placed upon them by others or self-ascribed. The concept of self-guardianship consists of participants' reporting of experiences of cultivating resilience, endurance, strength and care for themselves on their own. Self-guardianship is related to participants feelings and experiences of isolation as compulsive hair-pullers.

Section one: Experiencing pressure.

The participants shared depictions and experiences of the varying ways that they feel pressured socially. These pressures: come from other people and from themselves, focus around the concept of self-disclosure and cause the participants to feel they need to meet certain social expectations. Another aspect of the experience of social pressure is the ways that the participants have shared their resisting of pressure.

Pressure from other people is depicted in Kay, Violet and Laura's body maps. Maggie's body map is void of any interactions or social experiences. She explained that this was an

intentional choice. The absence of these messages represents an absence of wanting to talk about these experiences. She shared that she was badly bullied in school about her hair, and that family members have said things that hurt her. Maggie shared that she does not talk about her hair-pulling with others and that she decided not to include messages from others because she has negative associations with these interactions and messages. Violet's depiction of social pressure portrays others as worrying about her. Violet sees others as concerned and confused by her hair and hair-pulling. She drew grey and black arrows on the left side of her head, pointing towards her head with the phrases: "Don't do it. It is just a habit. Hands down.", "I don't want you to pull because of me.", "Does it hurt? Why did you do it? Are you ok? How are you?", "BALD SPOT!" Of her choices to include these messages, she explained:

I also then, I've got the people who are curious. They want to know if it hurts, why do I do it, am I okay, and how are you? So I have a lot of positive responses as well, and the obvious, the bald spot, that's right there. That's just some of them, so I put them on.



Figure 23. Violet's depiction of messages from others.

Violet did not communicate that these interactions and pressures from others are entirely negative. She was the only participant to discuss her experience of others' being curious of her hair and hair-pulling. An example of social pressure Laura decided to include is a phrase that her mother has said to her: "Why can't you just stop?". She explains that "I didn't really want to put this there. But my mom says this to me so much. She even said it to me the last time I saw her. I know she means well". By explaining that she didn't want to include this message on her body map, but including it anyway, Laura has shown that this phrase is indeed meaningful to her. The repetition of this message from her mother, who "means well", is a representation of social pressure from others who may not completely understand hair-pulling and are pushing for their loved ones (or friends, family and acquaintances) to stop the behaviour. Laura also included two large messages in bold black capital letters beside her body. "DO NOT FUCK UP" and "YOU ARE TOO MUCH". Of their significance, Laura share that "This is some inner feelings I guess. That I think kind of come from stuff in my childhood, things I guess, I was made to feel...so that's definitely stayed with me." These messages are heavily laden with social pressure, as Laura put it "she was made to feel". These messages originated from outside of herself, and she chose to portray them on her body map as contributing to inner confusion and difficulty by connecting them to the dark scribbles within her tall figure's torso.

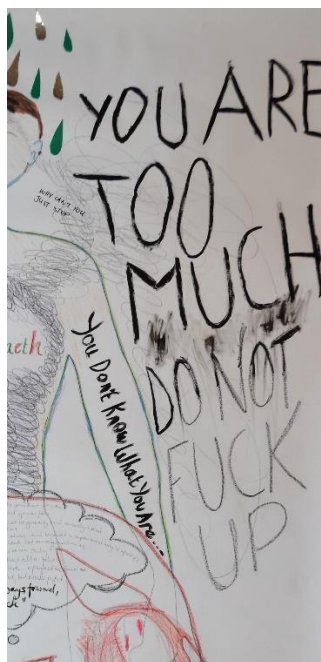


Figure 24. Messages on Laura's map.

The spatial positioning of these messages on the right-hand side of her body, above the crouching figure's head and beside the message in her right arm "You Don't Know What You Are" contribute to the messages and pressures that Laura directs inwardly at herself.

Social pressure is exemplified in Kay's body map through her depiction of coping with the difficulty of being vulnerable to "show up" in public hair-pulling community spaces because she perceives having been identified as a strong role model and leader for others who live with compulsive hair-pulling. She shared that this identity doesn't leave room for her to show her own difficulty and struggles and she feels pressure to present as a certain way all the time. She shares:

It's scary. I would rather not...I guess I don't want to be seen and I want to be seen at the same time. It's a fight, right? I don't want to admit it. And that's the part I don't want you to see. That I'm still vulnerable, and there's a lot of things I struggle with.

In this quote Kay connects the experience of being visible as a role model in the hair-pulling community to social pressure to meet expectations of invulnerability. The word “vulnerable” is a key word in Kay’s body map as it is featured in her personal slogan. She explains the choice of her personal slogan, “My personal motto is a Brene Brown quote ‘vulnerability is having the courage to show up and be seen’”, and she elaborates:

...which is essentially what I try to do with my life and struggle with every day. And you know, like, every time I have to tell someone about my hair, to somebody new in my life, it’s like I’m coming out, all the time. Um, feeling fear of, say, co-workers finding out, or...but also having to be true to myself because it is a very big part of me and I struggle with vulnerability.

In this quote, Kay explores her experiences of “coming out”, being “out”, being “[found] out” being visible and being vulnerable as someone who wants to honour this part of her identity in the context of feeling afraid of the idea of being vulnerable. This is connected to social pressure because her struggle with self-disclosure is experienced socially. Another part of her experience is her leadership role in the hair-pulling and BFRB community. She shared that:

I also feel like I have to be okay because people are looking at me and hoping that they can feel better eventually. I while I do agree that, yes, you can feel better eventually, it’s just that sometimes it’s not always good.

Her expression of “[having] to be okay because people are looking at me” exemplifies that she feels social pressure around her visible position in the BFRB community.

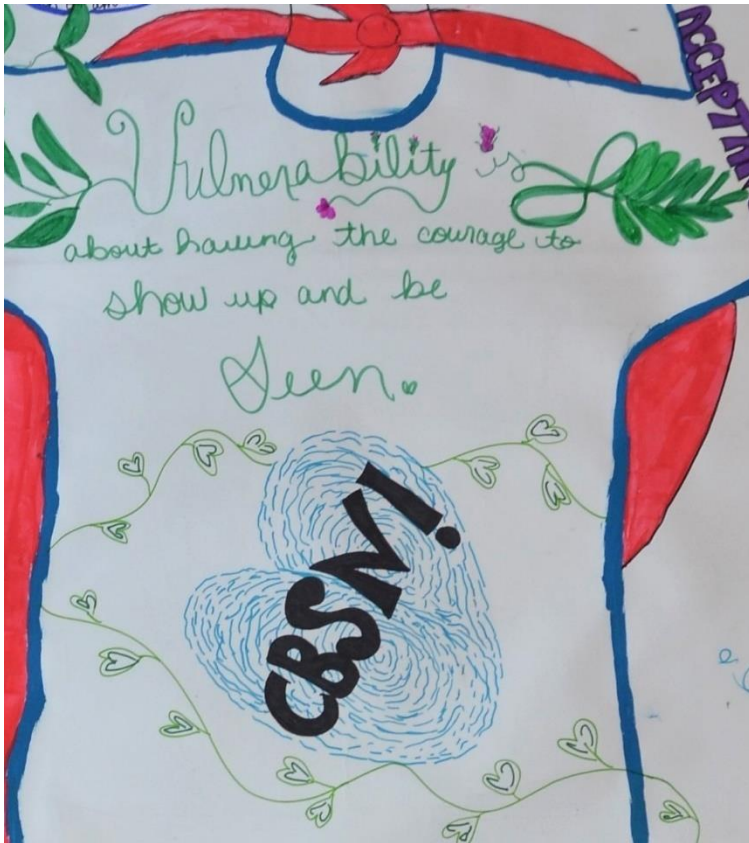


Figure 25. Kay's personal slogan.

Laura's depiction of two bodies reflects her feeling regarded as outwardly as either tall, proud and well or hidden, secretive, hurting, and ashamed. She shared, of the first tall figure she drew, that "Last week, I just wanted to focus on the strong, the positive. And this week I just went right to the doom. Angry, sad. And that felt a bit more honest. Right now." She also shared:

It didn't feel like the first one [outline] was honest. I was sort of thinking like, I really like last week, but it's really not the truth. It's just a little bit of a lie. I'm not like that all of the time.

This information aligns Laura's experience somewhat with Kay's experience. Both Laura and Kay feel a need to present as well, strong and positive in some ways. Both Laura and Kay have also shared that this presentation is not the truth for them all of the time.

Kay shared multiple perceptions of how others may regard her. Firstly, that others in the hair-pulling community see her as a role model and leader and that she feels pressure to be well all the time, and to present a certain way for others. Secondly, Kay shared that she feels she must hide her hair-pulling at work.



Figure 26. Kay's depiction of her workplace.

Thirdly, Kay shared her perception that others outside the hair-pulling community do not understand her experience. Kay receives the message “why don't you just stop?” and this means to her that others do not understand her experience. She explains that she tried to tell the woman who styles her hairpieces that “You don't know what it feels like.”

Three participants shared portrayals of the ways that they resist social pressure. Maggie depicts her body in a joyful, dancing position on top of the labels and diagnoses that she has received from others. Kay resists pressure to present as someone who is not experiencing difficulty by wanting to show others that even though she is a role model and a leader she is having difficulty. Kay wants others to modify their expectations of her as a public figure to be strong and well all the time. Laura depicted representations of resisting pressure to appear a

certain way. She locates strength in the crouched, hiding figure. She locates self-doubt in the tall, proud body.

Section two: Experiencing labelling.

In relation to participants' depictions of social pressures, a pattern in the participants' data also showed that they have represented their interactions with being spoken to or spoken about. This may include experiences of being labelled. The experience of labelling is portrayed overtly on Maggie's body map. As previously referenced, Maggie represents the labels she has been given by health professionals as represented in black and white, below her body, in a cluster or pile. She shared that "I'm stomping on my diagnosis into the garbage. I was like "okay it's all interlocking and I'm walking all over it" because it's all BS. Because, like, they gave me a bunch of personality disorders". The social pressure of living with multiple diagnoses is exemplified by Maggie in her portrayal of her body map's action of walking on them and in her verbal data that she calls the diagnoses "all BS". Maggie's reaction to health professional's labelling of her is to resist. Visually, they are separate from her body, they are not colourful in the way she has represented her body. They are flat, black and white. She has depicted herself stepping on them. An example of the impact of others' speaking of her is how Laura shows her proud body's torso containing scribbles representing confusion. Laura portrayed messages she receives around her body, and the confusion, contained within her body, represented as being fed by the messages. Particularly, the proud tall torso contains the dark scribbles. Violet's hand that pulls out her hair is a site where self-deprecation and negative self-talk are localized. The impacts of these phrases (which she has given herself) are held within her body and surface at the site of her hand, as it is depicted reaching up toward her head, in the act of pulling out hair.

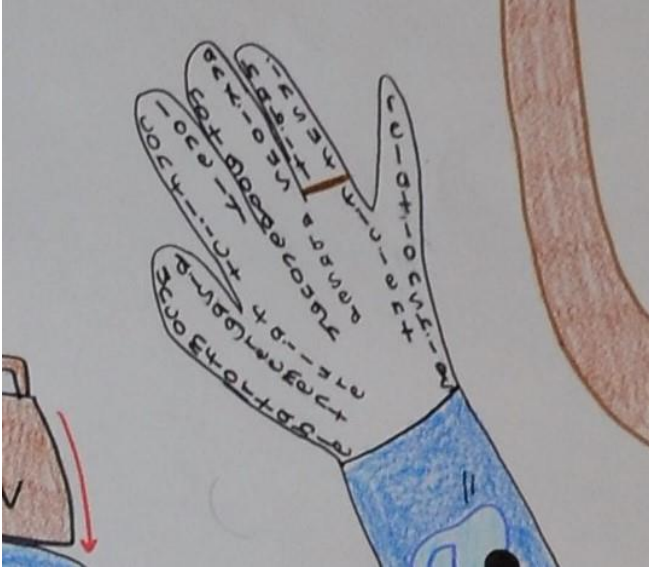


Figure 27. Violet's left hand.

Laura sees herself as enduring questioning and confusion from others. She depicts turning away from messages she receives and turning toward the people and connections that care for her, such as the arm of her partner holding her wrist, and the envelope that represents communication with a dear friend. She explains:

I was trying to think of a way to represent my best friend. Um, who has struggled with her own issues and we're able to talk to each other in a way that I can't really talk to anyone. I guess, we've had a lot of correspondence, we've lived in different countries for our whole friendship. So, an envelope.



Figure 28. Laura's depiction of personal supports.

Kay shared the impact of others' questioning "Why don't you just stop?" and how this contributes to her sense of uncertainty:

I wanted to be able to show like some type of feeling that I don't know where to go and I don't know what to do, and I feel blind and I feel lost. Even before I knew where we were going with this, the biggest thing I've heard my entire life is "Why don't you just stop?" and that is like one of the most frustrating things that I could probably write and entire book about, just those words. So that was like a huge deal, when I feel like, it's a block.

Kay shares in this quote that of others' questioning and misunderstanding of her experience impact her significantly, to the point where she is unsure of how to proceed, or "what to do".

One participant, Maggie, depicted certain labels inside her body. Maggie makes a distinction between these labels, which she depicts as having positive associations to, and the other ways she is labelled in her life such as the diagnoses she represented herself stepping on. Roles, occupations and identities are represented in her torso and in her shoulders. An important feature of these labels is that these are words that she chose herself and have not been chosen for her.



Figure 29. Maggie's depiction of self-chosen labels.

The four participants have each shown how they resist the labels others have given them, or the ways that others speak of them. For example, Maggie shared that she sees herself as much more than just someone who pulls her hair out compulsively. Of the diagnoses she has been given, she said “I know there are some things that do impact me a lot. But, I’m more than that. I have so many other things going on”. In her final narrative of her body map, she shared “I just want to say hair doesn’t make you who you are.” Her message to others is :

Take selfies every day! That’s something I regret. That’s because I was so embarrassed without my hair. Hair is nothing, there’s so many other things going on. I started a club. I’ve been teaching for years. Hair means nothing. I’m pretty sure there’s lionesses that like a lion without a mane, I will Google that. (laughs).

This is an example of resisting labels because Maggie is sharing how she pushes back against the power that social norms of appearance have over people. Another example of resisting labels is seen in Laura’s message on her arm “she would not say of herself ‘I am this, I am that’”, which was previously explored as an example of experiencing social pressure to be a certain way. Taken literally, the quote is an example of Laura denying labelling herself. Finally, Kay’s resistance of labels is portrayed in her demonstrating her difficulty of being vulnerable to “show up” in public hair-pulling community spaces because she perceives having been labelled as a strong role model and leader for others who live with compulsive hair-pulling. Kay sees herself as a cheerleader and hero for others, which is a way she helps reject one-dimensionality of labels. Kay perceives that her hair-pulling identity would take over the rest of her identity if she were to “come out” at work and she distances herself from being labelled at work by ensuring that her hair-pulling identity is not visible to her co-workers. This is a way that Kay resists being labelled.

Experiences of labelling are varied among the four participants. Some participants have depicted that their interactions with what others say about them creates confusion and uncertainty. One participant depicted self-ascribed negative concepts within the hand that was reaching up to pull out her hair. Another participant demonstrated that the labels others have given her are meaningless to her, while the labels she has given herself are held within her self-concept. All the participants shared ways that they resist the labelling of their experience in some way, and resist the impact that labels have on their selfhood.

Section three: Self-guardianship.

This theme is composed of patterns in the participants' data that are related to participants sharing that their identity as a hair-puller has rendered them isolated in some ways, and this isolation has resulted in the necessity arising that they are tasked with caring for themselves and being their own protector, helper and guardian. This theme, of self-guardianship, will be explored in this section.

Self-guardianship is overtly explored by Maggie who portrayed herself in her body map as having a pair of wings. She also alluded to herself as her own guardian angel. Maggie locates the majority of her power, coping and supports in her own self. This became clear during the exercise "Point of Personal Power", when Maggie did not identify a single location where she felt her power came from. Rather, she shared:

I don't think I have one area of personal strength. I think it's the whole thing." [referring to her whole body]. Every day I grow. I don't know how to show my strength because I feel like it's all of it. My strength is my whole body.

Maggie captured her strength as being her whole body by painting a glow around her figure on her body map. This is related to how Maggie did not choose to portray interactions or specific relationships with other people in her body map and chose to highlight her relationship with herself. This portrayal of being her own source of strength, and of building her own self up, is reflected in Maggie's personal symbol, which represents her guardian angel that lives within her. Maggie shared further insight into this during a group session. Please be advised that this quote contains content relating to suicide.

My personal symbol would be my angel wings. Because, for me an angel has a lot to do with who I am. Not just because of my religion. I've had numerous suicide attempts and I have had suicide ideation since I was in 7th grade. My first attempt was in 7th grade. There's this girl who stopped me the first time. And a few years later when I was in the hospital I saw this angel by this girl, by her foot, holding a book and I was like "that's me". So. Because it was like the first time that I realized that, it was like, I didn't know that I was sick. I didn't know Trich was a thing. But all I knew that I just wanted to end that pain and that loneliness. So for me like a guardian angel is someone who's there, who's protecting me.



Figure 30. Maggie's angel wings.

Maggie sees herself as her own guardian angel and sees herself as her own protector. The notion that Maggie sees herself as her own guardian is also carried in the depiction of her body, which contains numerous words that describe the multiple roles, positions, identities and self-descriptions that Maggie has held. These words are in her torso and her shoulders, written on top of the green fabric of her sari. Maggie depicted her body with angel wings, locating her protection inside of herself and explained "I firmly believe that I have a guardian angel, always have, always will". Maggie's overt portrayal and relationship with self-guardianship is a key feature of her body map.

Self-guardianship is exemplified by Violet and her depiction of a large umbrella that shields her from the storm outside her body. Violet tells herself that it is ok to be herself even though others question what she does and how she looks. She tells herself: "I am strong, I am me, it's



Figure 32. Violet rainbow detail.

Self-guardianship is also portrayed by Laura, who shows that she guards herself by limiting who has access the knowledge of her that she compulsively pulls out her hair. Laura limits access to the crouched figure she has represented and most often attempts to embody the proud tall figure. While discussing the placement of her black cat tattoo, Laura shared with me that she chose to locate the black cat in the crouching figure “Because that’s who I really am”. She had shared previously that the crouching figure is not what is presented to the world.

Kay chose the logo of the Canadian BFRB Support Network (“CBSN”) as her point of personal power. She connected it to her personal slogan, and to her supports down her legs using green hand-drawn vines. Kay’s self-care practices are depicted as being rooted in relationships with supportive communities and with herself. Her multiple involvements in community work

and advocacy are also depicted on her forearms as her hands are shown reaching toward her head, interacting with and pulling out her hair.



Figure 33. Kay's depictions of vines along her body.

This finding is related to self-caring and how participants care for themselves as their own guardians. For Laura, self-caring is represented in her depiction of including images of personal strength and self-love on the crouched, hurting figure. For example, her tattoo is an

example of a time she felt a positive connection to her body. She shared of the tattoo: “Things I’ve done to my body that are positive. My tattoo, things that have made me happy and make me feel empowered. So I wanted to include those as well...I designed it myself” and “I guess I wanted to mix it up because on the crouching figure I have what represents my strength, my tattoo and it has one of my favourite quotes.” Laura demonstrates through these choices of item placement that she protects, nurtures and cares for the crouched figure.

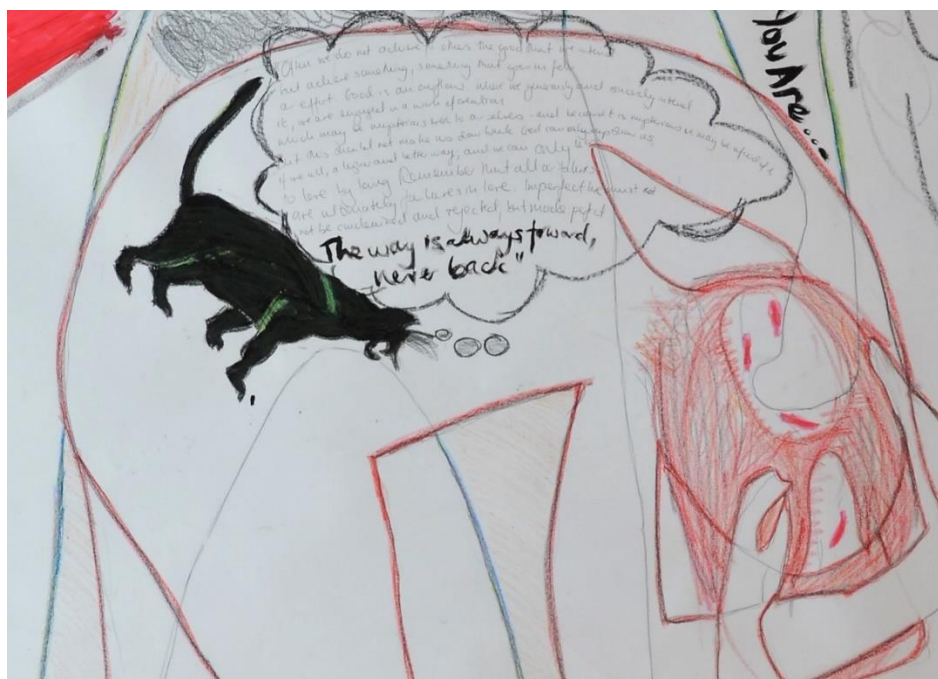


Figure 34. Laura's tattoo.

Finding Two, Impacts of the Social World on Compulsive Hair-Pullers captured patterns in the data composed of participants' interactions with the social world and the effects of these interactions on their selfhood and the meanings they make around their experiences. This finding was composed of three categories. Section One, Pressure, detailed participants' stories around the expectations of others including how these expectations are received, how they are impactful and how they are resisted. Section Two, Labelling, explored certain specific meanings

participants have drawn from what is said about them, including the specific experience of being labelled and how participants react to and resist instances of being labelled. Section Three, Self-Guardianship, explored how participants cultivate resilience and where they locate it, as well as how they nurture and protect themselves within a social world which is often presented as misunderstanding of them.

Chapter Five: Discussion

Section One: Revisiting Research Themes

I will guide the discussion of the study data by beginning with the research themes and associated guiding questions that were set out during the designing of the project. These are Discourse and Self, Discourse and Others, and Changing the Discourse.

Research theme: discourse and self.

The research questions of this theme were:

How do people with compulsive hair pulling see themselves as affected by social discourses surrounding their status as people with compulsive hair pulling?

What effects of stigma on their lives, sense of self and personhood do individuals themselves perceive?

The finding of Contrasting Experiences of Compulsive Hair-Pullers exemplifies that the participants experience duality in three different ways concerning hair pulling. Social discourses (including the ways that others speak of the participants, and the ways they speak of themselves) have the effects of fragmenting the participants' sense of selfhood, breaking participants down and affecting participants' perceptions of how visible their identity of hair-puller is. The finding of Impacts of the Social World on Compulsive Hair-Pullers exemplifies the following effects of social discourses on the participants; social discourses can create pressure on participants regarding their behaviour and self-presentation, social discourses are carried by labels which participants often resist, and social discourses contribute to participants having to guard and protect themselves.

Although it was a guiding concept in the research theme of Discourse and Self, the word "stigma" was not used in the body mapping facilitation guide and did not arise in any participant data. The decision not to use the word "stigma" was intentional as different people may have

different conceptualizations and understandings of the concept. The experience of stigmatization and the concept of stigma was referenced indirectly, rather than named overtly, in participant data. One participant, Maggie, referred to a fear of being judged as a reason for deciding not to include any visual depictions of the impacts of hair-pulling on her map. Laura used the word “shame” to describe why she portrayed a figure that is hidden and crouching. This shame is interpreted as being directly related to stigma.

Research theme: Discourse and others.

What perceptions do people with compulsive hair pulling have of how they are regarded by others and by themselves?

What social messages do people with compulsive hair pulling receive from others and what meanings do they draw from these messages?

The section of Visibility and Invisibility in Contrasting Experiences of Compulsive Hair-Pullers contained data that was directly connected to the participants’ interpersonal experiences with people who are outside of the hair-pulling community (in the data provided by Kay, Laura and Violet) and experiences with people who share the identity of hair-puller (in the data provided by Kay). This section explores participants’ experiences of modifying the way they appear to other people, either by using hairpieces or wigs (visually appearing a certain way), or through self-disclosure (verbally ‘outing’ themselves to others). The subject of visibility in workplaces came up in Kay, Laura and Violet’s data. Kay and Laura shared that disclosing their identity as hair-pullers (either by appearing at work with hair that would ‘out’ them in some way; Laura having a shaved head, or Kay appearing at work with a wig) is not something they perceive as an option. This implies that they perceived others in their workplaces would not be open to, or understanding of, them as people with this difference. This is contrasted by the experiences that Violet shared; being open, honest and visible as a hair-puller is part of her experience with co-workers and clients.

The messages that the participants receive from others about their hair-pulling, causes sadness (eg. Violet's tears resulting from messages in grey arrows at her head), confusion (eg. Laura's dark scribbles in her torso connected to messages outside her body) and uncertainty (eg. Kay's scarf "blinding" her which contains the words "Why don't you just stop?"). One participant, Maggie, completely omitted her interactions with others because the messages she has received were upsetting and troubling to her. Her data exemplifies that her experience with social discourses has resulted in her distancing herself socially. Violet's data included examples that show other people's messages might not always be negative. She included messages that conveyed others' curiosity and care toward her. The meanings drawn from these social messages are that, other people misunderstand their experience of hair-pulling; are confused by their hair-pulling, and sometimes they "[mean] well" as in the case of Laura's mother who repeated the question "Why can't you just stop?". Kay's data shows that she receives particular social messages from the hair-pulling community where she occupies a public role as a member of the Canadian BFRB Support Network. Kay perceives that the hair-pulling community has certain expectations of her, labelled as a "hero" and "cheerleader" for others that she cannot always meet. These expectations are carried by social discourses.

Research theme: Changing the discourse.

What recommendations may individuals with compulsive hair pulling have for social change with regard to their experience?

The session facilitation guide (Appendix A) included exercises titled "Message for Others" and "Vision for the Future" and these exercises were thematically linked to the research theme Changing the Discourse (outlined in Appendix B). The participants Kay and Violet shared messages outward to others on their body maps. These messages, for example, "You can do it!" (on Kay's cape) and "Go at your own pace", "Swim with the current", "Let the waves roll

off your back” (in Violet’s rainbow) are examples of counter-discourses. While these participants shared that the discourses they receive from others about their hair-pulling cause confusion, sadness and represent others’ misunderstanding, they have chosen to send messages outward that are positive, hopeful and inspiring to others. While not overtly described by the participants as a recommendation for change, they demonstrate that their unique perspective as hair-pullers suits them uniquely to having empathy for others. Their messages outward are different than the messages they have received. Maggie shared that her message to others is for them to celebrate the way they look, to not be embarrassed of their appearance, to “Take selfies every day!” as a method of resisting social discourses that pathologize hair loss.

In Finding Two, Impacts of the Social World on Compulsive Hair-Pullers, the participants shared data related to the ways they resist social pressure and resist labelling. These examples of resistance were not explicitly stated by the participants as their recommendations for change. I interpret them as ways of embodying counter-discourses in a social world which tends to impact hair-pullers negatively. An example of the embodiment of counter-discourse is the way that Kay presents herself as a hero that is also blinded. This demonstrates that a person labelled as a “hero” may not always behave in ways that are socially expected to be associated with that label. Kay’s choice of personal motto, and depiction of struggling with vulnerability is a counter-discourse to the social expectation that leaders and role models are invulnerable. Another example of embodiment of counter-discourse is that Laura chose to portray the crouched figure as containing her personal symbol, her tattoo, and she portrayed the tall figure as containing the dark scribbles of confusion. This demonstrates that she acknowledges the multi-dimensionality of herself, which is in direct conflict with social discourses which reduce experiences to one-dimensional labels.

Section Two: Exploring Meanings

This study set out to explore personal meanings:

Personal meanings around the way(s) people describe themselves as impacted by discourses.

Personal meanings around interactions with others and the outside world.

Personal meanings around resisting, coping and embodying counter-discourses.

These meanings are discussed in the following section under headings that organize the study findings according to key concepts present in the literature.

Dual Stigma and duality.

The concept of duality was a point of focus in the findings of this study. Finding One: Contrasting Experiences of Compulsive Hair-Pullers, explores three ways that the participants expressed their experiences of duality as it relates to living with compulsive hair-pulling. The notion of ‘both-ness’ is carried in this chapter; that participants in their unique ways have shared that they are *both*: wanting to be seen and to hidden, feeling like a whole person and broken up into bits, and are built-up and broken-down. Dual stigma, as explained by Kelley (2005) involves recognizing the complexity of stigmatization as it occurs for people who pull out their hair because social judgements, regarding both appearance and behavior, are co-reactive in their effect. This simultaneity in this experience of stigmatization, a ‘both-ness’ to the ways that it impacts hair-pullers, is reflected clearly in the findings of this study.

One dimension of dual stigma, that is, of looking a certain way that would violate social norms of appearance is carried, for example, in Maggie and Kay’s statements about their hairpieces. Capturing the idea of ‘normalcy’, in the context of how we are ‘seen’ (and whether we are seen as normal or not) was a recurrent pattern in participants’ data. Maggie said that “the wig is like another pill I take to seem normal” and Kay that “[A hairpiece provides] a modicum of normality, a good feeling”, insinuating that “seeming” (appearing, looking) normal is the

standard for being, that *normal is good*, and that if a person appears normal, they are good. These statements, the choice of the word “normal”, are reminiscent of Shilling’s (2013; in Dua, 2011) discussion of what is natural about a body, and the relating of the ideas of natural and normal. Maggie later interrogated social ideas about what makes a body with hair natural when she shared her final body map creation narrative with the group:

It’s pretty much human waste, technically speaking. It’s dead cells. And people judge you by it because of what society thinks. I’m pretty sure there’s like, tribes in the middle of nowhere where women keep their hair shaved. It’s like, for me, I never liked my hair. And when I did pull it off completely, people judged me. I just want to say hair doesn’t make you who you are.

She alludes to her idea that people will experience judgement, according to what “society thinks”, no matter what they look like.

The visibility of a stigmatized attribute is a key aspect of the operation of stigma (Brohan et al, 2012). To manage or control the impact of this stigma, participants all represented their experiences with concealment. The section Visibility and Invisibility in Finding One contains data that shows participants’ grappling with being seen. This theme rests mainly on the assumption that if the difference (or stigmatized attribute) is visible, the person with this attribute will be ‘found out’ and will be treated differently. Although hair loss itself may not be visible, self-disclosing the nature of hair-pulling renders the ‘deviant’ behavior to be visible. Laura’s crouched figure and Violet’s self-portrait show their heads as they appear. In Laura’s case, this portrait is shown as it appears without her hairpiece, as she describes it “the real me” and Violet describes her hair as “just me”. For Laura, Kay and Maggie, hiding part of themselves is their reality. This is in alignment with previous literature (Kelley, 2005; Marcks et al, 2015)

discussing identity management and social avoidance behaviours of people who pull their hair out. Laura also shared that she tightly controls who is privy to information that ‘outs’ her as a hair-puller: “There’s always these parts of myself that are really hidden, and I think about them every day and I don’t talk about them with anybody. Or maybe, like, a couple of people”.

Considering Marcks et al’s reporting that “more than 80% of people [with TTM, in their study] have concerns about their body image”, the lengths that Laura and Kay have shared they go to in their efforts to manage the visibility of their hair-pulling is in line with efforts reported in previous literature (as well as in my own experience being a part of hair-pulling support communities and a hair-puller myself).

Another dimension of dual stigma, stigmatization of the reason for a certain appearance, is represented visually in all the body maps with each participant showing, in some way, their hands (or hand) interacting with their head. Laura portrayed her crouched portrait with its hands over its head in a shielding or protective image. The tall portrait portrays one hand raised in the action of hair pulling and being intercepted by the grip of her partner who lovingly assists with interrupting the behavior. Violet’s hand is raised toward her head, inscribed with words like “anxious” and “habit”. Both of Kay’s hands are portrayed interacting with her hair because she shared that “that’s where they always are”. Maggie, as well shared that “My left hand is at my hair because it always is.”

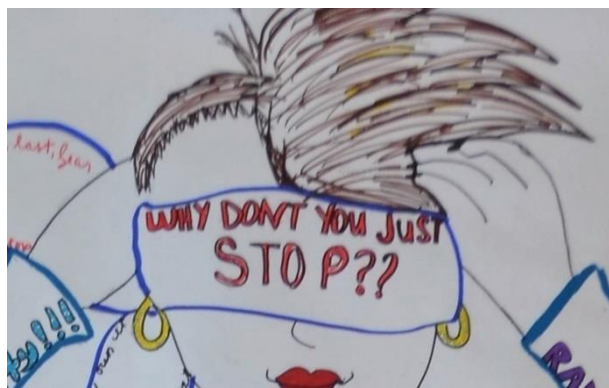


Figure 35. Kay's hands.

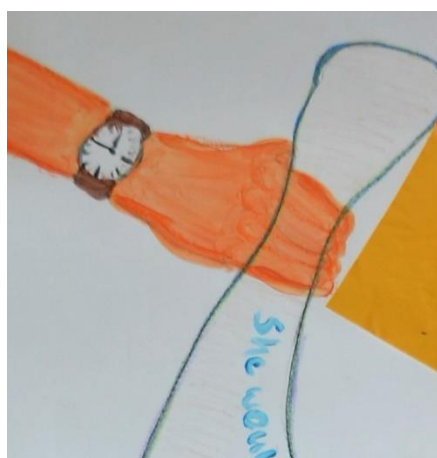


Figure 36. Laura's hands.



Figure 37. Violet's hands.



Figure 38. Maggie's hand.

Including a specific prompt in a body mapping session for participants to consider their hands (*How will you represent your face, hands and hair on your body map?*) was important, as the hands of hair-pullers are their tools for hair pulling. The study findings highlight that the hands of hair-pullers represent a site where norms, ideas and values or 'normality' may be localized. Kay and Laura included the statement "Why don't you just stop?" on their maps. The reality of the experience they shared is that they cannot stop – and this has caused me in my analysis to question whether this reality, in part, renders hair-pulling 'normal' for their particular bodies. Within the accepted societal norms of appearance, which are generally known to be mutable, fluid, changing and culturally and socially-based, could there exist a space for the idea of 'normal' to include bodies *as they are*?

The additive impact of the operation of dual stigma is represented in the participants' data. For example, Laura and Kay shared clearly that showing visible hair loss in their workplaces (or, presenting as deviant from certain expected norms of appearance) is not an option. As well, they

both shared that co-workers knowing about the reason for the hair loss is not an option. The perception that the corporate environment could see Kay as “less mentally competent” and would demand an explanation for Laura’s shaved head are two examples of reasons that being seen at work is not accessible to these two women. They do not perceive themselves as having access to the possibility of being ‘seen’ at work, even in the context of their workplaces having set some examples for inclusivity. Laura calls this contradiction “the weirdest thing”:

The weirdest thing is, like, a lot of people I worked with had experienced some kind of mental health issue, and a lot of people were very open about it. Oh yeah, amazing colleagues. And it’s so inspiring. But I have never told anyone, about this.

She shared that “At my work, “everyone is very passionate and focused on the work... there just isn’t room for it [being open about mental illness]” as well as that “I lied to my colleagues. I was like, I can’t come to work because, it was literally hanging off my head. So I was like, I absolutely hate lying to my boss.” She reasoned that “It’s not an option for me because my work, like, it’s a non-profit, and there’s a lot of corporate partners, and it’s a very corporate environment...and I’m just not going to explain why I have a shaved head.” Laura uses the phrases *there just isn’t room*, *I’m just not going to explain*, *I can’t*. She had also said that she is “good at hiding it”, which contains the possibility of a deeper sentiment that hiding her hair-pulling is a success. Laura described her colleagues who are open about their mental health difficulties as ‘amazing’ and ‘so inspiring’ and yet does not hold herself to the same standard or feel that she has access to be out in the open as her colleagues have been. Kay shared that she feels pride in her workplace’s mental health inclusivity initiative work, although she is cautious about this inclusivity in practice, stating “They [her workplace] have some mental health awareness and initiatives, and I’m proud of that, but do they really walk the walk or just talk the

talk?” As a result, Kay is deeply protective and conscious of her appearance in her workplace. The difficulty of poorly-made hairpieces weighs substantially on her when considering how to present herself at work. She shared, “I can’t go back to wearing a wig, I can’t go back to work magically with a full head of hair. I think my blood pressure went up talking about that” and that “I wish I could get more comfortable [with her hair]. I’m scared that people will think I’m ‘less than’ at work. I don’t want people to see me as ‘less mentally competent’”. Kay uses the phrases *I can’t, I’m scared, people will think, ‘less than’*. As an advocate and Canadian BFRB community leader, Kay has substantial experience ‘coming out’, being open about her hair-pulling and discussing it with other hair-pullers. In her workplace, where there appears to be an assumption that the majority of her co-workers are not hair-pullers (which is likely correct), Kay demonstrates a sense of uncertainty and not feeling safe to ‘come out’ or be ‘found out’. Perhaps, being Kay the hair-puller and Kay the respected employee are not compatible. Kay represented work as outside of her body visually, she connected it with feelings of worry and of wasting her time (represented by a drawn image of a calendar). Kay places her connection to work as separate from herself.

Laura and Kay make judgements about the way their workplace would react or treat them if they were to be open about their hair-pulling. As they perceive that their workplaces will judge them, they are also judging their workplaces and making assumptions about how they might be treated. Kay and Laura are rightly justified in making these assumptions and judgements of their workplaces. Scior et al (2013) concisely make the connection between the experience of a person with a ‘difference’ and the very real impacts that this may have on their opportunities in the workplace and society in general in the following excerpt:

Labelling a person's differences is key to the stigmatization process (Link & Phelan, 2001). Behavior that is perceived as significantly unusual is more likely to be labelled, and its exponent can become associated with the undesirable stereotypes that a society associates with that label in the form of negative beliefs and expectations (Bogardus, 1959; Hamilton & Trolie, 1986). Stereotyping can lead to dissociation, discrimination in the form of punitive reactions, and the withholding of opportunities (Crocker et al., 1998), with negative social consequences (Link & Phelan, 2001) (p. 211).

Woods and Twohig (2008) (in Casati, 2010) state that “nearly 1 million work days are missed per year due to TTM symptoms, and nearly 73,000 working age adults may have ended their employment because of TTM” (p. 2). The impact of dual stigma comes into clear focus in the work environment. In contrast to Kay and Laura’s experience, Violet shares that in her workplace, being out in the open about her hair-pulling is accessible to her.

I guess I’m lucky because of where I work. Like, with disabilities, it’s kind of like, everybody is their own person. Yeah, so, I don’t care if anyone were to ask me, if clients were asking me if there were problems with my hair. Co-workers, I don’t really mind it”

Violet uses the word *lucky* when she discusses her workplace. This discussion occurred in a group body mapping session when the topic of work came up. She attributes this open-ness to the fact that “everybody is their own person”. This discussion is reflective of Scior et al’s (2013) exploration of the saliency of differences as it relates to labelling and stigma. They shared the example that education campaigns increasing public awareness of depression results in stigma reduction by, in part, altering the saliency of the label ‘depressed’ and changing the stereotypes and assumptions associated with the label. Violet’s sharing of workplace interactions where stigma does not operate as significantly may be indicative of an altered level of saliency of labels

such as ‘hair-puller’ or ‘mentally ill’ or ‘physically/behaviourally different’ due to her work’s specific environmental context. Violet shared that she was simply able to explain to a co-worker why her hair appeared to be thinning when asked. This is a stark contrast to the beliefs that Laura and Kay shared about the possibility of disclosing their hair-pulling to co-workers. Violet is not deterred from having honest discussions with her co-workers, while Laura feels that she does not belong in the category of “amazing” and “inspirational” as her co-workers who are ‘out’ with their mental illnesses. Further insight into the mechanics of saliency and how these environmental and contextual differences influence a person’s comfort with self-disclosure and being ‘out’ presents itself as a novel and needed area of study.

Self-stigma.

Attractiveness was not specifically addressed as a concept in the body-mapping sessions. There was no prompt or questioning about the term ‘attractive’. The topic of attractiveness emerged among the literature sources during the literature review as being inherently interconnected to norms of appearance, behavior, social acceptability and stigma. Ideas of attractiveness did not feature overtly in participants’ data. Self-image, however, was overtly attended to and was also prompted in the session facilitation. The prompts: *Which areas on your body map feel important to you? How have you represented the way you see yourself today?* are the only indications in the body-mapping facilitation that participants’ self-image was included in the map creation, however, as reflected in the emergent topics in the literature review, ideas of self-image were highlighted in the participants’ data. Laura showed significant grappling with her concepts of the idealized self and the ‘real’ self, sharing “The top head is my idealized self, what I strive for, and then relapse. The bottom is what my head actually looks like.” She continued, sharing that “Well, I’ve got two heads. One is like, my dream, my ideal. And that’s

the kind of thing I'm always aspiring towards, being like, always, like, going, making progress and then...relapse. That's actually what my hair looks like, there." To Laura, what is real is not her ideal and she connected the cycling between 'making progress' (not pulling), approaching the ideal, and experiencing what she called 'relapse' (pulling hair). Laura states that she 'strives' for the idealized portrait. She does not want to appear as "what [her] head actually looks like". This may represent a way that Laura's own self-stigma works in her experience. Violet's rendering of her self-image is a plain reconstruction of what anyone can see when regarding her. She shared that "my hair, is just me" when discussing how she depicted her hair on her map.

Adaptation.

Kay's sentiment that she "[wants] to be seen at work, but I don't want to be seen because of my hair" encapsulates the beginnings of an idea that emerged throughout my engagement with the participants in the body mapping sessions, and with their data in the analysis. Maggie shared "Hair means nothing". Laura said that she placed her personal symbol in the crouched figure "Because that's who I really am.", and Violet shared "My hair, just looks like me." This idea, that hair and hair-pulling is a part of identity but not the whole picture, runs tandem with the 1995 work of Kathy Charmaz, documenting a longitudinal study following people living with chronic illness. She outlines "*one* mode of living with impairment or loss of bodily function: adapting" (p.657). Adaptation, as it is represented in the findings of this study, presents itself in one way as an ongoing negotiation with the threat of being reduced to *only* the thing(s) that make the participants 'different'. This negotiation is enacted in the choices that people make regarding how they manage what is known about them and by extension, how they appear. The quotes above are statements that resist the ways that social assumptions, stereotypes and values creep into self-identity. By placing clear boundaries between self and social norms that pathologize

(and seek to pit women against) hair loss, the participants open up a resistant possibility that wholeness, humanity and identity *may* include a ‘deviant’ attribute. I use the term ‘may’ with strong intention, as I do not follow this idea with discussion of acceptance. Rather, this possibility represents curiosity: what would it mean if women (and the greater social world) did not wage war against hair loss? This idea may look like a form of acceptance, however, labelling it in this way is not in line with the words and work of the participants.

I was drawn to Charmaz’s work because of the multiple links she made between concepts of ‘unity’ concerning body and stigma, as well as her articulate capturing of tensions illuminated by the study of the ways people adapt to being impaired in some way. I do not intend to assume that Kay, Laura, Maggie or Violet identify as living with impairment. It is my intention to include references to Charmaz’ work (within the scarce sphere of literature concerning this study’s topic) as bridges to ideological allying with Critical Disability Studies and social constructionism in paying close attention to the relationship between body and identity. Charmaz noted that people with chronic illness may find that the stigmatized aspects of their identity override their whole self (1995). This is reflected in what the study participants had to say and how they represented their bodies visually. Maggie resists the reduction of her identity to diagnoses by literally dancing upon them and forcing them into the garbage. Violet carefully designed a whole-body roadmap that connects every aspect of her life together. Laura intentionally included two full portraits to capture the full range of her whole self. Kay “want[s] to be seen at work” but not because of her hair. Illness does threaten a person’s sense of integrity of self (Kestenbaum (1983) in Charmaz, 1995) and the same is shown as occurring in the case of hair-pulling. The risk of becoming socially and self-identified exclusively by the ‘difference’ (Goffman, 1963) is a reality and Charmaz (1995) offers that defining “themselves as much more than their bodies and

as much more than an illness” (p.659) is a part of adapting to this risk. In her conclusion, she states “the self is of the body yet beyond it.” (p.675). In the journey of undertaking a body-mapping project with these four women, I have seen how the body and self come to the table at multiple intersections of identity, and I am still learning. To add a social/relational dimension to this statement, I offer that in addition to beyond the body, the self is rendered through the body. The body provides a site within the ever-changing landscape of social environment for the interfacing of selfhood, identity and understandings of what we see in/on the world and what is seen in/on us.

Chapter Six: Critical Reflexivity: Critiquing the Process

Doing this research study “right”, was a deeply-engrained concept for me as I began researching and designing the work. I hoped that by adopting an Anti-Oppressive stance, I would be “doing right”. Since concluding data collection and analysis, I now recognize that ‘doing’ Anti-Oppressive work is just one way to approach the reduction of power operations when taking on research projects with people who may be marginalized. Another way to approach doing Anti-Oppressive work is to be critical of the notion Anti-Oppressive work; where it came from, what it seeks to do and the claims it makes. My engagement with a critical perspective of AOP, subject positioning and intersubjectivity was encouraged and supported by work in two MSW classes, *Self Reflexivity* and *Disability and Social Work*. I engaged with the work of the following authors: Badwall (2016), Heron (2005), Kondrat (1999), Nadan & Stark (2017), Reid & Poole (2013), Rossiter (2001), Warren (2000) and Wilson & Beresford (2000). This brought three key themes to my attention as I considered my relationship to the women who participated in my research.

Contradiction of Position

In-group membership and the challenge of ‘distance’ and where we locate the issue and ourselves in relation to ‘the other’.

Badwall’s (2016) research with racialized social workers showed that in many cases, “racism was viewed as a personal issue belonging to the worker, as opposed to a professional practice dilemma that needed attention.” (p.3). I saw this mirrored in the way I locate myself in relation to the research participants, making it about being focused on “[client] needs” by putting distance between myself and them. For example, I did not make myself available as a source of peer support, I tried not to share my reactions to participants’ work, and recruitment excluded potential from a peer support group that I facilitate.

Even though I claim that this study is informed by AOP, is this merely a re-packaging of oppressive practice? In my research practice I sought to design a level of distance between the participants and I under the premise that I was following AOP (by lifting up their stories, as if their stories exist in a vacuum). Did the notion of distance also serve to reinforce a critical reflexive practice in me that centered my location through a site of dominance ('researcher', 'scholar', 'academic'?).

Badwall (2016) also explored the 'heroic' narrative, where White subjects in their reflexivity restore their professional identities to a place of innocence. I returned to some of my original journaling that was the beginning of my reflexive work in the class *Reflexive Practice*. I saw the hero narrative very clearly explored in the context of 'distance' in the following excerpt from my journal:

I can from tell my repeated journal entries concerning "being enough", "being good enough" and "proving myself" as a student, a hair-puller and a researcher that a clear theme strings my many roles together. A deep need to be impressive. Owning up to this was particularly hard for me. I know that it rings true because it sits perfectly in my gut when I recall my history of feeling ashamed (or being made to feel ashamed) of my hair-pulling. I wondered, if I cannot "beat" compulsive hair-pulling, perhaps I can embody some semblance of a "good" hair-puller who achieves excellence in her social work degree, and does research that positively impacts the hair-pulling community. I wrote that if I struggle with a label of "mentally ill", at least I can be "impressive".

Feeling some distance from others in the hair-pulling community helped me to put the subject of hair-pulling "over there" as I engaged in researching and designing my study. This distance functioned as a buffer which offered protection from my personal ties to hair-pulling, and from the uncomfortable acknowledgement that I carry shame with me. I see now that I felt able to take on the research, in some ways, because I othered other hair-pullers.

"Honestly -", I wrote, "where do I position myself among the people I'm doing research with?" I defaulted to an inspection of power relations when I thought of my position. I am privileged to have had access to my social work education, to be able to "pass" as sane and to have had the resources and capacity to take on a thesis. I hadn't supposed it pressing to dig into what it will be like, for me, to be in a room in the role of researcher with others who identify themselves as living with the same behavior as me. That same behavior was the impetus for my desire to do inhabit the researcher role in the first place.

Without my own hair-pulling, the room would be empty [without the participants, *their* hair pulling, and their performing of this]. When I read my dilemma this way, I see clearly how I have embodied a “dividing practice” (Rossiter, 2001) in my social work action.

I look back on these reflections and wonder: In which ways did I *need* the participants to be ‘insane’ to do the research to redeem myself as a ‘good’ insane person?

The powerful/powerless dichotomy “works against racialized workers when they attempt to reflect critically” (Badwall, 2016, p.5), and this dichotomy leaves no room for an ‘insane’ ‘researcher’ as they erase each other depending on the context of the encounter! This flattens the possibility of intersubjectivity. And brings me back to my original noticing that I only saw unequal outcomes positioned in favour of me, I never thought to see how I could be disadvantaged by the outcomes of the research. As Badwall (2016) said: “The workers are limited to discussing only the sites of domination in their work and how these may affect client populations.” (p.5). This leaves out the ways in which “subjects [*and including myself as a subject*] are mutually constituted moment by moment, through historical and social discourses of power” (p.11)

Maintenance of Innocence

Deeply connected to my sense of self being tied to “getting it right” and doing self-reflection in itself maintaining myself as innocent.

“Innocence” in this case is meant to be the term as explored by Rossiter: the obscuring of problems of power and privilege between the social worker and her client (2001). Badwall (2016) asserts that critical reflexivity must be analyzed and understood within the context of White dominance in social work settings. As colonization sets Whiteness as a racial standard, it also sets ‘sanity’ as an ableness standard. As a white settler, I see the installation of whiteness and sanity as standard through colonial production of moral superiority and innocence as

inscribed in notions of academic knowledge. I also see whiteness being a prerequisite to produce ‘moral superiority’ which inherently standardizes ‘objectivity’ in research.

Badwall (2016) discusses the encouraging of the invisible (White, sane) subject to mark themselves. Naming my ‘insanity’ doesn’t necessarily undo power relations in itself. I wondered whether my ‘insanity’ was packaged as my access card to a ‘morally superior’ anti-oppressive practice.

Knowledges: Discursive and Practical

(“what everyone knows” from Kondrat, 1999)

“What-ifs” around whether my research choices would be different if I didn’t share the identity of hair-puller with the participants.

Perhaps justifying my research decisions feels easier when I seat myself in my identity as a compulsive hair-puller (and sharing that identity with the participants) because I feel that I can claim this discursive knowledge and can claim discourses around that experience. Richards (2008) in *Writing the Othered Self* talked about how people with disabilities are *written about* and how autoethnography allows for self-definition. By being an in-group member I took on writing about the issue but also about myself because I am included in the issue. She discussed the intricacy of writing about the self and how it might not in itself prevent me reproducing oppressive individualization.

So, Now What?

My work in the class *Self Reflexivity* left me feeling hopeless and disheartened, that I truly did wrong, and I wasn’t doing anything tangible to undo those wrongs by claiming that my study was “Anti-Oppressive”. This next step has allowed me to continue to theorize my experience with the help of Badwall, Ahmed, Richards, Wilson & Beresford, Nadan & Stark, and Rossiter. I want to answer my hopelessness and perhaps comfort myself with the intention of

comforting myself, and to invite myself and other researchers to consider what “doing” AOP means to them.

I have generated six learnings that I drew from my critique of my own Anti-Oppressive work.

These represent a beginning and a place to start. I intend to continue to build upon my critical values and to continue to gather tools to support my reflexive project of the self as a self-labelled ‘insane’ person, researcher and social worker.

1. Heroism narratives are rarely discussed and are needed to enhance critical work that wants to “do” anti-oppression. When maintaining innocence is shamed, objectivity is shamed, and closeness is shamed – where are we to go? We must problematize social work values themselves and maintain a critical perspective on the ways that practice is regulated.
2. Set trespass and harm as the normative standard of Whiteness and saneness and locate research within trespass to ensure that each step from the inception of the research objective onward is an act of working toward undoing potential harm.
3. Avoid conceptualizing ‘reflexivity’ as a medicine that ‘does’ *good work* on its own and move toward conceptualizing ‘reflexivity’ as a project of the self, as said by Adams (2003) (cited in Badwall, 2016).
4. Saying “have I been sanist?” is not accurate. A better question would be “HOW sanist have I been?” because I am a carrier of colonial ideology.
5. Honour the healing potential that accompanies ‘writing oneself in’ to greater scripts of colonization.
6. Acknowledge and respect the dependence of social work values and practice principles (ie. Anti-oppressive practice) on service users/marginalized people and their experiences, knowledges and participation.

Chapter Seven: Conclusion

In this study, I set out to further highlight the voices of people who pull their hair out compulsively in an arena of research literature which often leans toward the medicalization, pathologizing and labelling of this experience. As a person who pulls out their hair myself, I sought to design and contribute to research knowledge that reflected my own value; that my experience of being othered by society cannot be completely attributed to me, that dimensions of being 'different' originate outside of my body, my appearance and my behaviour.

I set out to be curious, to ask big questions and to explore big answers. I chose an arts-based methodology route to give these questions and answers ample space to develop and be expressed. I met and worked with four women who made visible certain aspects of themselves that are reserved for very few viewers, if any at all. These women took on an abstract task, to share their visions of their bodies and selves artistically and came back each time for five weeks. In doing so, these women have helped to set a new stage for the way academic knowledge is produced and translated. These four body maps will be the foundation for the face of body-mapping in Body-Focused Repetitive Behaviour research and community programming.

Impact of this Study

I am still grappling with my own questions around why research literature on the phenomenon of hair loss in general tends to exclude or neglect the experiences of women who pull out their hair. By including research knowledge about appearance, stigma and social norms surrounding the experience of hair loss caused by chemotherapy and alopecia in my review of literature, I intended to bridge this ideological gap. A recommendation that this study brings forward into research applications is to urge the research community to question the partitioning of inquiry into the impact of hair loss into 'mental' (compulsive hair-pulling) and 'physical'

(alopecia, chemotherapy) domains. I am keenly interested in the intersections of stigma, appearance norms and labelling as they interact among different 'reasons' for hair loss and believe that bringing these experiences to the table together may offer researchers and those with hair loss alike further insight into why women who are dealing with hair loss feel isolated, ashamed and othered.

As an example of arts-based inquiry, this study has unique programmatic and policy implications. Examples such as Piko and Bak's (2006) study of children's drawings of their conceptions of health and illness, and Herman & Larkey's (2006) study on the changing of attitudes toward breast health using an arts-based curriculum show the potential of arts-based health research to affect health care policy and practice. The power of the arts to encourage public engagement, disseminate and translate new knowledge is noted by Boydell et al (2012). When I presented the body maps at a scientific poster event during a conference for Body-Focused Repetitive Behaviours, researchers, mental health practitioners and members of the community alike all shared with me that the visual representation of data encouraged them to look at the experience of hair-pulling in a new way. The life-size and vibrant colouring of the artwork encouraged those visiting the poster event to gather near my display and spend time discussing what they saw. Boydell et al (2012) share findings that document the use of the arts to foster a sense of community among the general public. In the way that arts-based research encourages creativity, enhances collaboration and confidence in those who participate in the research (Boydell et al, 2012), I also would like to extend these benefits to those who engage in viewing the art. The audience is also encouraged to think creatively in their encounter with the data, and to be in dialogue with the participants in new ways.



Figure 39. Presenting the body maps at a research poster event during the TLC Annual Conference for BFRBs, April 2018.

Limitations

I would have liked to have co-developed the session facilitation guidelines with people who pull their hair out. One way to go about this would be to have held focus groups to gather information from this community about what feels important to them regarding my research objectives. The strategy I used to develop the session facilitation guides, to generate ideas and questions from existing peer support group meeting minutes, was a sufficient way to stay close to the voices of the community. However, holding focused discussions on the content of the research would have generated a more targeted approach which could be more reliably understood to be grounded in the voices of the community.

With more time, this research could have also greatly benefited from the opportunity to test the body-mapping facilitation guide on a pilot group. I did 'test' the body-mapping guide on myself and found this very helpful in editing session content and deciding how much could be

expected of participants in certain time frames, whether certain questions were redundant, which exercises fit well together, and in which order. Testing the session guide with people who were outside of my own head and not as invested in the research project as I, would have been very useful to assist with streamlining the content. For example, my third research theme: "Changing the Discourse" which included the session exercise "Vision for the Future" did not appear to resonate with the participants. I noticed that most of the participants preferred not to follow the session guide as it appeared on paper. Each participant referenced the guide, considered the questions, and made their own sense of it. I am very interested to learn what they thought of the structuring of the sessions and the questions I asked.

Future Directions

I do wonder what could be possible for this type of methodology in terms of a more intensive session format. For example, condensing the session timeline to two consecutive days where participants were together for the whole day, creating together, and more immersed in the art-creating process and in their telling of their experiences. On the other hand, body-mapping can also be attenuated to suit shorter durations of time, in which participants represent parts of the body (perhaps the hands, as were highlighted in the findings of this study, or the head or face). The development of a short-format version of body-map storytelling could be easily taken-up as a research data collection method, or a therapeutic tool.

My study took a general look at people's experiences with discourses. Trends emerged in the findings that indicated clear separations between participants' experiences with social discourse in their workplaces, in the community, and with health professionals. Future explorations into each of these domains of discourses could highlight power and stigma's movement in these different settings and offer insight into how workplaces, employers, health

professionals and support circles of people who pull out their hair can adapt to better meet their needs (instead of implicitly or explicitly pressuring hair-pullers to change themselves). A finding in the data, that environmental and contextual differences may influence people in different ways regarding their comfort with self-disclosure and being ‘out’.

During the stage of recruitment, many people contacted me and were interested in participating in the body-mapping study but were unable to attend for certain reasons. The positive response I received has planted the seed that this type of exercise is something that people are interested in, can benefit from, and may enjoy. Whether body-mapping with compulsive hair-pullers (or those with other BFRBs) becomes an ongoing project of research, or community programming, or therapeutic activity, I plan to continue to develop the session facilitation methods to develop what this type of activity may offer this community, my community.

I will author an article to be shared with the Canadian BFRB Support Network on their website. I plan to show the body maps as an exhibit in community spaces in Southern Ontario and the Greater Toronto Area, and to display this exhibit in collaboration with the Canadian BFRB Support Network future public events. This study will be presented at Social Work research and practice conferences. I plan to author articles about my experience designing the body-mapping facilitation guidelines to add to current literature about this exciting, transformative and emergent methodology. To echo the words of my academic advisor, Magnus Mfoafo-M’Carthy, who agreed to work with me on this project on the condition that the research would never sit on the shelf and collect dust – the resulting art pieces which were imagined, designed, created and analyzed, belong on display for as many eyes to see them as possible, to

invite broad audiences to participate in a completely unique experience of storytelling data and to truly stand beside these women who pull out their hair.

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Appendices

Appendix A: Five-Session Facilitation Plan

| |
|--|
| <u>Session 1: Introduction</u> |
| Introduction <i>Group Introductions</i> <i>Safety and Security Rules/Group Norms</i> <i>Research Consent</i> <i>Art Demonstration</i> <i>Examples of Body Maps</i> |
| Collective Reflection* |
| Body Tracing <i>How will you decide the position would you like to be traced in?</i> <i>How will you decide on the colour to trace with?</i> |
| Debrief and Self-Care |
| Homework: Key Experiences, Personal Symbol and Slogan |
| <u>Session 2: Being You</u> |
| Collective Reflection |
| Body Scanning Consider Your Body Image: <i>Think of how you view your body. Which areas on your body map feel important to you?</i> Consider Your Self-Image: <i>Think of how to represent the way you see yourself today.</i> <i>Has living with compulsive hair pulling shaped who you are?</i> Your Key Experiences <i>What are the key moments (“turning points” “lightbulb moments”/moments that stand out) in your life that relate to your hair pulling? What is the best way to represent them on your body map?</i> Personal Symbol and Slogan <i>Which symbol and slogan have you chosen to represent your journey as a person who pulls out their hair?</i> <i>Where do you want to place these on your body map? What does the placement mean to you?</i> |
| Debrief |
| Homework: Self-Portraits and Point of Personal Power |

*Collective Reflection (5 min)

Participants given session handout with theme and exercises

Session theme introduced

Participants may ask questions to clarify what the session will entail

Participants may take time to gather thoughts and ideas

Session 3: Seeing Yourself

Collective Reflection

Self Portrait

How would you like to represent your face, hands and hair on your body map?

How would you like to show their connection to your experiences?

How will you express your beliefs about your hair pulling on the map?

What would you like to say to yourself about your journey?

Point(s) of Personal Power: Resilience and Coping

Where on your body map do you want to represent your inner strength? What do you want this point to look like?

How would you like to represent your (internal or external) supports and where they come from?

Debrief

Homework: Interacting with Others, Messages to Others, Vision for the Future

Session 4: Being With Others

Collective Reflection

Interacting with Others

What messages do you receive from other people regarding your hair pulling?

What have interactions with others looked like? How will they look on your body map?

Messages to Others

What would you like people to know about living with hair pulling?

Vision for the Future

What does your vision look like on your body map? What changes do you see? What changes would you like to see in yourself, your situation, other people?

Finishing Touches

Are there any important aspects of your experience that you would like to further highlight on your body map?

Debrief

Homework: Personal Narratives, Consent to Share

Session 5: Sharing

Personal Narratives

- You are invited to share your finished body map with the group and to tell your story/experience of creating it.

Debrief

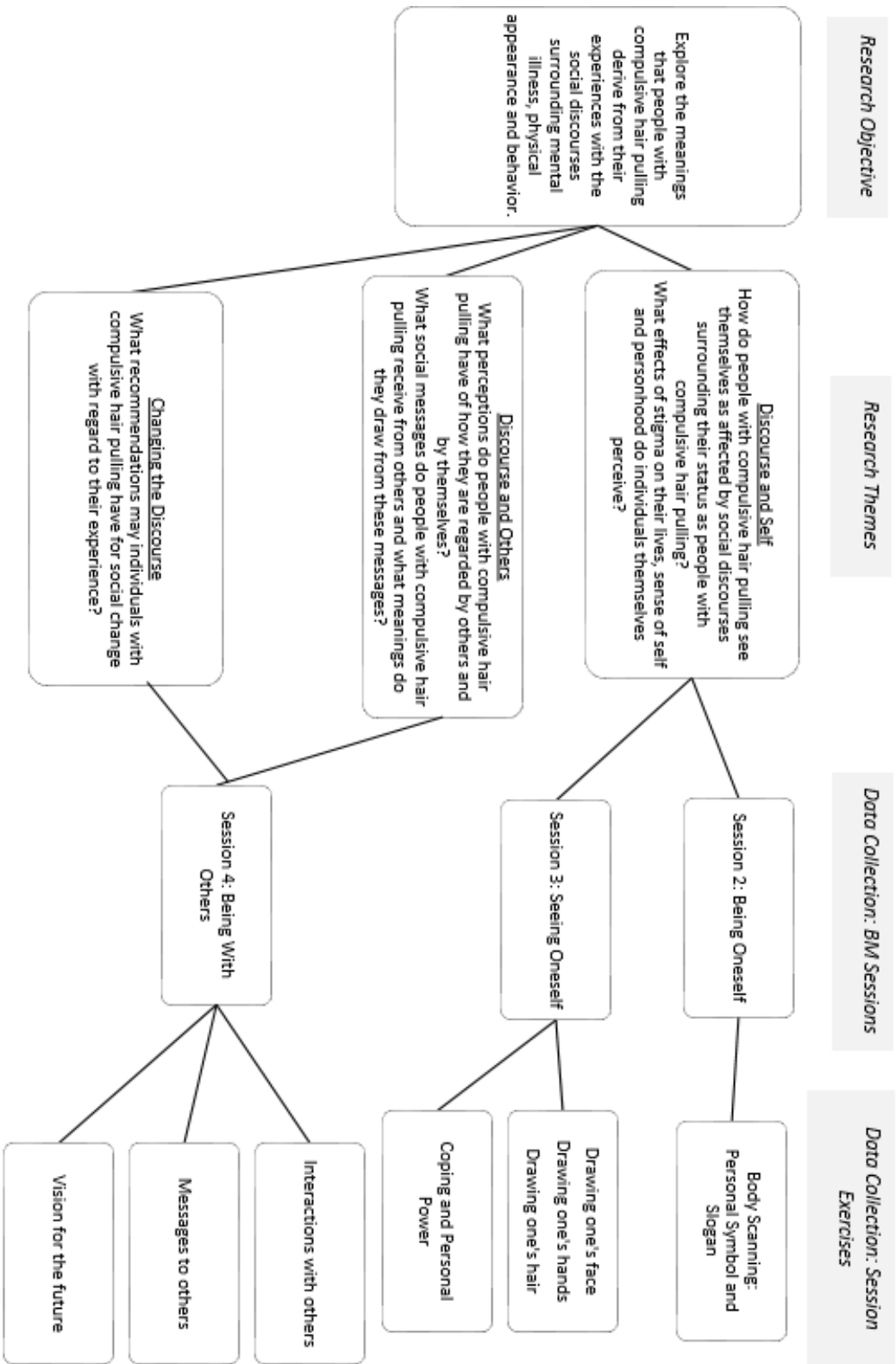
Consent to share maps and personal narratives

- Would you like to keep your body map? (Will need 2 weeks to photograph)
- Now that you have created your body map and shared your personal narrative, do you give your consent to have these two pieces of work incorporated into the research report?
- Group consensus on drop-out window

Personal Information Removal

- Identify anything in/on your body map or personal narrative that reveals personal information and decide whether you would like to alter or remove these items to protect your privacy

Appendix B: Research Themes and Objectives Flowchart



Appendix C: Advertising Poster

UNIVERSITY RESEARCH ETHICS BOARD APPROVAL REB5387



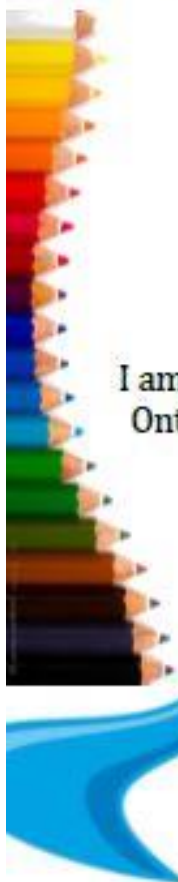
Do you live with compulsive hair pulling?

Or have you been diagnosed with Trichotillomania?

*I would like to make art with you!**

My name is Julia Mason and I have Trichotillomania.

I am a Master of Social Work student at Wilfrid Laurier University in Ontario. I invite you to participate in my research study in Toronto about living with compulsive hair pulling.



\$50 compensation

If you are interested please contact me for more information:

maso4970@mylaurier.ca or **519 803 1420**

**Artistic experience NOT required!
(not even a little bit)*

Appendix D: Participant Screening Form

Participant Screening Interview Script

Name:

Address:

Email address:

Telephone number(s):

Do you pull out your hair compulsively?

Have you been diagnosed with Trichotillomania? (This is not a requirement to be eligible for the study)

I am hoping to recruit a group of people who compulsively pull out their hair to participate in a research study. I am interested in including people in the study who have a wide range of life experiences. Would you mind if I ask some personal questions? You are under no obligation to answer any questions that feel uncomfortable to you.

Age:

Gender Identity:

Race, ethnicity:

Are there any other things about you that you think are relevant as a person living with compulsive hair pulling?

Are you available to participate in 4 weekly focus group sessions which will be 2 hours each?

Are you open to participating in research that is arts-based? This study involves you drawing a life-sized portrait of you body to express your stories of living with compulsive hair pulling.

I will get back to you shortly regarding whether you will be included in the study and if this is so, I will provide details about the study time and how to be a part of it.

If you would like to discuss this further or have any questions please feel free to contact me:

Telephone: XXX XXX XXX Email: maso4970@mylaurier.ca

Thank you for your interest and time.

Appendix E: Informed Consent Form for Participants



WILFRID LAURIER UNIVERSITY

Informed Consent Statement for Research Participants

Research Project Title: Exploring the Discourses of Compulsive Hair-Pulling: A Body-Mapping Study

Principal Investigator

Julia Mason
Master of Social Work Candidate

Research Supervisor

Magnus M'Fofo-M'Carthy, PhD
Wilfrid Laurier University
Associate Professor, Faculty of Social Work

Contact us at:

maso4970@mylaurier.ca

mmfoafomcarth@wlu.ca

519 884 0710 x 5238

Do you live with compulsive hair pulling?

*I would like to make art with you!**

My name is Julia Mason and I am a Master of Social Work student who lives with compulsive hair pulling. I invite you to participate in my research study about living with compulsive hair pulling.

Artistic experience NOT required! (not even a little bit)

This study has received WLU Research Ethics Board Approval

Reference: REB 5387

STUDY INFORMATION

I am seeking people aged 16 and older who live in the Greater Toronto Area who:

- Pull out their hair compulsively or identify as having the Body-Focused Repetitive Behaviour called Trichotillomania

A formal diagnosis of “Trichotillomania” or “Hair-Pulling Disorder” is not required

How Much Time Are People Asked to Commit?

Participants will be asked to commit to five weekly two-hour group sessions, beginning in early October 2017.

Will I Be Compensated?

Participants will receive \$50 cash for participating.

What Will Happen in the Sessions?

Seven participants will meet as a group in a secured, private meeting room. Room location is to be finalized in collaboration with participants to make sure that a location is found that is accessible to everyone. I (Julia Mason, the principal investigator), and a co-facilitator will facilitate five sessions of Body-Map Storytelling where participants will create a life-sized portrait of themselves. Participants will also be audio recorded throughout each session to gather more information about the process and products of making these portraits, called “body maps”.

What is “Body-Map Storytelling?”

This method of arts-based research, originally developed as an art therapy method by clinical psychologist Jonathan Morgan in South Africa. It was adapted as a research tool in 2002 to reflect the experiences women living with HIV/AIDS². Body-mapping engages participants beyond “just asking people questions, in language”³.

What to Expect in Each Session

The co-facilitators will follow a facilitation guide which will lead the group through the process of body-mapping. Participants will be asked to respond to questions both visually, through expressing their responses on the life-sized image of their body, and verbally, in discussion throughout the sessions.

² Gastaldo, D., Magalhães, L., Carrasco, C., and Davy, C. (2012). Body-Map Storytelling as Research: Methodological considerations for telling the stories of undocumented workers through body mapping. Retrieved from: <http://www.migrationhealth.ca/undocumented-workers-ontario/body-mapping>.

³ Gauntlett, D. & Holzwarth, P. 2006. Creative and visual methods for exploring identities. *Visual Studies*, 21(1), 82-91.

POTENTIAL RISKS AND BENEFITS OF PARTICIPATING

It is important that interested people know what to expect when considering whether they will commit to participating.

Potential Risks of Participating

A foreseeable risk that may accompany participation in this study is the emotional impact of discussing one's mental health history. This may result in participants feeling vulnerable or uncomfortable. The principal researcher of this study lives with compulsive hair pulling and has experience with the emotional toll of living with compulsive hair pulling. Discussing hair pulling with others may be out of the ordinary for those who do not openly disclose or share this information.

Participants who wish to be connected with supportive resources following participation in the study will be provided information on counselling and support groups. The facilitators of the research sessions will be available to participants for ongoing support and will be open to feedback regarding the experience of participating in the research sessions.

In one activity of the research sessions, participants are asked to create an outline of their body on a large sheet of paper. Some participants may find it uncomfortable to have their body traced. Participants may choose to trace someone else's body onto their sheet of paper, or may choose to draw an outline of a body without tracing to reduce discomfort with this exercise.

Participants will be referred to the following mental health help lines:

Toronto Distress Centre: 416-408-HELP (4357)

York Support Services Network: 1-855-310-COPE (2673)

ConnexOntario Mental Health Helpline: [1-866-531-2600](tel:1-866-531-2600)

Participants will receive information packages from the Canadian BFRB Support Network, which is the only Canadian resource which specifically provides support for people living with BFRBs. Should a participant feel they need a person to talk with during or immediately after a body-mapping session, both the principal investigator and co-facilitator will be trained active listeners available to support a participant experiencing distress or discomfort.

Potential Benefits of Participating

This study is one-of-a-kind research that will benefit the mental health field, and those living with Body-Focused Repetitive Behaviours and their circles of friends and family.

Participants will be offered resources to connect with community and a support network specific to compulsive hair-pulling, and may benefit from a reduction in isolation and feeling alone in their experience of compulsive hair-pulling.

As the method body-map storytelling was originally conceived as a method of art-therapy, participants may experience therapeutic benefits from participating in arts-based exploration of their experience. It is hoped that participants may experience greater agency and self-advocacy, and self-empowerment through exploring their experiences with hair pulling.

Participants may benefit from engaging in research facilitated by someone who also lives with compulsive hair-pulling, as some people have never met anyone else who lives with the same behaviour.

MAINTAINING PARTICIPANTS' CONFIDENTIALITY

Free and Informed Consent

Prior to Participation in Research Sessions:

The primary investigator will verbally repeat confidentiality measures during participants' individual screening interviews.

During the first body-mapping research session, confidentiality measures will be repeated to confirm participants' informed consent and understanding of the research process.

During the Last Research Session:

In the last body mapping research session, participants will be asked to give their consent to have the data they created in the sessions included in the research report and possible later publications.

In the last session, participants will also be asked to provide consent for their quotes to be included in the research report and possible later publications.

Participants can sign a withdrawal form that outlines the procedure that will be followed if they withdraw, confirms understanding that data will be destroyed, and asks if they wish to be contacted further or not.

Anonymity in Data: Use of Body Maps

Participants will be asked to provide their initial consent for their final body maps to be photographed and/or exhibited (possibly in the future). If a participant consents to the photographing of their body map, they will be able to provide consent to have images of their body map included in the final study report and/or subsequent publications using the data collected in this study.

Consent to photograph/exhibit their body map will be reviewed during the final session of body-mapping to allow participants to remove their consent, should their decision change throughout the course of the research sessions.

During the final body-mapping session, the research team will work with participants to review their body map should they want to alter or remove potential identifying information that may compromise their anonymity.

Participants will be invited to confirm that their privacy has been maintained in the final draft of the report. Participants can opt to review the final report draft and ask the principal investigator to modify or remove any information that they decide is too personal to be included.

Anonymity in Data: Use of Audio Recordings

Participants will be asked to provide a pseudonym which will be connected to their data in the research process following data collection, in lieu of the name(s) that they provided at the time of the screening interview/body-mapping sessions.

Confidentiality will also be addressed in a process of “data cleaning” whereby participants’ personal identifiers (names) will be replaced with their chosen pseudonym in the transcript of the audio recordings of interviews conducted with them.

Through a member-checking process, participants will be consulted when considering the inclusion of contextual information that could disclose their identity in the final draft of the research report.

Security of Data

Participants will be anonymous in the data and final research report. Participants will choose a pseudonym which will replace their name in all data and sharing of research findings.

Participant identifying information and contact information will be stored on an encrypted USB stick stored in a locked cupboard in a locked office.

Body maps will be stored by the research team in between sessions in a secured, locked office. At the end of the five body-mapping sessions, body maps that participants consented to be donated to the research team will be kept in a secured, locked office for 5 years.

Participants can opt to have their data withdrawn from the research findings at any time throughout the research process. Data and identifying information will be destroyed within 24 hours of their request to withdraw.

PARTICIPATION

Participation in this study is voluntary; people may decline to participate without penalty and may withdraw from the study at any time without loss of benefits to which they are otherwise entitled. If a person withdraws from the study, every attempt will be made to remove their data from the study, and have it destroyed. Participants have the right to omit any question(s)/procedure(s) they choose.

Due to the nature of the research occurring in a focus group style, at the first research session the co-facilitators will outline procedures for maintaining confidentiality among the group to respect the privacy of all involved. This will include creating group “rules” for respectful participation, not sharing any stories or identifying information outside of the research session, and not discussing other participants outside of the research sessions.

Audio recording from the research sessions will be used for research purposes in this study only. Only the project team will have access to the audio recordings. At the end of the study, the audio recordings will be kept locked as secured for one year, and then will be destroyed. Following the study, the audio recordings will not be used for any additional purposes without participants' additional permission.

The principal researcher will transcribe the audio recordings and will keep all information confidential.

Opting to Withdraw

Participants can opt to have their data withdrawn from the research findings at any time throughout the research process. Data and identifying information will be destroyed within 24 hours of their request to withdraw. Hard-copy documents will be shredded and electronic files will be deleted.

Participant Termination from the Study

The co-facilitators of the research sessions may terminate a participant's participation in the research regardless of their consent. This would occur in the interest of protecting the safety and privacy of all involved in the research. The circumstances under which this will apply are:

- If a participant disrespects the group "rules" as set in the first research session
- If a participant displays disrespectful behaviour toward another participant or a co-facilitator
- If a participant violates confidentiality measures (ie. Reveals private or identifying information about another participant without their consent)

COMPENSATION

For participating in this study participants will receive \$50 cash and compensation for travel to/from the location via public transit. If a participant withdraws from the study prior to its completion, or misses any sessions, they will receive the same compensation. Participants will receive this compensation on the date of the final research session.

FEEDBACK AND PUBLICATION

Participants can opt to receive a hard copy of the final research report. The final research report will be available in July of 2018.

The research report will be published as a Master's level thesis dissertation on Wilfrid Laurier University's Theses and Dissertations database. The study report will be shared with the Canadian BFRB Support Network's website and social media pages.

The results of the study may be presented at future Canadian BFRB Support Network information events, conferences organized by the TLC Foundation for BFRBs, and at Wilfrid Laurier University educational events.

CONTACT

If participants have questions at any time about the study or the procedures, (or they experience adverse effects as a result of participating in this study) they may contact the primary investigator, Julia Mason, at maso4970@mylaurier.ca, or the research supervisor, Magnus M'Fofo-M'Carthy at mmfoafomcarth@wlu.ca or 519 884 0710 x 5238.

This project has been reviewed and approved by the University Research Ethics Board. If a person feels they have not been treated according to the descriptions in this form, or their rights as a participant in research have been violated during the course of this project, they may contact:

Dr. Robert Basso
Chair, University Research Ethics Board. Wilfrid Laurier University
(519) 884-0710, extension 4994, rbasso@wlu.ca

PARTICIPANT DECLARATION OF CONSENT – PARTICIPANT COPY

Participants may choose to alter their consent at any time throughout the length of the research study.

- 1) I understand the research study, how I am involved, and understand the risks posed by participating in this study. I have received a copy of this form. I agree to participate in this study.

Participant's signature _____ Date _____

- 2) I consent to be audio-recorded during the five research sessions.

Participant signature _____ Date _____

- 3) I consent to the investigator including my quotations in the research report (Optional).

Participant signature _____ Date _____

Use of Body Maps

- 4) I consent to my completed body map being photographed and the images used in the final research paper, or subsequent publications of the study data.

Participant signature _____ Date _____

- 5) I consent to donate my completed body map art piece to the Principal Investigator upon completion of the research study (Optional).

Participant signature _____ Date _____

COMPENSATION

For participating in this study participants will receive \$50 cash and compensation for travel to/from the location via public transit. If a participant withdraws from the study prior to its completion, or misses any sessions, they will receive the same compensation.

Participant's initials: _____

Researcher's initials: _____

PARTICIPANT PSEUDONYM: _____

This pseudonym will be used in the final report to maintain the participant's anonymity.

CONSENT – RESEARCHER COPY

Participants may choose to alter their consent at any time throughout the length of the research study.

- 1) I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature _____ Date _____

- 2) I consent to be audio-recorded during the three research sessions.

Participant signature _____ Date _____

- 3) (Optional) I consent to the investigator including my quotations in the research report.

Participant signature _____ Date _____

Use of Body Maps

- 4) I consent to my completed body map art piece being photographed and the images used in the final research paper, or subsequent publications of the study data.

Participant signature _____ Date _____

- 5) I consent to donate my completed body map art piece to the Principal Investigator upon completion of the research study.

Participant signature _____ Date _____

PARTICIPANT PSEUDONYM: _____

This pseudonym will be used in the final report to maintain the participant's anonymity.

Appendix F: Example Participant Data Table

| Exercise | Participant Data | |
|-------------------------------|---|---|
| | Graphic: Julie's Description of Body Map | Narrative: Transcript Quotes |
| <i>Body Tracing: position</i> | <p><u>First Session</u> Standing, left arm with elbow bent, hand in fist Right arm straight down along body Outlined in blue and green</p> <p><u>Second Session</u> Added second figure, over top of standing figure Standing, bent over, head down and cradled within arms and hands Outlined in red and black</p> | <p>(First session): "Transition from shame to strength."</p> <p>(Second session) L: "It didn't feel like the first one [outline] was honest"</p> <p>L: "I was sort of thinking like, I really like last week, but it's really not the truth. It's just a little bit of a lie. I'm not like that all of the time."</p> <p>L: "It's weird because normally I would say that red is my favourite colour. And I wouldn't use it for something I associate with negative emotions."</p> <p>L: "Like last week, I just wanted to focus on the strong, the positive. And this week I just went right to the doom. Angry, sad. And that felt a bit more honest. Right now."</p> <p>[From Julie's session notes – session 2]: Second figure hunched, crouching down, hands almost in position of covering/shielding head.</p> <p>Chose to outline hunched figure in red and black - anger, sadness - note that red would normally be Laura's favourite colour.</p> <p>[From Sarah's session notes – session 2]: Traces a second pose. Movement/transition. Last week described the transition of from shame to strength. This week was asked about this and said that it's "more of a cycle between the two"</p> <p>L: "So, in position. I'm standing up. I've thought there's always this conflict where</p> |

| | | |
|---------------------------------------|---|---|
| | | <p>I try to observe myself as this confident person. And the other thing about my hair-pulling, is that I've always been really, really good at hiding it. And then a few months ago I couldn't hide it any more, so I paid some money to stick something on top of my head. There's always these parts of myself that are really hidden, and I think about them every day and I don't talk about them with anybody. Or maybe, like, a couple of people.</p> <p>So that's why there's this kind of ghostly person who's like, crouching down and if you take away all the cover-up that's essentially...the bald patches and red marks because I pick my skin as well and it bleeds. For me, it's a lot about shame. And hiding things away. I thought when I saw this, should I look in my old diaries? But I would never write anything really personal."</p> |
| <i>Body Scanning: important areas</i> | [n.d.] (no data) | |
| <i>Body Scanning: self-image</i> | Black circular scribbles in chest Around right shoulder, going into forehead | <p>L: "A lot of the time I looked at these questions and I thought "oh my god, I don't know, I don't know". What do I do to support myself? I don't know. When did I start this? Where does it come from? I can't remember how old I was when I started. I can't remember why, what was happening. So that's also why I've got a lot of cloudiness inside because I just feel that it's been quite hard to think about the answers to all these things. It's not clear to me. And I've always thought that I'm really self-aware but I guess there's things that I find a bit mysterious."</p> |

Appendix G: Example of Open Coding

Open Coding: Laura

Laura sees herself as inhabiting/having two bodies / presentations / presented selves / curated selves
The tall body is what Laura strives toward and she describes it as “not the truth”, not what she is like all of the time

The crouched body shows what Laura sees when the things she does to cover up and hide are removed
Laura shows that she embodies the tall self and lives in the tall self more and the crouched self is a part of her true self but not the whole self

Laura’s tall body is filled with a cloudy sense – uncertainty, confusion, connected to her head/mind and the messages beside her body

Messages that Laura receives settle in her body and contribute to confusion and self-doubt

Laura soothes herself and cares for herself as part of being well and feeling proud

Laura locates love and good body experiences within the crouched body

Laura inhabits both bodies but not equally

Laura’s sense of longing and intergenerational family cultural connection (Hiraeth) is not cloudy, this sense is clearly felt

It is important to Laura to keep in touch with a dear friend that she cares for and that cares for her

Being held/supported by a loved one stops her hair pulling and literally immobilizes her

Laura shows a story in the hand that goes up to pull her hair lets go of her writing book, and then her partner’s hand grabs her wrist. Hair pulling interferes with Laura’s passions, and her partner interferes with her hair pulling

Laura feels commanded by the messages she receives that originate from outside herself

Laura shows that what appears outside may not reflect inner processes / feelings / experiences

Laura presents a counter-discourse, that a seemingly ‘normal’ body is containing hardship and the seemingly ‘abnormal’ body is containing joy and love

The crouched head, ‘ghostly’ figure is lowered, pushed down, pushed away

Staying connected to people who understand her keeps her proud and strong and well

Losing connection to passions and people and supports gets Laura slipping into the ‘ghostly’ body

Hair pulling causes Laura pain

Laura sees her “real” head as a site of soreness, anger, pain, “doom”

Laura shows the messages from outside as weighing down, pushing, crowding, sitting on top of the crouched head

Laura’s feet are floating, Laura is floating, not standing on anything

Laura’s tall figure is more substantive, legs are shaded in, face is depicted

Caring for herself is higher up than anything else

Below torso, ‘ghostly’ self is empty

Discourse and Self

Laura sees herself as split

Laura sees herself as enduring questioning and confusion

Laura sees part of herself as hurt and hiding

Laura depicts turning away from messages she receives and turning toward the people/connections that love her

Laura wants to appear strong and proud and well

Laura shows the impacts of discourse on her proud body in the torso, confusion, scribbles, it is hard to be proud while enduring these messages within an unstable sense of self
 Laura carries self-stigma within her body

2. Being either/or outwardly

Having to cultivate strength within the crouched body, loving and caring for the hurting parts of herself

Discourse and Others

Regarded as “either / or”

Regarded outwardly as EITHER tall proud well, OR, hidden, secretive, hurting, ashamed

The “real me” is reserved for Laura and only few trusted people to perceive only

The two figures share strength

2. Why don't you just stop? You don't know who you are. You are too much. Do not fuck up.

Is she fucking up?

It appears that Laura both is and isn't fucking up.

Pressure to be a certain way – tall proud well

Pressure to know who she is, repeated depictions of confusion regarding sense of self

Pressure to have a unified sense of self – the impact of having a secret is significant

Pressure to know what will help her, what could help

Laura is wanting to change, longing for something, but doesn't know what to do (Hiraeth in scribbles)

Laura is seeking a connection to self

Changing the Discourse

There is strength in the hurting body

There is self-doubt in the proud body

Laura doesn't know the answers for herself and does not share a message for others

Laura cares for herself even though messages from others and self-doubt interfere with her sense of self and wholeness

Laura honours the things that are separate from her hurt/pain and that remind her of her passions and abilities (running, reading, writing, drawing)

Laura shows in her body map that although the majority of her map depicts confusion and pain that she recognizes her capabilities and the things in her life that nurture her

Laura STICKY NOTES

Unstable / unsure sense of self on arms

Envelope close to head, part of what keeps her strong

Fist? No detail in fingers

“She” third-person

Arm raised up to pull, lets go of book, is grabbed by her partner

Purple dots from heart to envelope from within the scribbles to outside body – connection

Book is a big element – falling away, passions neglected?

A faint sun outline – natural element

Eyes closed, not seeing, not wanting to see?
Nose piercing – identity
Confusion in proud head
Tall “proud” self – what others see – what Laura strives toward
Head is an active dynamic location
Soothing, self-care, gentleness, medicine?
“Why can’t you just stop?” among the scribbles, confusion, same side as messages from others
“You” don’t know what you are. “You” are too much.
Messages coming in from outside are the biggest element of the map aside from body
Hiraeth is clear, calm, sure
Whole torso of proud self is filled with scribbles, uncertainty, doubt?
Unsure sense of self
Commands from others, being told
Words from others impacting pain
Overt depictions of raw, hurting, bloody head
Bald spot shown, red, angry, hurt, doom
Iris Murdoch quote takes up almost whole crouched torso – love and pain
Giving love and receiving love, self love (tattoo) held within crouched figure
Tattoo – body love, positive experience with body – on crouched figure
Contents inside vs what appears on outside
Bent over figure, hiding, shame
Blood
Hands touching / protecting
Empty legs crouched figure
Shaded legs proud figure
Shoes apart from body
Detail in depiction of shoes, reminder of positive body experience
Feet floating, no ground to stand on
Eyes closed