PATHOLOGIZING THE UNKNOWN:
A CROSS-CULTURAL STUDY OF THE HAIR-PULLING DISORDER

A THESIS SUBMITTED TO
THE GRADUATE SCHOOL OF SOCIAL SCIENCES
OF
ISTANBUL ŞEHİR UNIVERSITY

BY

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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR
THE DEGREE OF MASTER OF ARTS
IN
SOCIOLOGY

MAY 2015

This is to certify that we have read this thesis and that in our opinion it is fully adequate, in scope and quality, as a thesis for the degree of Master of Arts in Sociology.

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I hereby declare that all information in this document has been obtained and presented in accordance with academic rules and ethical conduct. I also declare that, as required by these rules and conduct, I have fully cited and referenced all material and results that are not original to this work.

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ABSTRACT

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May 2015, 85 pages

This thesis aims to analyze the pathological discourses of “hair-pulling” disorder, known in psychiatry as *trichotillomania*, in two different contexts: Turkey and the United States, through the perspective of science and technology studies (STS). By conducting semi-structured interviews with psychiatrists, psychologists, patients and their families, participant observation at the annual conference of the Trichotillomania Learning Center, the biggest patient organization for trichotillomania around the world, and virtual ethnography in online support groups at both contexts, the *co-production* of trichotillomania as a psychological disorder is examined. My findings demonstrate that although experts in the U.S. are well-informed on trichotillomania and hair-pullers improve their knowledge through Trichotillomania Learning Center, patients are being treated with the same manner of categorizations, regardless of the context, and are subject to tr(ial-and-error)eatments rather than treatments. As a contested psychological disorder, trichotillomania is persistently analyzed by scientists at the molecular level, which still has not led to a possible treatment. Rather than constructing lay expertise by getting involved in the evidence-based activism like the famous patient organization

ACT UP for HIV, Trichotillomania Learning Center focuses on popularizing trichotillomania and generating hope among the patients for the success of future research. Through multi-sited ethnography and cross-cultural analysis of trichotillomania, this thesis provides insight into the co-production of psychological disorders by both the social and material world, and puts forward a vivid example of the molecularization of psychological disorders at the crossroads of psychiatry, genetics and neuroscience at the present time.

Keywords: trichotillomania, co-production, molecularization, science and technology studies, lay expertise, Turkey

ÖZ

BİLİNMEYENİ HASTALIKLAŞTIRMA:
KIL YOLMA BOZUKLUĞUNUN KÜLTÜRLERARASI İNCELEMESİ

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Tez Danışmanı: Yrd. Doç. Dr. Ebru Kayaalp

Mayıs 2015, 85 sayfa

Bu tez, psikiyatride trikotilomani olarak geçen kıl yolma bozukluğunun patolojik söylemlerini bilim ve teknoloji çalışmaları perspektifiyle Türkiye ve Amerika bağlamları üzerinden analiz etmeyi amaçlamaktadır. Psikiyatristler, psikologlar, hastalar ve aileleri ile gerçekleştirilen yarı-yapılandırılmış mülakatlar, dünyanın en büyük sivil toplum örgütü olan Trikotilomani Bilgi Merkezi'nin her yıl düzenlenen konferansında katılımcı gözlem ve iki ülkede de yer alan online dayanışma gruplarında gerçekleştirilen sanal etnografi yoluyla psikolojik bir hastalık olarak trikotilomaninin ortak-üretim (co-production) süreci incelenmiştir. Her ne kadar Amerika'daki uzmanlar ve hastalar trikotilomaniyle ilgili daha çok bilgi sahibi olsalar da, iki ülkedeki hastaların bilinçli ve sistemli bir tedaviden ziyade deneme yanılma yöntemine maruz kaldıkları gözlemlenmiştir. Hala tam olarak anlaşılamamış psikolojik bir bozukluk olarak trikotilomani, uzmanlar tarafından ısrarla moleküler düzeyde incelenmektedir ve henüz etkili bir tedavisi bulunamamıştır. Trikotilomani Bilgi Merkezi, ünlü HIV hasta örgütü ACT UP gibi kanıta dayalı aktivizme (evidence-based activism) başvurarak amatör uzmanlık (lay expertise) oluşturmaktansa, trikotilomaniyi popüler hale getirmeye ve hastalar arasında gelecekte yapılacak olan araştırmalar için umut vaadetmeye odaklanmaktadır. Trikotilomaninin çok yönlü ve kültürlerarası analizini ortaya koyan bu tez, psikolojik bozuklukların sosyal ve materyal dünya tarafından nasıl ortak üretildiğinine ışık tutmaktadır ve günümüzde psikolojik bozuklukların psikiyatri, genetik ve nöroloji alanlarının kesişiminde maruz kaldıkları molekülerleşme sürecinin canlı bir örneğini ortaya koymaktadır.

Anahtar Kelimeler: trikotilomani, ortak-üretim, molekülerleşme, bilim ve teknoloji çalışmaları, amatör uzmanlık, Türkiye

To my eyebrows, which I have pulled out in return for academic success…

ACKNOWLEDGEMENTS

I would like to thank my thesis advisor Assist. Prof. Ebru Kayaalp for believing in me and being my supervisor. I am very grateful to her for accepting my “weird” research topic and supporting me throughout my thesis both academically and psychologically. Without her guidance and tidying me up, I would be lost in the STS literature as well as in my academic career. I am so lucky to have her as my advisor and will always benefit from what I learnt from her comments on my thesis research in my future academic career.

I would like to thank my jury members, Prof. Ferhat Kentel and Assist. Prof. Aslı Telli Aydemir, who took their most valuable time to read my thesis. During my M.A. program, I had the chance of serving as a teaching assistant in one of the courses lectured by Prof. Kentel for three semesters and attending his masters-level courses. He has been a role model for me not only in academic terms, but also with his successful adaptation of sociological thinking into his own life, and with his modesty and insightfulness. Assist. Prof. Telli Aydemir is my first professor, who showed me the richness of the field of science and technology studies in her course on digital media and I always admire her networking intelligence and her leading me to the right path whenever I feel lost and seek her advice. It is an honor for me to receive feedback from these two esteemed academicians about my work.

I would like to thank all my friends, whom I ignored, complained to about my stress all the time and sometimes even acted aggressively, for tolerating me and my faults over the course of my M.A. thesis. I would also like to thank my parents, who supported me during my M.A. program and encouraged me to conduct academic research in sociology all the time.

Lastly, I would like to acknowledge the Scientific and Technological Research Council of Turkey (TÜBİTAK) for supporting me with BİDEB 2210-E Basic Sciences Graduate Scholarship Program in pursuing this M.A. degree in the years of 2012-2014.

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LIST OF ABBREVIATIONS

ACT UP	AIDS Coalition to Unleash Power
ADHD	Attention Deficit Hyperactivity Disorder
AZT	Azidothymidine
BDD	Body dysmorphic disorder
BFRBs	Body-focused repetitive behaviors
BPM	Body Focused Repetitive Behavior (BFRB) Precision Medicine Initiative
FDA	Food and Drug Administration
fMRI	Functional magnetic resonance imaging
NAC	N-acetylcysteine
NIMH	National Institute of Mental Health
OCD	Obsessive-compulsive disorders
PCP	Phencyclidine
PET	Positron emission tomography
SPECT	Single-photon emission computed tomography
SRI	Serotonin reuptake inhibitor
SSRI	Selective serotonin re-uptake inhibitor
STS	Science and technology studies
TLC	Trichotillomania Learning Center

INTRODUCTION

This thesis aims to study how "hair-pulling" is co-produced by science, technology and society as a psychiatric disorder, trichotillomania, in two different contexts: Turkey and the United States. Through semi-structured interviews conducted with psychiatrists, psychologists, patients and their families, different constructions of trichotillomania will be examined. I will analyze variations in categorizations and treatments of trichotillomania offered by psychiatrists and psychologists as well as the coping and hiding strategies of the patients. By doing that, I aim to focus on how the process of removing body hair is both spatially and temporally differentiated as a disorder from being a mundane act, which changes the physical appearance of the individual while these differentiations at both patient and expert levels are mostly based on the social standards of normalcy and beauty. The spatiality of the construction of trichotillomania as a disorder refers not only to its variations in different physical and social contexts around the world, but also to the role of the environment in affecting the hair-pulling behavior of the subjects at the micro level. In other words, trichotillomania in Turkey and the United States may not correspond to the same disorder, as the medical expertise and institutions in both countries are not equivalent. Yet, the hair-pulling behavior of an individual takes place mostly in isolation rather than in public and he/she may cover the bald spots with wigs, fake eyelashes or eyebrows outside while baldness may not disturb the person at home. Trichotillomania is also temporally differentiated. Firstly, its medical categorizations have been modified by time since the end of the 19th century, when the first diagnosis of trichotillomania was recorded. Secondly, the behavior manifests itself with younger and older people in a different manner. My fieldwork demonstrates that although no trichotillomania individual is identical, they are being treated with trial-and-error regardless of the context, and haphazardly prescribed pharmaceuticals, which produce almost no change in individual's hair-pulling habits.

I chose this topic firstly because I am one of the trichotillomania sufferers. I have been pulling out my eyebrows for almost ten years. While at the beginning I was blaming myself for my psychological disorder and feeling as if I was the only person, who was pulling out her eyebrows in the world, I started to notice the socio-cultural aspects of my disorder through time. Throughout my last ten years, I have surfed on the Internet about my situation quite often and fallen back upon a couple of psychologists and psychiatrists in order to find a solution for my disorder. However, the more I read sociological texts during my undergraduate and graduate studies, the more I questioned the medical view of the self as “pharmaceutical” rather than a “social” agent, and lost hope on any psychiatric explanations or pharmacological solutions for mental disorders. I believe that critical reflexivity and analysis is necessary not only for psychiatry, but also for the sociological perspective that I am using to investigate the issue. Having undertaken a non-academic auto-ethnography of hair-pulling over the years, I value my personal history with trichotillomania as an opportunity to uncover the “patient” experience, which is difficult to observe for non-hair-pullers, and by doing that, to avoid the asymmetrical and one-sided inferences based on either only the expert or the patient knowledge. Even though the time constraint for conducting a multi-sited ethnography may have served as a limiting factor for covering the patient-expert dichotomy on an equal basis, throughout my research I tried to touch upon both sides evenly.

As I will discuss more in the next section, trichotillomania differs from other types of obsessive-compulsive or impulse-control disorders since it is socio-cyclic. Along with the fact that increasing levels of stress and anxiety are the main reasons behind the disorder, it is social because concerns regarding how to hide hair loss on the body comprise a major cause for such an increase. It is also cyclical since an action of hair-pulling is repeated through its physical consequences such as questions by others who realize bald spots. In this regard, trichotillomania recurs like a vicious circle through social interaction, which focuses on the material changes in the individual as a result of the pulling behavior.

My thesis consists of two main chapters. In the first chapter, I analyze the medicalization, pharmaceuticalization and molecularization processes of trichotillomania by investigating the discourses of the patients and the experts. I focus on how the diagnostic criteria, categorizations and treatments of trichotillomania are generated in the contexts of Turkey and the United States; how the recent findings and research contribute to its construction as a medical condition; and in what ways the patients cope with their so-called psychological disorder and respond to the on-going obscurity of their behavior, which still remains as a contested disorder in psychiatry. At the end, I reach the conclusion that both patients and medical experts alike try to generate treatments experimentally, which I call tr(ial-and-error)eatments.

In the second chapter, I evaluate the Trichotillomania Learning Center (TLC) as the organization for trichotillomania patients and analyze its role in creating lay expertise among the patients through a comparison with ACT UP, which is one of the most well-known and powerful patient organizations for people with HIV, and question in what ways the TLC helps the patients cope with their disorder along with the role of online support groups. My ethnography shows that different than the practices in ACT UP, the TLC spreads the hope for the success of future research among the patients, calls for donations to support research on trichotillomania and relies on the expert knowledge rather than bringing the expertise of the patients forward. Furthermore, my fieldwork demonstrates that online activism of hair-pullers and support groups on Facebook can serve as powerful tools for circulating the lay knowledge and experiences in both contexts, sometimes even surpassing the influence of offline support platforms.

1. Historical Background of Trichotillomania: The Hair-Pulling Disorder

Trichotillomania or the compulsive hair-pulling disorder refers to the repetitious pulling of hair from any part of the body such as the scalp, eyelashes, eyebrows, beards, moustaches, armpits, arms, legs and the pubic area (Penzel, 2003, p. 7). Derived from the Greek words *trich* (hair), *tillo* (to pull) and *mania* (denoting an abnormal love for or morbid impulse toward a specific object, place or action), the word trichotillomania was first used in 1889 by François Henri

Hallopeau, a French physician and dermatologist, who examined an adult male hair-puller (Penzel, 2003, p. 2).

The second case of trichotillomania was diagnosed in 1927 by the British clinician Dr J. D. Rolleston, and this time the patient was a 10 year old boy, who was pulling out his scalp hair and eyelashes while suffering from typhoid fever (Rolleston, 1927, p. 1187). Dr Rolleston (1927, p. 1187) noted in his report that trichotillomania is in some cases associated with other tics, such as onychophagia (the medical name of nail biting) or even “sex perversion”. Some of the treatments he mentioned were “putting the both arms in splint” and “keeping the hair so short that the patient could not pull out”. He claimed that “if this were continued for a considerable time, the hair-pulling behavior might be forgotten” (Rolleston, 1927, pp. 1187-1188).

While only 33 reports had been recorded around the world for the diagnosis of trichotillomania between the years of 1890 and 1970 (Grant, 2014b), the first dermatological group study of hair-pullers was published in 1972. In their research, Muller and Winkelmann (1972) examined 24 patients, 15 of which were male with the chronic hair-pulling behavior on the scalp in a three-year period at Mayo Clinic. The researchers claimed that the treatment of trichotillomania is simple and effective: clipping the hair close to scalp and keeping the hair short put the hair-puller off track and the habit could disappear over time or be replaced by another tic. These studies were important in the sense that medical scientists started to have a general idea of trichotillomania and its possible treatments (Grant, 2014b).

In 1980s, 68 scientific reports were published on trichotillomania, including the first medication report on amitriptyline, which is a tricylic antidepressant for treating depression (Grant, 2014b). Due to the fact that the pharmacological spectrum of action for amitriptyline is analogous to chlorimipramine, which is found to be effective for severe compulsive behaviors, amitriptyline was tested on a young adult with trichotillomania and his hair-pulling behavior was found to be decreasing with progressively increasing dosage of amitriptyline (Snyder, 1980). In a 10 week double-blind comparison of clomipramine and desipramine conducted with 13 women suffering from severe trichotillomania, clomipramine usage resulted in significant improvements in the symptoms than the desipramine, which is a standard tricyclic antidepressant (Swedo et al., 1989). These reports are regarded as the first examples testing the role of several antidepressants on treating trichotillomania.

In 1990s, the number of scientific reports on trichotillomania reached 255, many of which were the first of its kind (Grant, 2014b). The largest clinical sample of trichotillomania with 60 hair-pullers was drawn by Christenson, Mackenzie and Mitchell (1991), who conducted semi-structured interviews with the hair-pullers in order to classify the demographic and phenomenological features of chronic hair-pullers and assess the psychiatric comorbidity of the behavior. Most of the subjects described either tension before or relief/gratification after pulling hair from the primary site, but 17% (10 out of 60) of the hair-pullers failed to describe both of these characteristics and thus failed to fulfil the DSM-III-R criteria for trichotillomania (Christenson, Mackenzie, & Mitchell, 1991). Moreover, while 82% of the subjects (49 out of 60) were considered to be qualified for past or current Axis I diagnosis other than trichotillomania, several characteristics of the study group suggested the existence of phenomenological differences between the obsessive-compulsive disorders and trichotillomania (Christenson, Mackenzie, & Mitchell, 1991).

In 1991, the brain scan study was first conducted with 10 adult women suffering from trichotillomania and 20 age-matched female controls in order to compare the cerebral glucose metabolism, which is considered to be responsible in the brain functioning and to cause psychological problems when disrupted. The results showed that the cerebral glucose rates of people with trichotillomania are higher than the rates of the people suffering from obsessive-compulsive disorders (Swedo et al., 1991). Apart from the brain scan, throughout 1990s, studies of the family, prevalence, gender, neuropsychology, MRI and immunology were conducted for trichotillomania for the first time, while the behavioral treatment for children and a diagnostic scale for the hair-pulling behavior were generated and tested as well (Grant, 2014b). These studies were found to be suggesting a necessity for more clinical data on trichotillomania by showing the similarities and/or differences of the “trichotillomaniac” brain with/from other brains suffering from psychological disorders (Grant, 2014b).

After 2000, along with the neurocognitive studies, research on the genetic background of trichotillomania have been conducted ranging from the gene mutation studies (Zuchner et al., 2006; Welch et al., 2007) to a twin study (Novak, Keuthen, Stewart, & Pauls, 2009) (as cited in Grant, 2014b). Between 2010 and 2014, the number of the published scientific reports increased to a considerable extent and the studies of brain imaging (Lee et al., 2010) and medication (Bloch, Panza, Grant, Pittenger, & Leckman, 2013) in children as well as the cross-cultural research on the African-American hair-pullers (Neal-Barnett, Statom, & Stadulis, 2011) were published for the first time (as cited in Grant, 2014b). Medical experts regarded these latest findings as leading to a greater understanding of the brain, more clinical data on the heterogeneity of the disorder, more treatments, animal research and genetics of trichotillomania (Grant, 2014b).

According to Jon E. Grant (2014b), the head of Scientific Advisory Board of Trichotillomania Learning Center in the United States, research on trichotillomania so far has allowed the medical experts to know more about its clinical presentation; to design scales for measuring its diagnostic criteria and symptoms; to fathom its comorbidity with other psychological disorders; to obtain information about animal research, genetics and neuroimaging; and to develop more promising treatments such as cognitive behavioral therapy (CBT) and habit reversal training (HRT). However, Grant (2014b) also underlines that lack of cross-cultural research in diverse populations and subtypes, small samples and limitations in research on neuroimaging and genetics, non-individualized treatment samples and laggings in medication treatments cause trichotillomania to remain still an understudied and contested psychological disorder. Even though a number of studies support the therapeutic effect of pharmaceuticals such as N-acetylcysteine, a pharmaceutical drug specifically treating trichotillomania has not been developed and put on the market yet.

Trichotillomania was first mentioned in the revised third version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R), which was published in 1987 by the American Psychiatric Association, as an impulse-control disorder, and was not classified elsewhere (Stein et al., 2010, p. 612). In DSM-IV, which was published in 1994, “the increasing tension before the hair-pulling behavior" and "the social distress and/or impairment" resulting from the disorder were included in the diagnostic criteria (Stein et al., 2010, p. 612). In the latest version of DSM-5, which was published in 2013, trichotillomania is classified under the obsessive-compulsive and related disorders, and its other name "hair-pulling disorder" was added parenthetically for the first time (American Psychiatric Association, 2013b, p. 7). Furthermore, the word "noticeable" in the criterion of "[r]ecurrent pulling out one's hair resulting in noticeable hair loss" in DSM-IV is excluded in the new version of DSM-5 and the criterion of "[r]epeated attempts to decrease or stop hair pulling" is added (American Psychiatric Association, 2013a). The criterion of "[t]he increasing tension before the hair-pulling behavior", which was added in DSM-IV, and "[p]leasure, gratification, or relief when pulling out the hair" were excluded again in DSM-5 (American Psychiatric Association, 2013a). Moreover, DSM-5 also distinguishes trichotillomania from other dermatological and/or psychiatric conditions, which cause hair loss due to other medical problems, delusions or hallucinations (Stein et al., 2010, p. 612).

Trichotillomania also appeared in the International Classification of Diseases (ICD) by the World Health Organization in its ninth version (ICD-9) in 1975 under the impulse-control disorders (Grant & Stein, 2014, p. 60). It was named as a separate impulse disorder in the section on disorders of adult personality and behavior firstly in ICD-10, which was approved in 1990. In ICD-10, trichotillomania is characterized as following:

> A disorder characterized by noticeable hair-loss due to a recurrent failure to resist impulses to pull out hairs. The hair pulling is usually preceded by mounting tension and is followed by a sense of relief or gratification. This diagnosis should not be made if there is a pre-existing inflammation of the skin, or if the hair pulling is in response to a delusion or a hallucination. Excludes: stereotyped movement disorder with hair-plucking. (as cited in Grant & Stein, 2014, p. 60)

While the epidemiological studies are considered limited and unrepresentative, the prevalence rates of trichotillomania in different studies, which are mostly conducted among college students, adolescents and older adults in the United States and Israel, range from 0.5% to 2.0%. Although the first examples of the hair-pullers diagnosed with trichotillomania in the 18th and 19th centuries are with adolescent and young adult males, today it begins at younger ages, mostly between 10 to 13 and is more prevalent in females (Mansueto & Rogers, 2012). According to the findings of a large-scale Internet survey on the hair-pulling practices of 1697 subjects, the scalp is the most common site for pulling (72.8%), followed by the eyebrows (56.4%), eyelashes (51.6%), pubic area (50.7%), legs (21.8), arms (12.4%), armpits (12.4%), trunk (7.1%), moustache (5.4%), beard (4.3), hair of other people (0.4%) and other sites (7.1%) (Woods et al., 2006; as cited in Mansueto & Rogers, 2012, pp. 12-13).

2. Social Science Literature on Pathologizing Diseases

Before starting my ethnography, I researched on how illnesses, particularly the psychological disorders, are analyzed in the medical sociology literature. While I have not encountered a study, which handles specifically trichotillomania from the perspective of medical sociology, so far the social science literature has addressed both physical and psychological health from many different aspects including medical expertise, techno-scientific inventions, neoliberal policies, welfare state, pharmaceutical industry, patient activism among others. As the studies discuss health from different perspectives, they show that the disorders are socially constructed.

Recent changes in the idea of welfare state have led to the medicalization of public support, which considers the sick and/or disabled citizen helpless and disadvantaged rather than the financially poor, who remains deprived for no legitimate health problem. According to a study (Hansen, Bourgois, & Drucker, 2014), it is observed that with the end of the welfare state in the United States, the diagnoses of chronic mental illnesses have increased due to the disability benefits received for such illnesses. In their ethnography in New York, the authors note that with the social insurance support, which has been turned into a necessary source of income for the disadvantaged families, the stigmatization of being labeled as mentally disabled has paved the way to a survival strategy, signifying a shift in the neoliberal definition of the poor and the unemployed (Hansen, Bourgois, & Drucker, 2014). The study shows that the political-economic change is directly related to transformations of diagnostic criteria, understandings of disability and the forms of stigmatization, which suggest the social construction of the diagnostic criteria.

Such alterations in the neoliberal understandings of being disadvantaged have been nourished by the shifts in medical discourses as well. Recently, the role of medicine has been transformed from treating disorders and illnesses to preventing them, and also converting the individuals to responsible citizens, who are required to sustain their health. Through an analysis of the case of osteoporosis, Skolbekken, Osterlie and Forsmo (2008) argue that the transformations in the medical practices from treatment to prevention can be seen in the diversified experiences of different age groups, who suffer from the disease. While the older generations of patients with osteoporosis see the disease as a difficulty, and consider themselves victims of the disease, the younger generations feel guilty and irresponsible, and blame themselves for becoming sick and therefore not fulfilling the duty of a responsible healthy citizen (Skolbekken, Osterlie, & Forsmo, 2008). Although osteoporosis is a bone disease that is linked to aging and calcium intake, the construction of the self as a patient through two distinct paths provides an insight into possible understandings of trichotillomania sufferers.

Along with the shifts in medical discourses as well as in the public policies over the sick individual, neoliberal economic policies, which affect the practices of pharmaceutical companies as in the case of direct-to-consumer advertising of pharmaceuticals, play an important role as in transforming the patient to a consumer. Studying the case of premenstrual dysphoric disorder, Ebeling (2011) argues that by “branding” a disease, it is possible to re-market an available drug, such as an anti-depressant (Prozac) under another name (Sarafem), through branded disease awareness campaigns, which advertise the self-diagnostic criteria of diseases and symptom checklists. Ebeling (2011) suggests that rather than being a tool of classification for medical experts, self-diagnostic criteria have become a marketing tool for pharmaceutical companies to usher in self-educated consumer patients. Similarly, re-branding is also evident in the case of anxiety disorders for which available serotonin selective re-uptake inhibitors are marketed as anxiolytics, (i.e. anti-anxiety agents) as if there is a difference between the two (Healy, 2004).

The author observes that with the help of such marketing strategies, anxiety, one of the most common psychological conditions of the pre-1980s, has made a comeback as the major diagnosed condition in the post 9/11 era after the panic attacks and mood disorders of the 1980s and the 1990s were out of fashion.

The social constructions of rare diseases through medical expertise, institutions, pharmaceutical industries, patients and patient organizations have also come under scrutiny in the social sciences. For instance, the peanut allergy, which was once a relatively unknown and rare health problem, has become a major social concern and has turned into a potentially fatal and contested epidemic (Waggoner, 2013). Waggoner argues that despite more frequently observed and lethal allergies (e.g. seafood), the change in the understanding of peanut allergies took place through a co-construction of it as an epidemic due to its materialization as a social problem while especially being a favorite snack of kids. The co-construction was a result of interactions among medical professionals, parents, scientists, government authorities and media, and it has yielded material changes from food labeling to new regulations in schools and airlines. The new construction of peanut allergy as an epidemic contributes to a "biolooping", where the changes in classification affect both individual identifications with the disease, and increase the biological sensitivity for peanuts (Hacking, 1999; as cited in Waggoner, 2013, p. 54). These new social policies, which advertise peanut allergy and encourage society to avoid consuming peanuts, lead to a greater allergen sensitization within the population (as cited in Waggoner, 2013, p. 54). This bioloop is akin to the socio-cyclic nature of trichotillomania at a macro level. Similarly, it has been shown that previously untreatable psychiatric conditions such as personality disorder (PD) and psychopathy have been deemed treatable through a process of interaction among legal structures, clinical establishments and policy makers in the United Kingdom (Pickersgill, 2012).

What I find most relevant for my research on trichotillomania is that some of the studies from the social science perspective bring into light the fact that the medical pathologies of diseases, and especially of the psychological disorders, are based on the social and cultural standards of health, normalcy and beauty. Furthermore, giving voice to patient experience and thus lay knowledge shows the complexity and sociality of human behavior and psychology, which cannot be reduced only to the neurochemical and genetic level. In a research, body dysmorphic disorder (BDD), a relatively unknown condition that may be compared to trichotillomania from some aspects, an increased preoccupation with non-existent or minor defects in the body, was studied through patients' narratives (Silver & Reavey, 2010). The findings showed that contrary to common sense assumptions that the individuals would be affected more by beauty standards, the major concern in this disorder stems from a yearning for the past and especially of childhood, which is always characterized by innocence and the lack of responsibilities (Silver & Reavey, 2010). In this case, patient narratives show that the picture is more complex than what is seen in the first sight, and apart from the socially constructed beauty standards, the emergence of BDD can be linked to the idealization of the past self that is lost through aging, the traces of which can be found in the personal history and social life of a particular person (Silver & Reavey, 2010).

Although cultural standards of beauty are not the direct effectors as in the case of BDD, socio-cultural differences play a fundamental role in the recognition of a condition as psychiatric or psychological disorder, which necessitates cross-cultural work from a social sciences perspective. In a comparison of the U.S. and Egyptian psychiatric practices through medical records, Coker (2003) argues that the diagnoses are based on cultural understandings of the "self" and the "other", just as the "normal" and the "abnormal", which are determined socio-culturally rather than scientifically. The author notes how psychiatry uses its power to decontextualize the case of an individual, where local discourses of mental disorders are cleansed of localness and purified as an internationally recognizable psychiatric entity, a "biomedical object".

In this research, I will use Sheila Jasanoff's "co-production" concept as a theoretical background, which is a post-structuralist and interpretive approach. Even though not all of the research I mentioned above have benefited from the theory of co-production in science and technology studies (STS), all of them show in one way or the other that medical conditions and identities are co-produced by both the social and the material world. Jasanoff defines co-production as the "shorthand for the proposition that the ways in which we know and represent the world (both nature and society) are inseparable from the ways in which we choose to live in it" (2004, p. 2). Why do we need co-production from science and technology studies (STS) instead of social construction, which has been a fundamental framework for sociological analysis? Although constructivism does not give precedence in the temporal sense to social reality over natural reality, and it does not only consider social factors in making physical reality, social construction as a term implies such meanings (Hacking, 1999; as cited in Jasanoff, 2004, p. 19). In this regard, Jasanoff argues that co-production prevents leaning towards nature or society, and thus is a move away from social or material determinism.

According to Jasanoff, there are two types of co-production that has been developed in the social sciences, specifically in the STS literature: constitutive and interactional co-production. While constitutive co-production follows the footsteps of Foucault, as it is interested in the emergence of socio-technical systems or "the ways that stability is created and maintained" (Jasanoff, 2004, p. 18), interactional co-production is interested in the conflicts, issues of credibility and thus the epistemologies within these systems. Jasanoff considers making identities, institutions, discourses and representations as the four major pathways or instruments of co-production.

Making identities as the first instrument of co-production refers to the formation and shaping of identities and social roles based on the knowledge and its production through science and technology (Jasanoff, 2004, p. 39). According to Jasanoff (2004, p. 39), regardless of being individual or collective, redefining identities allows people to re-establish order out of disorder and the co-production process plays a substantial role in transforming the power and meaning of a particular identity. Secondly, institutions serve "as the stable repositories of knowledge and power" and carry the mission of "putting things in their places at times of uncertainty and disorder" (Jasanoff, 2004, pp. 39-40). By drawing an analogy with Latour's concept of inscription devices, Jasanoff argues that institutions can be regarded as the vehicles, which decide for the validity of new knowledge, the safety of new technological systems and accepted rules of behavior through knowledge-making (Latour, 1987; Latour & Woolgar, 1979; as cited in

Jasanoff, 2004, p. 40). Institutionalized ways of knowing are reproduced throughout time and in different contexts as they can be considered social actors as well as entities subject to re-examination, while institutions like legal systems and research laboratories also carry the mission of problem-solving through expertise, inquiry and credibility (Jasanoff, 2004, p. 40). As the variety of institutions aim at securing order in society, they benefit from the discourses of medical, legal and ethical languages and modify and/or retailor them when needed, such as in the case of the lay expertise of the patients (Jasanoff, 2004, p. 41). These discursive choices play an important role in constructing scientific authority and drawing the boundaries of the “promising” and “fearsome” aspects of science and technology (Jasanoff, 2004, p. 41). Lastly, the making of scientific representations within society takes place in diverse communities and are affected by the historical, cultural and political influences as well as their acceptance by other social actors (Jasanoff, 2004, p. 41).

I chose to study trichotillomania through the theoretical framework of co-production since I neither argue that disorders or illnesses can be reduced to the biological level nor claim that they do not materially exist and are mere products of social construction. As I will discuss throughout my thesis, trichotillomania is not limited to the material factors, which range from the irresistible urge to pull to the physical aspects of repetitious hair-pulling, and is shaped by the social world as well. Likewise, the behavior as a medical entity is co-produced by not only the experts and the patients, but also the material world, which range from the hair, wigs, bald spots, coping tools and pharmaceuticals, to the online and offline platforms where the interactions among the patients and experts take place.

At the crossroads of these four instruments of co-production, my research will analyze the making of the identity of the hair-puller as a patient; the making of the patient organizations as institutions representing the patients along with the psychiatric expertise; the making of the medical discourse produced by the psychiatric experts and other researchers of trichotillomania; and the making of representations of trichotillomania as a contested psychological disorder by scientific authorities, patients, patient organizations and hair-industries. By drawing on the relevant concepts of STS, especially *inherent illness* (Dumit, 2002) and *neurochemical selves* (Rose, 2007b), as well as *lay expertise* and the *political* *economy of hope* (Novas, 2006), I will examine the ways in which trichotillomania or the hair-pulling disorder is co-produced as a medical and pathological entity.

3. Methodology

My research is a cross-cultural, multi-sited study (Marcus, 1995) conducted in both Turkey and the United States, involving both online and offline fieldwork in these two contexts. My findings on the hair-pulling disorder are mainly based on my fieldwork during the 21st Annual Conference on Hair Pulling & Skin Picking Disorders organized by the Trichotillomania Learning Center in Los Angeles, California on 25th-27th April 2014. Trichotillomania Learning Center (TLC) is located in Santa Cruz, CA, in the United States, and is the biggest grassroots organization around the world, providing education, outreach, and support of research into the cause and treatment of body-focused repetitive behaviors (BFRBs) including trichotillomania (Trichotillomania Learning Center, n.d.). TLC was founded in 1991 by Christina Pearson, who was an ex-hair-puller, and the organization is largely run and supported by people with trichotillomania and skin picking disorders (Trichotillomania Learning Center, n.d.). Furthermore, TLC has a Scientific Advisory Board, which consists of medical experts, researchers and clinicians on BFRBs from the United States and around the world (Trichotillomania Learning Center, n.d.). As the conference appeals to the experts, patients and their families altogether, diverse sessions on different themes, ranging from animal research on trichotillomania to meditation and breathing techniques for hair-pullers took place. In these sessions, I had the chance of obtaining up-to-date information about the latest research and findings on trichotillomania and conducting participant observation among hair-pullers, psychiatrists, psychologists and other experts in the United States.

I was interested in analyzing the medicalization process of trichotillomania in Turkey as well. At first I aimed at conducting around 10-15 semi-structured interviews with medical experts, mainly the psychiatrists and psychologists. However, in one year I was able to conduct only five semi-structured interviews, three of which were with psychiatrists and two of which were with psychologists.

This happened due to the fact that it was hard to find psychiatrists and psychologists, who were specialized particularly in trichotillomania. Moreover, many of them did not reply to my emails or repeatedly canceled our meeting in the last instant. Except for a psychologist, with whom I met outside in a café in person, all my interviews with the medical experts took place in their offices. The interviews took around 20-35 minutes for each informant and I asked them about their knowledge on the diagnostic criteria, possible treatments, latest research as well as their opinions on the molecularization of psychological disorders. All of my informants allowed me to record, store and transcribe their interviews for academic purposes.

In Turkey, in order to reach hair-pullers, I published an article about my own experience with trichotillomania on the blog of a popular Turkish daily newspaper, *Radikal*, in 2013. In that autobiographical piece, I discussed the diagnostic criteria of trichotillomania and its effects on my personal life as well as on my sociological research, and called hair-pullers to contact me to starting up at least 5 focus group meetings. Over the course of a year, 25 people contacted me through e-mails. However, contrary to my expectations, only four of the hair-pullers were living in Istanbul. Therefore, the idea of arranging focus group meetings as I previously planned was not feasible. Instead, I conducted semi-structured interviews with 17 trichotillomania sufferers. 16 of these interviews were conducted on the phone and only one of them was made in person. Due to the personal nature of the issue, most of my informants did not want their interview to be recorded. Only one of them, with whom I met face-to-face, allowed me to record her voice, but this happened only after our third phone call. Therefore, only this interview was recorded and transcribed. Furthermore, one of my interviewees wrote to me every week for around two months about her hair-pulling experience to see if her methods to stop trichotillomania were working or not. In my semi-structured interviews, I asked the hair-pullers briefly about their history with the behavior; the differences and similarities of their friends' and families' reflections on trichotillomania; whether they seek treatments and, if they do, in what ways and whether they succeeded, and if not, why; and lastly various solutions or tactics they apply for coping with their disorder. The interviews took different durations with each person, ranging from 20 minutes to 2 hours.

Apart from conducting interviews with hair-pullers and psychiatric experts in both contexts, I was interested in observing the online interactions of the patients and knowing whether an online support group exists on social media. As it secures the privacy of the users by allowing the option of establishing secret groups, which people only can join by invitation from a group member, I was expecting Facebook to accommodate more support groups on trichotillomania than other social network sites. Yet, I could not find any group for Turkish hair-pullers on Facebook, except for a number of inactive groups with 10 to 15 members. Four months after I published my article on *Radikal*, I received a Facebook message from a professional soldier, who wrote that he had founded a confidential Facebook group, which had more than 250 members, and wanted to add me to this group. After becoming a member of the online group with my original account on Facebook, I conducted virtual ethnography among the members and followed their posts, which gave me important clues about their experiences of trichotillomania for six months. During my virtual ethnography, I also shared my thoughts and interacted with the other members of the group. However, even though it was the largest online Turkish support group that I found for trichotillomania on Facebook; after several months, the founder terminated the group due to a dispute. Apart from the Turkish support group, I conducted virtual ethnography in the biggest and most international Facebook group of hair-pullers, which consists of mostly hair-pullers from the United States and Europe, having more than 4000 members. Many people shared their troubles in regard to trichotillomania as well as giving advice to others about how to stop their disorder. Facebook groups became an important information source for my research since not only could I keep being up-to-date about people's different ways of coping with trichotillomania, but also I could follow people's discussions about whether trichotillomania is a mental disorder for them, and if it is, how they define their disorder and seek treatment.

In both my online and offline fieldwork, I regarded the Internet not only as a tool for sharing information, but also as a place or way of being, which serves as a milieu where people communicate and construct their identities (as cited in Flick, 2009, p. 272). Therefore, during my virtual ethnography, I started with observing the members' interactions in both Facebook groups, and after a while, became an active participant of the group, similarly to a real-world ethnography (as cited in Flick, 2009, p. 272). I also kept in mind that "the virtual ethnography is never holistic but always partial" (Flick, 2009, p. 273). For this reason, in my online interactions with the hair-pullers, I expected to "find the knowledge based on the strategic relevance rather than faithful representations of objective realities" (as cited in Flick, 2009, p. 273).

CHAPTER I: THE MEDICALIZATION, PHARMACEUTICALIZATION AND MOLECULARIZATION OF TRICHOTILLOMANIA

1.1. Psychiatry: Treating Disorders or Threatening People

After Professor Grant finished the question and answer session for the "Medications for Hair-pulling and Skin-picking Disorders" in the Annual Conference of the Trichotillomania Learning Center in 2014, I went to him in order to have my copy of his book *Trichotillomania, Skin Picking, & Other Body-Focused Repetitive Behaviors* signed. There were around ten other people waiting to ask him personal questions about what kind of medications they or their children should use and whether those medications would have any side-effects if used together. Interrupting the endless questions at one point, I introduced myself while others were there. He was fascinated by the fact that TLC's reputation has reached all over the world, even to Turkey. I asked him a long and very specific question, which according to my notes was:

> According to Andrew Lakoff, who is a medical anthropologist, psychiatry, as a discipline tends to categorize mental illnesses according to the drugs the patients respond to. He gives the example that if a person gets better with antidepressants, then, in most cases doctors assume that he/she is suffering from depression. In Turkey there aren't many medical experts, who research trichotillomania, and are knowledgeable compared to the ones in the United States. However, I see that the situation of the hair-pullers is the same in both contexts. While in Turkey patients take risks alone and try whichever treatment they find or hear by themselves, in the U.S., the experts encourage the patients to try many kinds of medications, which in both contexts I would call methodologically trial-and-error. Do you think that more categorizations in psychiatry really lead to knowing more about the disorders and treating them?

I was aware that such a harsh criticism through a direct question was not suitable for discussing on the run. I wasn't expecting a clear answer as the issue I raised was one of the core problems of psychiatry from the perspective of the social scientists. Nonetheless, everyone turned their eyes to Professor Grant, as no one including the professor was expecting such a question, which challenges not only the legitimacy of the psychiatry's diagnostic criteria, but also the legitimacy of psychiatry as a discipline itself. He smiled and answered:

> Well, I don't think that what you mention is quite relevant. Of course, we as psychiatrists researching on trichotillomania, skin-picking and other body-focused repetitive disorders are always aware of the fact that there is so much progress to be made, which is directly related with sufficient funding and collaborations in research. However, we also have to acknowledge that now we know more about these behaviors, we have already come a long way and it would be harsh to say that we assign the drugs before diagnosing the disorder. Even though some people suffer from the same psychological disorder, each and every person requires different treatments and we have to try certain ways until we can see which treatment works best for the person. As I mentioned yesterday at the opening ceremony, we don't treat disorders, we treat people.[1]

As a social scientist, who is critical about the diagnostic criteria and categorizations of psychiatry, I totally agree with his confession that psychiatrists do not treat disorders, they treat people. One of the most contradictory facts within the discipline of psychiatry is that it still problematizes personal traits based on the socially constructed assumptions of "normal behavior". Whether a behavior threatens the social order in a particular context, serves as an important criterion for deciding its normalcy. Today, a child, who acts naughty at home, is diagnosed mostly with Attention Deficit Hyperactivity Disorder (ADHD). When we look at some examples of psychiatric survivors, whom I mention briefly below, in old and recent history, we see the same pattern over and over again.

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[1] The dialogue between Professor Grant and I was not recorded, but the dialogue was written to the best of my memory.

In 1860, Elizabeth Ware Packard, who later had become an activist fighting for personal liberty laws and founded the Anti-Insane Asylum Society in the United States, was committed to the Illinois State Hospital for the Insane by his husband on the grounds for questioning his religious ideas and refusing to be an obedient wife (Grob, 1994; as cited in Lewis, 2013). After nearly a century, in 1962, Leonard Roy Frank, who was the only son of a wealthy family, a graduate of the Wharton School of the University of Pennsylvania and the owner of a real-estate company in San Francisco, was committed to a psychiatric hospital by his family, according to his psychiatrists for the symptoms of "not working, withdrawal, growing a beard, becoming a vegetarian, bizarre behavior, negativism, strong beliefs, piercing eyes, and religious preoccupations" (as cited in Lewis, 2013). Reading Gandhi's writings and applying his philosophy in his daily life cost Frank thirty-five electro-shocks and fifty insulin comas (Lewis, 2013).

The declassification of homosexuality in the seventh print of DSM II in 1974 by the American Psychiatric Association (APA) is one of the most important examples of how psychiatric classifications can be deceptive. A psychological disorder of 30 years ago like homosexuality can be cleared as normal whereas a once-normal behavior can be labeled as a mental problem in the future. Furthermore, while psychiatry of today cooperates with multidisciplinary research ranging from genetics to neuroimaging, the scientific experts still cannot reach unchanging categorizations of and treatments for the mental disorders. Yet, they do not lose their hope of creating a standardized data pool for diagnosing and treating psychological disorders while at the same time admitting the uniqueness of each individual, just like Professor Grant.

In the light of the contradictory nature of research and diagnosis, this chapter aims to discuss the medicalization process of trichotillomania. In the first part, before I focus on my fieldwork, I provide a theoretical framework based on the interdisciplinary area of science and technology studies as well as medical sociology and medical anthropology. The second part of this chapter focuses on the diagnostic criteria of trichotillomania and the problems of categorization. In the third part, I discuss the medicalization process of trichotillomania based on my fieldwork in Turkey and in the United States. Lastly, in the fourth part, I discuss my findings in the light of the theories I mention in the first part.

1.2. Theorizing Medicalization

"[The term] medicalization has become a cliché of critical social analysis," says Rose (2007a, p. 700) in the first sentence of his short essay with the title *Beyond Medicalisation*. According to Rose (2007a), medicalization has been used for stating many different issues in the social sciences due to the fact that as time passes, it encompasses much broader processes, involves more actors and takes place not only in the West, but also all over the world.

The concept of medicalization entered to the terminology of sociology firstly during 1970s (Bell & Figert, 2012, p. 775). Scholars like Michel Foucault or Irving Zola as well as the anti-psychiatrists such as Thomas Szasz or Erving Goffman problematized the increasing power and control of medicine over mainstream society (Bell & Figert, 2012, pp. 775-777). The categorization and diagnosis of everyday feelings and behaviors, specifically by the discipline of psychiatry, as psychological disorders were at the core of the criticisms (Bell & Figert, 2012). While the medical expertise as an institution was criticized to a considerable extent, the states' involvement in creating the clinical gaze and benefiting from it in regulating the societies was brought to the discussion by many scholars, mainly by Michel Foucault.

In *The Birth of the Clinic*, Foucault (2012) discusses the history of the institutionalization of medicine in the hands of the state in Europe. He claims that institutionalization and nosology in medicine was supposed to generate a happy world, which is comprised of healthy people and the state aimed to define an obedient model of citizen shaped by the borders of normal/abnormal by assuming the responsibility of the clinic itself (Foucault, 2012). According to Foucault (2012), medicine and nosology have become a system of knowledge, which can be controlled only by itself. Such supremacy of knowledge turned the status of medical doctors into the status of clergy, who cure the souls of people, while the doctors not only cure but also know the mysteries of the bodies (Foucault, 2012).

Within the modern society, the social prestige of the medical doctors makes the public think highly of their scientific judgements and obey them without questioning their accuracy. Foucault questions such robust authority and power of the medical expertise, and the state's control over the social bodies, and generates the term biopower, which he defines as "an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations" (1978, p. 140; as cited in Bell & Figert, 2012, p. 777).

Following Michel Foucault, the medical sociologists have examined medicalization as a process taking place in the modernization of the West. When the increasing rationalism and systemization of the medical realm are taken into account, medicalization is considered both the cause and the product of modernity along with the capitalist mode of production (Bell & Figert, 2012). However, today the term medicalization involves not only the power of states and the medical expertise, but also the involvement of pharmaceutical industry as well as the patient organizations, support groups and the consumers of healthcare. Moreover, medicalization today does not take place in the West only; it is both a global and local phenomenon. From postcolonial experiences and political (in)stability to economic wealth, social stratification and cultural context, medicalization is dependent on many social and economic factors and its multi-faceted nature is experienced differently both at the geographical and individual level (Bell & Figert, 2012). As Rose argues, differences in age, class, race, nationality or sex play an important role in shaping the medicalization experiences of people and mostly "women more than men, the wealthy differently from the poor, children more than adults" have been subjected to medicalization (2007a, p. 700).

1.3. Moving from Medicalization to Pharmaceuticalization

The unequal distribution of medicalization around the world, as overmedicalization or undermedicalization, was maximized especially with the rising influence of the pharmaceutical industry over medical expertise (Bell & Figert, 2012). While the pharmaceutical companies open up a huge global financial sector for developing and producing new drugs, their profit-maximizing urge has shaped the medicalization process. With their financial power, pharmaceutical companies have become important funders for developing research and therefore key decision-makers in shaping the destiny of the patients around the world. For instance, pharmaceutical industries prefer to fund research on common diseases rather than rare diseases, which are seen in a very small percentage (around 1 in 2500 people) of the world population. From the perspective of the free market economy, patients become the consumers or demanders of the pharmaceuticals, whereas pharmaceutical companies are the producers or suppliers of the drugs. The tendency of the pharmaceutical industry to focus on the "more profitable" illnesses, the drugs of which are feasible to produce, less costly and appeal to a significant number of patients, has changed the entire dynamics of the medicalization.

As pharmaceutical companies, along with the technoscientific innovations and health care reforms (Bell & Figert, 2012, p. 778), transformed the patients into consumers, the patients themselves have become the ones who buy the health regardless of their needs. This resulted in the rise of direct-to-consumer-advertising (DTCA) of the pharmaceuticals especially in the United States, addressing the patients or consumers rather than the medical experts. In order to make the consumers aware of their disorder, symptom checklists for self-diagnosis have been created (Bell & Figert, 2012, p. 778). In some cases, while the drug or a treatment for a certain disorder or illness is commercialized but the illness itself is not known, the marketing of the illness is done through advertisements or awareness campaigns in order to create potential customers. Medical sociologists call this process *disease mongering*, and this is one of the most developing areas of research (Illich, 1976; Moynihan, Health, & Henry, 2002; Payer, 1992; as cited in Bell & Figert, 2012, p. 778). One of the most prominent examples of disease mongering is the case of Attention Deficit Hyperactivity Disorder (ADHD). While the claimed symptoms of ADHD such as laziness or difficulty in completing tasks can be found almost in every average person and the attention spans of people living in 21st century may have dropped due to the effects of technology on our lives, such a social trend is medicalized through constant media advertising. Disease mongering can also be a powerful strategy for medical experts to get the attention of the pharmaceutical companies to obtain funds for rare or contested disorders or illnesses by proving that a huge number of patients exist, who may not be aware of the fact that they are sick. In Moynihan's own words, moving from medicalization to pharmaceuticalization, "[t]he social construction of illness is being replaced by the corporate construction of disease" (as cited in Bell & Figert, 2012, p. 778).

The increasing abundance and usage of pharmaceuticals have created a crowded generation of drug dependents especially in the West. As it is addressed by many scholars as drug saturation, the situation has become so severe that even many of the clinical trials are conducted outside the United States since especially the populations with higher income are already using many drugs and the results of the clinical trials might be biased in the existence of other drugs (Martin, 2006, p. 284). Not only can the drugs for coping with different diseases circulate, be sold and bought easily, but also a huge market for food supplements or cognitive enhancement drugs has emerged.

Considering the increasing dependency of people on medications, Dumit (2002) discusses the paradigm shift from the *inherent health* to the *inherent illness* within contemporary medicine. While formerly the body was assumed as a healthy entity, which is subject to the outside threats of microbes, bacteria or viruses, after the 1990s, the body has turned to a being, which "naturally" tends to become ill and the subject, who owns the body, should take care of it through outside help, which can be drugs, therapies and exercise (Dumit, 2002). He also claims that the drug advertisements use depression curves, showing the treatment phases of a psychiatric patient and in these drawings, the normalcy is shown to be reached through medication, which is considered as the best part of recovery. The drawings display that even though the person feels better and may withdraw from medication after a while, the maintenance of the normalcy should be assured by continuing with the medication, encouraging the patient to depend on drugs for the rest of his/her life (Dumit, 2002, p. 125). In other words, Dumit (2002, p. 127) problematizes the fact that the pharmaceutical industry imagines pharmaceuticals a necessity for patients not only to eliminate the symptoms, but also to not experience them again in the future, just like the diabetic patient, who has to depend on insulin throughout his/her life. Dumit (2002) calls the illustration of maintained recovery through medications as *dependent normalcy*.

Similar to Dumit’s arguments, in her article the “Pharmaceutical Person”, Emily Martin (2006) addresses the fact that people have become dependent on pharmaceuticals in coping with psychiatric disorders. Martin (2006) interviews people diagnosed with bipolar disorder about their opinion on pharmaceuticals. According to Martin, drugs are presented as a “menu of reasonable choices” and the patients or consumers of the drugs should choose which one to use (2006, p. 275). Psychiatric experts prescribe pill cocktails, and when drugs are causing problems or side effects, the solution is mostly prescribing more or different drugs (Martin, 2006, p. 276). As it happens in the case of the people suffering from bipolar disorder, people are prescribed mostly more than one medication, and they love or hate a certain pharmaceutical based on how it affects their mood. Patients claim that pharmaceuticals transform them into a new person, as one of the informants of Martin’s study states: “Depakote—it is like a new suit of clothes! I am a snake who has shed its skin, I am all new and shiny” (Martin, 2006, p. 276).

1.4. From Pharmaceuticalization to Molecularization

As the developing pharmaceutical industry and the increasing number of the pharmaceuticals have moved social scientists from the concept of medicalization to pharmaceuticalization, the latest progresses in science and technology have changed the medical expertise to a considerable extent and created the need for a broader concept encompassing all of these processes. Recent scientific developments have allowed experts to understand causes and mechanisms of many illnesses. From neuroimaging to genomics studies, new fields of research for disorders have unleashed a large amount of data; however, the findings are only representative of a specific population, and are mostly regarded as risk factors, rather than direct causes of a disease. Even in psychiatry, one’s genetic background has started to be considered as the main cause of some psychological disorders, sometimes even disregarding the social environment of the patient. While psychiatrists underline the importance of psychotherapy for cure and receive huge amount of money for their services, drug therapies have become the main treatment for many psychological disorders.

In the chapter “Neurochemical Selves”, Nikolas Rose (2007b) discusses the ways in which global psychiatry has turned to a pharmaceutical sector, which aims at maximizing the profits of the drug companies rather than developing reliable explanations and cures for people, who suffer from a particular mental disorder. He claims that the quest for standardizing and categorizing the symptoms and diagnosis of psychological disorders has led psychiatrists to focus on the biological bases of a particular mental illness. With the rise of technology, genetic mapping and brain imaging have been expected to sweep away the mysteries of mental disorders, and finally the brain would become a tangible and readable area of the *clinical gaze* (Foucault, 2012).

While the terms medicalization and later pharmaceuticalization, were mentioned in the medical sociology literature to a considerable extent, Nikolas Rose brings another concept into light: molecularization. With this new terminology, he refers to the shift in psychiatric observation “from molar to molecular” (Rose, 2007b). The discovery of neurotransmitters such as dopamine and serotonin paved the path for the neurochemical explanations and drug therapies of psychological disorders, from depression to schizophrenia.

Diagnosing and treating mental disorders based on the molecular level brings a host of problems in itself. Firstly, as Rose (2007b) argues, susceptibility to a disorder cannot be measured according to a single gene. Many disorders including mental require mutations of multiple gene systems over a long period of time, which involve the effects of the phenotype more than the genotype. However, researchers concentrating on the genetic basis of disorders ignore this fact by trying to discover the single gene that is responsible for the disorder since pharmaceutical treatments bring more profit to the sector and decrease the labor work of the psychiatrists when compared to the psychoanalysts.

Furthermore, the molecularization of mental disorders increases the acceptance of the illness by the so-called patients (Rose, 2007b). Self-harm or lack of self-control due to a chemical problem in the brain sounds less scary and less dangerous to both the patients and their social environment than doing it for a psychologically unknown reason. In that respect, explaining trichotillomania on its molecular level and relieving it by playing with the neurotransmitters in the brain is to the preference of the patients as well. Instead of focusing on the real life problems, which cause stress or anxiety, patients prefer to solve neurochemical problems in their brain. Treatments of the brain can be realized mostly with pharmaceuticals, which are easier than conducting introspection or psychoanalysis for the problem for both the patients and the experts.

In his book, *Picturing Personhood: Brain Scans and Biomedical Identity*, Dumit (2004) analyzes how positron emission tomography (PET) scans are interpreted by the experts. By giving place to the words of the PET scanning experts, he shows how imaging and making the brain something readable excite them even though the reliability of the data is quite problematic. One of the inventors of PET calls it “an observer that doesn’t disturb you (the person)” and likens the effect of PET scanning as an invention to sending a satellite to the space (Dumit, 2004, p. 3). While the molecular flow across the body including the heart can be visualized through PET scans, the brain is the trickiest area since the results of the PET scans on the brain cannot be calibrated and controlled surgically (Dumit, 2004, pp. 4-5). Beside the fact that the neurochemistry of the brain is changing each and every second, and it cannot be crosschecked, the brain differs from other organs such as the heart, kidney or stomach in the sense that each individual’s brain is unlike the other. The biggest controversy is that experts compare different people’s brain scans and categorize people as different because their brains do not look the same (Dumit, 2004, p. 6). What Dumit (2004) questions in his book is the equilibrium drawn by the experts that a person is equal to his/her brain, his/her brain is equal to its scan, and the brain scan’s results are equal to diagnosis of his/her illness or disorder.

While the monopolization of pathological knowledge takes place in almost every sphere of medicine, psychiatry is one of the most “unstable” disciplines, which is quite affected by the local context (Lakoff, 2005). The questions of where to pinpoint a particular mental disorder, how to categorize it and universalize its treatments are still relevant today. In his book *Pharmaceutical Reason: Knowledge and Value in Global Psychiatry*, Lakoff (2005) argues that lack of stability of causes and treatments in psychiatry makes its relationship with biomedicine even more dubious. As a discipline that was “born in asylums, places of exclusion”, psychiatry still serves the purpose of pathologizing the abnormal rather than curing any disorder (as cited in Lakoff, 2005, p. 5).

Today, mental disorders are not limited to the so-called extreme mental disorders, which are easily stigmatized as abnormal, such as schizophrenia. While the medicalization of mental illnesses takes place, the number of defined and categorized mental disorders increases to a considerable extent; some of them are even named as the disorders of our age - modernity. The more mental disorders enter into the ordinary modern citizens' life, the less they are allowed to be pathologized as abnormal for having an unknown and out-of-control psyche since they cannot be excluded from society as well as from the processes of production and have to be controlled and "kept normal" in their daily lives. At this point, genomics studies as well as neurochemical and neurobiological research rescue contemporary psychiatry from multiple and unreliable explanations based on social and environmental factors, and on the contrary, allow it to elucidate each and every mental case through particular genes, which serve as risk factors, and neurochemicals. Bipolar disorder, obsessive-compulsive disorders and anxiety disorders are some examples of common mental disorders of today. As genomics and neurochemical studies try to explain such mental disorders through genes, the drug therapies become the main treatment of mental disorders in spite of the fact that categorizations of such mental disorders still remain quite problematic. In the next part, I move to my fieldwork and analyze the medicalization and pharmaceuticalization of trichotillomania based on the theories I have discussed above.

1.5. Diagnosing Trichotillomania: A Specified Obscurity

Christina Pearson, an ex-hair-puller and the founder of the Trichotillomania Learning Center, calls trichotillomania *a disorder of isolation* or *the lonely epidemic* (as cited in Penzel, 2003, p. 28). The loneliness or isolation of trichotillomania does not only stem from its being an obscure and underrated disorder, but also from the fact that it is experienced mostly in isolation, behind closed doors. In other words, a person pulls out his/her hair mostly when he/she is alone or even asleep, and from the experts' perspective, its private and isolated nature makes illness narratives and experiences of the patients important in calling the repetitive activity a psychological disorder.

One of the biggest problems arising from the isolated and subjective nature of trichotillomania is that experts cannot come to an agreement on its universal diagnostic criteria. Even though it was included in DSM III for the first time and then was specified in detail in the later versions, what to call and how to categorize trichotillomania is still a matter of debate among the experts and the patients. The behavioral aspect of the disorder creates ambiguity in pathologizing the activity of hair-pulling since it varies from person to person to a considerable extent. First of all, "which area(s) of the body is/are pulled?" is an important issue due to the fact that the visibility of the absence of hair depends on whether the public or the private parts of the body are targeted. For instance, a person pulling out his/her scalp hair might be considered mentally ill while another person pulling out hair in genital area might not be labeled as a hair-puller by the society. Moreover, the last version of the DSM (DSM-5) admits that hair-pulling does not necessarily refer to a self-harming behavior since there are cases, in which the individuals pull others' hair such as the facial or scalp hair of their siblings, hair of baby dolls or other hairy items (American Psychiatric Association, 2013a). Different target locations prompt the experts to take different measures for diagnosing and treating trichotillomania.

Apart from the public/private distinction, the differentiation between necessary and unnecessary hair exists in diagnosing trichotillomania. A man pulling out his beard can be regarded as pulling out the necessary hair, which is an important aspect of the manhood, whereas a woman pulling out the hair on her chin might be seen as doing the right thing: plucking the unnecessary hair. Even though the obsession with getting rid of hair regardless of the different body parts and repetitive hair-pulling seem to be at the core of the problem, social norms based on gender categories play a substantial role in determining the experts' diagnostic criteria as well.

How often or how much hair is pulled out is another measure for pathologizing trichotillomania. Some doctors set several thresholds for the quantity of pulled hair in order to decide the severity of the disorder. These thresholds are set mostly in relation to the hair growth cycles in these areas. For instance, experts suggest that 50 to 100 scalp hair loss a day is “normal”, whereas losing more than 100 hairs per day continuously can result in bald spots. Based on this assumption, some of the experts claim that pulling out 100 or more hairs per day can be considered a serious problem, which should be handled with. For these experts, hair-pulling becomes problematic as soon as it causes observable hairlessness, which again stems from the social attributions to hair.

How the hair is pulled out also differs from one individual to another. As I mentioned before, it happens mostly alone or in relative isolation while people are present and the hair-pulling process can be done consciously, or unconsciously – during the sleep or focused – with fingers, in front of a mirror or using tweezers (Penzel, 2003). Categorizing hair-pulling as conscious, unconscious or focused behaviors allows the experts to apply different treatments for each style. The more the behavior becomes unconscious, the more the expert tends to prescribe pharmaceutical drugs until the person develops conscious awareness for his/her act.

Apart from the ways in which the hair is pulled, the post-pulling behaviors vary from person to person as well. After the person pulls out a particular hair, there are several rituals of playing with the hair, such as playing with the root of the hair, examining it in detail, touching it to the lips and cheeks, biting or even swallowing the hair, which results in hairballs in the stomach called trichobezoars and can cause death if not removed by surgery (Penzel, 2003). These diverse post-pulling behaviors may demand treatments from other areas of expertise in medicine for recovery.

Even though the experts admit that the behavioral aspects of trichotillomania may be dissimilar for each person, the psychological process leading to hair-pulling and post-pulling feelings is considered more or less alike. The experts I interviewed as well as many others in their books and articles address a rise of tension before the person starts pulling and a temporary relief, until another hair is targeted. Based on the narratives of the patients, experts have constructed “tension-relief-tension” triad and until DSM-5, whether the person experiences this triad during the pulling activity in order had been specified as a diagnostic criterion for trichotillomania.[2]

Maybe one of the main ambiguities about the diagnosis of trichotillomania is the patient’s self-acceptance of his/her disorder. Trichotillomania as the lonely epidemic cannot be diagnosed unless the person admits that and seeks treatment. Therefore, before the psychiatric expertise comes to this conclusion, self-diagnosis is a must. Yet, self-diagnosis is affected by the socially constructed assumptions on hair and gender roles. One of the main proofs for this is that hair-pulling had been defined for years as a disorder of women due to the fact that research on trichotillomania was and still is highly female biased, meaning that most of the research done on trichotillomania include females more than males. Similar to the findings of a study (Christenson, Mackenzie & Mitchell, 1991; as cited in Mansueto & Rogers, 2012, p. 6), based on my fieldwork, I can say that women are the ones who consider themselves as sick and seek treatment since scalp hair is an inseparable part of womanhood, and baldness is socially considered to be disrupting the feminine look of women while male baldness is a socially acceptable thing and this allows them to hide and live with their disorder. At this point, it is meaningful to claim that even self-diagnosis of suffering from an illness for different sexes may implicate the values of society over beauty, femininity, manhood and gender roles.

The relativity and uncertainty of the factors discussed above makes it quite difficult for the clinical experts to make a universal categorization of trichotillomania. Even though the disorder is indicated in each DSM in more detail, experts face the problem of zooming, referring to the problem that the more the diagnostic criteria of trichotillomania are specified, the lower the prevalence rates are reported (Mansueto & Rogers, 2012). Therefore, the diagnosis of trichotillomania is neither truly objective, nor subjective; instead, it is based on personal, social and scientific explanations and assumptions of the psychiatric expertise, patients and the society.

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[2] As a hair-puller myself, I can claim that this triangle is not always the right formula since even for the same person each and every hair-pulling is a different performance and the more the person pulls out hair, the more his/her tension replaces the relief as the shame and guilt of the behavior are added.

1.6. Researching Trichotillomania: Neurochemical or Genetic?

Even though the first medical diagnosis of hair-pulling disorder was recorded more than a century ago, research done on trichotillomania is still insufficient due to several factors, such as its underestimated prevalence rate and its comorbidity with other anxiety disorders or depression. While Schachter's study, which was conducted in 1961, showed that the prevalence rate of trichotillomania was as low as 0.05%, based on the formal and informal records, it is considered that 4.4% of the population today around the world suffers from the hair-pulling disorder (as cited in Mansueto & Rogers, 2012, pp. 3-4; Penzel, 2003). According to Mansueto and Rogers (2012), the discrepancy in the diagnostic criteria of trichotillomania causes researchers to report quite different prevalence rates from each other. Furthermore, as the hair-pulling activity occurs mostly in the presence of other psychological problems and might be temporary or infrequent for certain individuals, the disorder itself can be reduced to transient or sub-threshold symptoms (Mansueto & Rogers, 2012). Also small sample sizes, the difficulties in conducting cross-cultural research on trichotillomania and inadequate resources of funding due to the little interest of drug companies can be mentioned as limiting factors of the research conducted on trichotillomania (Mansueto & Rogers, 2012, p. 4).

Although the validity of the universal medical consensuses like DSM is highly debatable, experts still seek to find out a common biological basis for the emergence of trichotillomania, and by doing that, to cure it at the biological level. Until now, no particular drug has been approved by the Food & Drug Administration (FDA) specifically for curing trichotillomania. As trichotillomania is considered a contested and comorbid disorder with depression, anxiety or other psychological disorders, many patients do not consider themselves sick and seek help. Since its prevalence rates are biased, it does not sound very profitable for the pharmaceutical industry to invest on a special drug for trichotillomania. The lack of interest of the pharmaceutical companies in funding clinical trials for trichotillomania limits the research of the medical experts. In order to cure trichotillomania, experts mostly use anti-depressants or other medications used for the obsessive-compulsive disorders and conduct placebo studies to measure the effectiveness of these drugs. So far, there had been only 13 controlled clinical trials conducted for trichotillomania (Grant, 2014a), which were mostly antidepressants, predominantly the serotonin reuptake inhibitors (SRIs) (Chamberlain, Odlaug, Boulougouris, Fineberg, & Grant, 2009, p. 834). Among these SRIs, clomipramine, olanzapine and NAC seem to be the more effective when compared to fluoxetine, known as Prozac by its trade name in the U.S. (Grant, 2014a). However, small sample sizes of these trials make the experts skeptical about the findings and they call for additional research on pharmaceuticals as well as the molecular and genetic basis for the trichotillomania (Grant, 2014a).

Research on trichotillomania after the second half of the 20th century focuses mainly on understanding the diagnostic criteria. Questionnaires had been conducted among adolescents in order to decide where to place trichotillomania within the borders of obsessive-compulsive spectrum and to create psychological models for trichotillomania (Chamberlain et al., 2009). While it has also been suspected that trichotillomania is an impulse-control disorder as well as it can directly stem from high levels of anxiety (Penzel, 2003), recently trichotillomania is cited with the “Body Focused Repetitive Behaviors” along with skin picking and nail biting (as cited in Chamberlain et al., 2009). These researches have aimed at understanding the roots of trichotillomania and its prevalence rates rather than generating possible treatments for it.

Recently, the familial link of trichotillomania and the individual’s genetic background have also been studied by the experts. In these studies, the relatives of people with hair-pulling behavior are found to show higher rates of grooming or other trichotillomania-like behaviors such as nail biting or thumb sucking (as cited in Chatterjee, 2012). Moreover, twin studies measuring the heritability rates of trichotillomania show 39% concordance in monozygotic (identical) twins and 0% concordance in dizygotic (fraternal) twins (as cited in Chatterjee, 2012, p. 260). Animal models have also been generated using mice with grooming behaviors. It is shown that the deletion of Sapap3 gene increases the grooming behaviors in mice to a considerable extent and hypothesized that the same process can make the same effect on humans as well based on the assumption that mouse and human

Sapap3 gene are highly homologous (>90% similarity) (as cited in Chatterjee, 2012, p. 260). While the sample sizes are too small and there is not any cross-cultural research conducted so far, findings are both limited and hypothetical. Another problem with the findings of the previous research is that the results supporting the existence of the genetic and familial links do not show in fact direct link with trichotillomania. As I cited above, patients or relatives of people with trichotillomania are found mostly to have so-called *trichotillomania-like behaviors*; however, scientists are still unsure about whether the behaviors of thumb sucking or nail biting do really belong to the same spectrum with trichotillomania. Moreover, even though the person and his/her relatives show these similar-assumed behaviors, we can also think that the behavior is learnt by the parents or the family has a stressful life, causing the members of the family to show similar symptoms. Also in the case of mice, it might be too reductionist and misleading to assume that grooming or barbering behaviors of the mice are equal to the hair-pulling behaviors of human-beings, even though the genes in both organisms are homologous. However, these researches still boost the hopes of the experts for finding a genetic cause of trichotillomania in humans.

Neurobiology and brain-imaging are also recent popular research areas of trichotillomania. Research on structural imaging of trichotillomania has shown that there is no difference in size of the caudate (as cited in Dougherty, 2014), but reduced left putamen volume, which is also seen in the patients of Tourette's syndrome (as cited in Dougherty, 2014). Another study on persons diagnosed with trichotillomania has found decreased cerebellar volumes and increased grey matter in the left striatum, the left medial temporal lobe and multiple cortical regions bilaterally (as cited in Dougherty, 2014). Also the PET scans showed increased brain metabolism in bilateral cerebellum and right superior parietal cortex, whereas SPECT studies found reduced neural activity in the left putamen and frontal regions with SSRI and an fMRI study that used task to interrogate striatal function found no differences in trichotillomania (Dougherty, 2014).

As the information I share above does not make sense for me as a person with a social science background at all, I can at least say that these complicated sentences have not yet led to any concrete findings on how to treat trichotillomania. While the consistency in neurochemistry of the different brains excites scientists to a considerable extent, they are still not knowledgeable about what definitely causes a part of the brain to be activated. As they cannot watch the neurochemical activity of a person's brain throughout his/her life, still they cannot crosscheck whether a certain brain function is directly related with the hair-pulling behavior or there are other independent variables misleading the results. For that reason, the so-called unique "trichotillomaniac brain" is reduced to its again so-called biological and neurochemical difference from other brains of "normal people" – as if all brains have to be the same – based on colorful pictures without any grounded proofs, and the findings still do not suggest any solution. This seems to be a serious concern of the medical researchers like Brian Odlaug, a public health researcher on addictive, impulsive and compulsive disorders, who stated during his presentation on neuroimaging at TLC's annual conference:

> What do we use these imaging results for? I think this has a vital importance that these imaging studies, they're very pretty pictures, journals love them. But you know you can't translate it to actual treatment relevant. […] I think it's quite a delimitative constraint. […] And quite honestly, this cortical thickness, it has, it has been looked at in a number of conditions like schizophrenia, depression, I believe a little bit in OCD as well. The benefit of it, that is how we translate it to actually treatment, is still way unknown. I mean what do we do with knowing that certain parts of the brain are thicker?

Apart from the researchers studying the human brain, neurobiology or genetic background, dermatologists are also the experts, who play an important role in diagnosing trichotillomania. As the hair-pulling is done mostly in isolation, scalp biopsies may reveal a hidden behavior. In PubMed, I found many articles about trichoscopic research on hair-pulling, and they are mostly about children with trichotillomania. In these articles, parents of children with trichotillomania bring their child to hair dermatologists in order to understand the reason behind the hair-loss. In one of the articles published in Turkey, dermatologists have studied a 12 year old red-haired girl and her scalp dermoscopy "revealed black dots, coiled fractured short hairs besides broken hairs of different lengths. There were many dystrophic hairs, some with frayed ends, sparse yellow dots, but no exclamation-mark hairs.” (Mansur, Aydingoz, & Artunkal, 2013). These criteria led the researchers to diagnose trichotillomania and they sent her to a psychologist. In her meeting with the psychologist, she confessed that she pulls out her hair (Mansur, Aydingoz, & Artunkal, 2013). I find it very interesting that dermatology, which is a very different area of medicine, can detect hair-pullers by coincidence based on the scalp biopsy, which they conduct to understand how the hair is lost. In line with my fieldwork experience and the scientific knowledge mentioned above, dermatologists’ expertise may be used to diagnose trichotillomania especially for the children, who either lie to their parents and hide their behavior or pull their hair unconsciously and are not aware of their behavior along with their parents.

Researches focusing on the genetic and molecular background of trichotillomania and other body-focused repetitive behaviors (BFRBs) are conducted to develop pharmaceutical treatments for the patients; however, as Brian Odlaug claims, they can hardly be translated into treatments. Still the medical experts, clinicians and animal behaviorists in TLC do believe that these areas of research will develop useful knowledge in generating pharmaceutical treatments for trichotillomania and other BFRBs. During the TLC conference, Jon E. Grant (2014b) as the Chair of the Scientific Advisory Board of TLC announced the launch of the Body Focused Repetitive Behavior (BFRB) Precision Medicine Initiative (BPM) by TLC, which was later publicized in more detail on its website. The main mission of BPM was defined by Grant (2014b) as “increasing BFRB remission rates from 10-20% to >70% within 5-7 years” by the means of “understanding, for the first time, the neurobiology of these disorders, identifying molecular targets for treatments and identifying new and targeted pharmacological and behavioral treatments”. BPM’s vision was stated by Grant (2014b) as “securing a nationwide collaboration among BFRB researchers and more than 20 academic and medical institutions around the U.S., with large-scale private money and the engagement of National Institute of Mental Health (NIMH) along with the pharmaceutical industry”. In the next chapter, I discuss BPM in detail from the perspective of economies of hope.

1.7. Comparing Two Contexts: Tr(ial-and-error)eatments

As I mentioned in the anecdote I shared at the beginning of the chapter, I name the treatments of trichotillomania in both Turkey and the United States as tr(ial-and-error)eatments. Even though the experts on trichotillomania in the United States are much more knowledgeable than the experts in Turkey, I think that the situations of patients in these contexts are not quite different. During the TLC conference I participated in 2014 as well as based on my fieldwork on online support groups on Facebook, I have observed that psychiatrists and other medical experts in the U.S. encourage the patients to apply trial-and-error in using off-label pharmaceuticals and alternative medications by stating their risks and side-effects. They even claim that even though a drug is proven scientifically to be indistinguishable from placebo, patients should still try it themselves based on the view that "psychiatrists do not aim proving the efficacy of the drugs, they aim to treat people" (Grant, 2014b). Since there is an old and well-known patient organization for trichotillomania, which is Trichotillomania Learning Center, hair-pullers in the U.S. have the opportunity of consulting the experts at the TLC, receiving information from their website and attending their annual conferences or other events. Conferences such as the one I attended are valuable platforms for patients to increase their knowledge on trichotillomania, to consult experts and decide to what kind of treatments they should follow. Also there are many institutions other than patient organizations in the U.S., from which hair-pullers can benefit, such as centers for obsessive-compulsive disorders, clinics or support groups.

Experts generally diagnose and treat patients based on their textbook knowledge, which mostly does not contain trichotillomania, but covers outdated categorizations of obsessive-compulsive behaviors from the older versions of DSM. Since they might not have so many trichotillomania patients, they use the Internet to learn about the disorder if they need. When I knocked the door and entered the room of a psychiatrist in Turkey, whom I sent an e-mail before to arrange an interview, I found him watching a video about trichotillomania. When I tried to start my interview, he cut me short and asked for five minutes as if he was checking his e-mails while the video was playing. Besides, during the interview, his descriptions of the hair-pulling behavior were exactly based on what he read or heard online, stereotypical definitions of the medical expertise. As he tried to answer my questions, it was apparent that he was not knowledgeable about trichotillomania and his responses were based on his experiences with his patients diagnosed with dissociative identity disorder rather than trichotillomania. Since he assumed me at the beginning of the conversation as a lay person and a hair-puller, who is not expected to be informed about the medical knowledge on trichotillomania, he shared with me his speculations about the diagnostic criteria and possible treatments of trichotillomania rather than his scientific knowledge without any concern. At the end of the interview, he told me that I have become "almost a medical expert" of the hair-pulling behavior and told me that he is interested in talking to me about psychiatry in the future too. This was an interesting example of how medical experts may rely on the out-of-date information as well as any information shared on the Internet about trichotillomania without checking the reliability of the resources, similarly to what patients do, and their categorizations of trichotillomania may depend on their common-sense assumptions based on their expertise of another disorder.

One of the psychiatrists I interviewed in Turkey told me that he has seen around ten patients of trichotillomania during the 22 years of his career and claimed that all of his patients responded positively to the treatments and stopped hair-pulling behavior. While the information he provided about trichotillomania and treatments were quite outdated and in some cases even contradicted the latest research, he was very confident in his words. For instance, during our interview, he claimed that trichotillomania is a disorder that starts in most cases after the age of 17 and its prevalence rate is 0.5%, although today we know that there are many infant hair-pullers and the statistics he gave was stated in Schachter's study, which was published in the year of 1961, almost 55 years ago.

While the psychiatrists in Turkey try to create the impression of being knowledgeable and professional on trichotillomania, hair-pullers and their families I talked to are very skeptical about their knowledge and patients quit their treatments mostly after a while. There was a 12-year old girl, Ceren, whose father contacted me through e-mail to get my advice about what to do for her daughter. He told me that they took Ceren to a state-hospital in the city of Izmir and she has started therapies with a psychiatrist. After several appointments, the psychiatrist prescribed a drug to her, the name of which her father could not remember. While the drug made no change in her pulling behavior, the psychiatrist prescribed another additional drug for her, which according to Ceren's father was not suitable for adolescents as it was stated in the prospectus of the medication. However, these two medications together did not decrease the repetitive behavior and led to nonchalance and changes in mood. The father stated:

> Ceren has become a ghost, doesn't care anything about school or anything or what we tell her. She became a rebellious adolescent, doing the opposite of what we say. My wife and I are worried about her. What should we do? If she quits the therapy, then what about the drugs? We really don't know what to do.

Based on their limited knowledge, many psychiatrists in Turkey conduct trial-and-error. Both the psychotherapies they conduct and pharmaceutical drugs they prescribe seem outdated as they do not have so many patients. Therefore, they seem to be not following the latest research and improve their knowledge on trichotillomania. Their lack of interest as well as the ineffectiveness of the treatments lead patients to learn about the most recent developments in treating trichotillomania and applying the unconfirmed and unpublished treatment methods, which I discuss in the next part. Following the latest research abroad ranging from genetic studies to brain-imaging, hair-pullers in Turkey are not satisfied with the treatments, which mainly consist of psychotherapies and antidepressants, provided in Turkey and even try medications, which are not experimented on human beings, such as N-acetylcysteine.

N-acetylcysteine (NAC) is a modifiedamino acid and is believed to reduce oxidative stress, which is a chemical mechanism and not at all related to the social stress, in human beings. There is some unpublished and limited research claiming that N-acetylcysteine can reduce hair-pulling behavior. During the TLC Conference, an animal behaviorist Dr. Joseph Garner from Stanford University presented the latest research of his research group on NAC experimented on mice. Mice may show barbering behavior, which is believed to correspond to the hair-pulling behavior in human-beings. When mice become overweight, it is claimed that the oxidative stress level in their bodies increased to a considerable extent (Garner, 2014). In these times, mice tend to pull out each other's hair, causing big visible bald spots on each other's bodies (Garner, 2014). According to his research, mice that received certain amounts of NAC in a period of time, had a significant decrease in barbering behavior since NAC is considered a powerful anti-oxidant. For Garner (2014), NAC can also be tested on humans and may decrease their hair-pulling behavior similarly.

Even though NAC is not an FDA approved medication for trichotillomania, some of the experts in the U.S. encourage the patients to buy NAC from GNC stores, take it on a daily basis and see whether it really works. However, the feedback of the patients is very different from one another. While some hair-pullers claim that it works well on them and they see the difference, others could either stop hair-pulling temporarily or observe no effect at all.

In 2012, two years before the TLC conference, an anonymous Turkish hair-puller, who kept an online dairy of her pull-free 991 days and had hundreds of followers, shared a blog post in Turkish on NAC. She wrote that a psychiatrist friend of her father advised her to try NAC for the possibility that her hair-pulling behavior may recur in the future, even though she had been pull free for three years without any medication. Having written about its possible effects and warned people not to try it without consulting their doctors, she claimed that the psychiatrist cured 3 of his 4 patients suffering from trichotillomania and advised hair-pullers to use 1200mg daily for 6 weeks and 2400mg daily for another 6 weeks. The most interesting part was that she wrote how to find NAC in Turkey. The psychiatrist told that NAC is the chemical in the expectorants and can be bought from the pharmacy without getting a prescription. Hair-pullers in Turkey, who did online research about their disorder, read her blog post and tried NAC on themselves without consulting a doctor.

> I tried everything, psychotherapies, antidepressants, stress kits, sport... I tried even N-acetylcysteine. Have you heard about it? I read somewhere about it and bought expectorant from the pharmacy. I took 1200 mg a day.

> During my first month, I stopped pulling out my beard. It was like a miracle. But then it started again. Still I wanted to continue, but couldn't resist the side effects of the expectorant and stopped taking NAC. It made me cough a lot and was even waking me up. Nothing works, I feel so bad. My last chance is hypnosis, I'm gonna try it. Have you tried it before?

The quote I shared above was the words of a male hair-puller, with whom I conducted a telephone interview and who pulls out his beard and works in a company as a marketing manager. There was also another female hair-puller, who works in a company as a high-ranking industrial designer and pulls out her eyebrows and eyelashes. During our phone interview, she said that she tries many ways to stop her behavior and explains why:

> I always try to hide my disorder, only my parents and closest friends know that I suffer from trichotillomania. I have to hide it, especially in the workplace, because there are people working under my authority and I don't want them to know my weak points. I have to pretend that I am a strong person; my authority would be destroyed if my colleagues knew that I pull out my eyebrows and eyelashes. Every day I wake up very early to draw my eyebrows and put on my fake eyelashes. They notice of course, especially they notice my eyebrows, but I tell them that I put permanent makeup because I like it so much. What can I do else?

In another dialogue, she told me that she tried physical exercises and had even started Zumba dancing for increasing her mood. Even though she said that she felt better and enjoyed it, not being able to stop her behavior had discouraged her from continuing. She said that she wanted to try hypnosis as well.

1.8. Discussion

In both Turkey and the United States, online platforms play an important role in spreading the latest research among patients. The Internet allows the patients to circulate their knowledge and in a sense democratizes the situation of patients by eliminating the geographical, economic and social differences for achieving healthcare. For instance, patients in Turkey can learn about the possible treatments for trichotillomania and newest findings from the patients living in the United States. While experts continue to make trial-and-error treatments and switch between the drugs, patients also do the same based on their knowledge and experience shared especially on online support groups. As the patients in the United States are encouraged by doctors to try medications and alternative treatments, patients in Turkey, who cannot get better, lose hope from medical doctors, try to find their own treatments ranging from taking NAC to drinking the tea of St John's Wort[3]. However, even though patients take part in self-trials of medications, their role in the co-production (Jasanoff, 2004) of knowledge on trichotillomania is neglected by the experts.

Medical experts on trichotillomania act controversially in diagnosing, treating and researching it. It seems hard to find a biological basis and an objective or standard treatment for a psychological disorder. As they categorize trichotillomania as a separate disorder in DSM, create public awareness and prove that prevalence rates of trichotillomania are higher than they are estimated, they believe that they can divert the attention of the pharmaceutical industry and national institutes of mental health in order to receive more funding for research. Apart from psychiatrists and psychologists, scientists from different backgrounds, ranging from neurologists and geneticists to animal behaviorists and dermatologists, research trichotillomania, especially in the United States and their studies reduce trichotillomania to the biological level and focus on the risk factors of the disorder only, which is simply undermining the complexity of its nature.

It is also important to underline that this controversy does not stem from the personal attitude of the psychiatrists or other medical experts towards trichotillomania. Along with the other medical disciplines, psychiatry of the 21st century has constructed its own rationality, which values the genetic and neurochemical research over others, and the same trend is followed for researching other psychological disorders as well, such as schizophrenia, bipolar disorder, attention deficit hyperactivity disorder (ADHD) etc. The complexity of the psychological problems, which involve both social and biological factors altogether,

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[3] St John's Wort is a type of tea and is assumed to decrease stress.

is reduced to the neurochemical and genetic explanations, which still do not suggest any solution for the patients.

While the opinions of the psychiatric experts are the key factors in shaping the research conducted on trichotillomania, it is also important to underline that also hair-pullers want to make themselves believe that trichotillomania has a genetic or neurochemical cause. Hair-pullers want to have concrete proofs of their disorder; it can be their brain images or their DNA; they prefer that their behavior has a biological or molecular root. Lacking self-control for no reason makes both hair-pullers and their social environment question their agency. As Rose (2007b) argues, justifying their disorder as a biological illness helps the patients get rid of their feeling of shame for doing something they do not want and that is considered abnormal. It also turns them to docile and predictable people and decrease their stigma and self-stigma to a considerable extent. Even though the absurdity or abnormality of the behavior remains the same for others, suffering from a neurochemical or genetically-caused problem whitewashes the hair-pullers as well as trichotillomania and turn them to misfortunate people, who have to suffer from what the life has brought to them. While the psychologically and socially relieving effects of the molecularization of trichotillomania play an important role in patients' compliance to this process, patients also prefer to take the easy way out for getting cured. Who would not want to get cayenne pepper drugs[4], which –if really– boost metabolism and burn calories faster, for losing weight instead of spending hours in the gyms or sticking to a diet?

As I analyzed in my fieldwork in detail, trichotillomania is tried to be cured by trial-and-error in both contexts. This proves us that categorizing a psychological disorder more, setting more specific diagnostic criteria or developing more expertise and research on it are not equivalent to treating people. With or without medical expertise, patients are left alone to take the risks of conducting trial-and-error and have to continue to self-track their disorders. Hair-pullers are responsible for their illness trajectories, and the existence of a more developed psychiatric

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[4] Cayenne pepper drugs are made of cayenne peppers, which are very hot and therefore famous with boosting metabolism. These drugs are sold around the world for the people, who want to lose weight quickly and easily.

expertise does not decrease those risks and does not go further than a consultancy service.

I find Dumit's (2002) concepts of inherent illness and dependent normalcy quite relevant for my research on trichotillomania. As I mentioned in the theoretical part, Dumit (2002) argues that while the body was regarded in the past as inherently healthy and threatened by the outside factors, recently the body is considered as tending to be inherently ill and can reach health through pharmaceuticals, which the normalcy and therefore health depend on. I see the same paradigm shift in psychological disorders, particularly in trichotillomania as well since an individual who overcame his/her trichotillomania still feels threatened by the recurrence of the hair-pulling behavior, which depends on the triggers within the social environment. Many hair-pullers, including me, can manage to stop their behavior even for years and sometimes it recurs for certain people, some of whom can easily control it and some of whom cannot resist their urge. However, instead of focusing on how to eradicate or overcome these triggers, the pharmaceutical industry hand in hand with psychiatry encourages the recovered patients to continue with their medications or psychotherapies until an unknown date, from 1 year to 15 years or more. The urge of hair-pulling cannot be destroyed fully, but can be kept dormant through medications and other kinds of treatments, and a trichotillomania patient or ex-patient has to track him/herself throughout his/her life in order to keep their "dependent normalcy" (Dumit, 2002).

While the patients in the U.S. are also aware of the fact that research on trichotillomania is insufficient, current medications and treatments are not effective and indistinguishable from trial-and-error, they do not criticize the situation. As the experts complain about the lack of interest of the pharmaceutical industry and the research agencies for funding research on trichotillomania, patients believe that increasing awareness for trichotillomania and supporting experts for finding funding as well as for categorizing trichotillomania in DSM as a separate disorder, play a vital role in rescuing themselves and other hair-pullers. Patients regard organizations like Trichotillomania Learning Center and their scientific advisory boards as the advocates of their cause. Having analyzed two different patient organizations, which engage in political advocacy and biomedical research, Novas

(2006) argues that the activism of the patient organizations today is based on the hope of generating possible treatments in the future by capitalizing the biological samples such as blood, tissue and DNA as well as fundraising for future research. Novas (2006) defines this process, in which patients invest both money and hope to the patient organizations, as the political economy of hope. Similarly, I think that TLC's announcement of Body Focused Repetitive Behaviors Research Initiative (BPM) in 2014 and call for donations as well as participation in research is an important example of how patient organizations make patients believe in future research and encourage them to devote both their money and biological data to the uncertain results of future research.

I find it important to underline that patient organizations play a substantial role in shaping the future research on disorders or illnesses both politically and economically. As Foucault's (1978) term biopolitics refers to the increasing controls, modifications and regulations of life and its administration by different types of expertise ranging from physics to urban planning from 17th century onwards, contemporary biopolitics (Rose, 2001) of the 21st century involves more actors taking part in the political calculations of life (as cited in Novas, 2006, p. 290). Today, the individuals recognize themselves as biological entities, form biosocial groups and have a voice in determining technologies and scientific knowledge (Novas, 2006, p. 290). As I will discuss in the following chapter in detail, patient organizations not only serve as support groups of patients, who come together only to feel better and share their sorrow, but also aim at increasing their lay knowledge, organizing fundraising, coordinating the scientific research and taking part in the policy-making on health (Novas, 2006). By participating in these activities, patient organizations generate hope among the patients for a better and healthier future, which is directly related with the hope over the scientific breakthroughs. With Nik Brown's (1998) words, "hope serves to designate a vocabulary of survival where survival itself is at stake" (as cited in Novas, 2006, p. 291), and I think that the genetic and neurochemical vocabulary of survival for trichotillomania and future treatments on the biological level generate more hopes for the patients than its social and subjective explanations. According to Brown (2003), today we are subject to an increasing number of scientific breakthroughs, which compete with each other about their promises for a better future ranging from nuclear power to nanobiotechnology. These competitive futures are constructed and advertised at the present and their benefits as well as risks are overestimated and exaggerated, leading to hype rather than hope when these projects end up in failure or even do not meet their past promises (Brown, 2003). Based on my fieldwork, I can state that the hype of the molecularization of trichotillomania so far, is hidden by the discourse of the medical experts, mainly the scientific advisory board of the Trichotillomania Learning Center, who claim that the disorder itself still remains contested and is neglected by other scientists as well as the pharmaceutical industry. Therefore, they claim that the inadequacy of current research stems from the fact that they, as scientists, cannot do their best due to their limited resources and scientific collaborations around the world. For them, the hope for future research depends on the maximization of resources and funding, which calls for the efforts of the patients as well.

In this chapter, I discussed the ways in which trichotillomania is pharmaceuticalized by the medical experts in the United States and Turkey and patients are subject to tr(ial-and-error)eatments in both contexts. My research demonstrates that trichotillomania as a contested psychological disorder involves mysteries for the researchers and the uncertainty leads them to more categorizations, which still do not result in more effective treatments. Neither the medical specification of the disorder, nor the knowledge of the medical expertise changed the situation of the patients in the two countries, and the recovery of the patients depend on the personal efforts rather than the developed treatments for trichotillomania. In the next chapter, I focus on the patients' expertise of trichotillomania, coping and hiding strategies of the hair-pullers and the role of the TLC and support groups in developing the lay expertise of trichotillomania.

CHAPTER II: LAY EXPERTISE AND PATIENT SUPPORT AMONG HAIR-PULLERS

2.1. Social Support or Lay Expertise? Patient Groups of Trichotillomania

Who can be regarded as the expert of an illness? Can somebody become an expert of his/her own disorder? Is it possible that the knowledge of ordinary patients may surpass the expertise of the medical doctors? What are the limitations of the textbook knowledge of the clinicians? Are there any advantages of being a lay expert? Who does, a patient or a medical expert, hold as more of an expert in diagnosing and treating an orphan disease? In what ways do the patient organizations (un)change or reproduce the existing medical discourse of the experts? How do the rising voice of the patients by the spread of information and communications technologies and the increasing institutionalization of patient groups transform the lay expertise? By what means does this alter the dichotomy of medical expertise versus lay expertise? All these questions become even more complicated when it comes to studying a mental disorder, especially a less known one.

Increasing usage of information and communications technologies all over the world has paved the path for bringing the patients together, expanding their knowledge on their disorder and sharing their experiences. A person suffering even from a stigmatized disorder can reach many so-called “abnormal individuals” and no longer feel alone. Online support groups, which allow anonymous memberships and can be reached 24 hours a day 7 days a week, have become a valuable and life-saving platform for people, who feel depressed, anxious, lonely or have suicidal thoughts. As a person, who has suffered from trichotillomania for many years, I have benefited from the therapeutic effect of the online support groups on social media.

For people suffering from contested illnesses like trichotillomania, which carry many controversies over its diagnostic criteria and possible treatments, patients’ organizations and support groups play an important role in supporting the patients. Spending time together with other patients, trying to understand the symptoms, feelings and stigma that come along with the disorder, and developing strategies to overcome it, create a healing effect among the trichotillomania sufferers. The differences among the illnesses, such as being biological or psychological, chronic or temporary, rare/contested or well-known, as well as in which context or time they take place, are influential in shaping the motivations of the patient organizations and support groups. Moreover, in the case of the individuals suffering from a psychological disorder, sustaining the well-being requires continuous efforts to self-check over time and to remain positive and hopeful for recovery. Online groups of patient organizations and support groups can be very helpful in settling a person's depressive mood immediately as he/she shares feelings with others.

This chapter aims to analyze in what ways the Trichotillomania Learning Center[5] in the United States and patient groups in Turkey construct their lay expertise and how the patients in both contexts engage in social support, share their coping strategies with hair-pulling and circulate their lay knowledge. In order to do this, firstly I will briefly draw the conceptual framework of the lay expertise in the area of STS, and discuss how medical sociology addresses patient experiences and lay knowledge of the patient organizations. In the second part, I will compare and contrast Trichotillomania Learning Center with ACT UP, the most famous patient organization for HIV patients. In order to do that, I will discuss the construction of the lay expertise of the HIV groups within ACT UP as one of the first patient groups, which challenged the medical expertise and got involved in conducting science with the medical experts. Lastly, I will analyze how the patient support and lay expertise of these two different patient groups differ from each other and discuss the role of patient organizations, especially for the psychological disorders.

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[5] Trichotillomania Learning Center is the biggest patient organization of trichotillomania around the world.

2.2. Patient Organizations and Lay Expertise in Social Science Literature

The relationship between science and society has been one of the core topics in the area of STS. Whether the scientific and technical knowledge is political and to what extent the scientific expertise contradicts with the idea of democracy are some of the theoretical questions raised by the scholars of public understanding of science, and the sociology of scientific knowledge (Sismondo, 2010). In the 1950s and the 1960s, during the first wave of science studies, most of the scholars of STS held a positivist approach in analyzing the scientific knowledge and discussed the "success of the sciences rather than questioning their basis" (Collins & Evans, 2002, p. 239). As the aim of the sciences was to understand the nature in a positivist and an empirical way, the scientific knowledge was not considered as a social product in the past, and the social authority of the scientists and engineers was questioned by the STS scholars lately (Sismondo, 2010, p. 168).

After the 1970s up until today, science and technology have been studied through the social constructivist approach, which focuses on the application of scientific and technical knowledge in social institutions such as schools, courts of law, hospitals, etc. (Collins & Evans, 2002, p. 39). During this period, the works of the sociologists like Foucault have put forward the constructedness of the legitimacy of the expertise, which is an inseparable part of the social relations of power. Furthermore, the variety of scientific claims and the accuracy of the public knowledge over the debates on scientific solutions in some recent examples (Wynne, 1996) have tarnished the image of the scientific expertise of the scientists and brought the importance of the public's knowledge and understanding of science into light.

The authority of the expert has also been addressed from a critical perspective within the field of the medical sociology; however, patient knowledge has been largely ignored until the second half of the 20th century. In 1950s, following Parsons' (1951) theories of illness and the patient identity emerging with the chronic illness, medical sociologists focused on the illness behaviors of the patients (Alonzo, 1984), social and demographic variables and factors such as stress, living conditions etc. (Mechanic, 1995; as cited in Pierret, 2003, p. 6). Moreover, they conducted sociological case studies, analyzing the ways in which patients become aware of and cope with their different health conditions such as tuberculosis (Roth, 1963), polio (Davis, 1963), visible disabilities (Goffman, 1963) and dying (Glaser, & Strauss, 1965, 1968) (as cited in Pierret, 2003, p. 6). During the 1980s, the concept of illness was starting to be discussed through its subjective as well as contextual meaning. From the perspective of stigmatization; however, patient knowledge was still regarded by some of the scholars inaccurate rather than just different and subjective (Prior, 2003, p. 41). For instance, in their sociological study, Segall and Roberts (1980) analyzed the level of medical knowledge – or medical ignorance – among patients in Winnipeg by measuring how much the patients knew and understood common medical terms such as malignant, cerebral and fatal, and the number of the correct answers were found to be quite low (Prior, 2003, p. 41). In such studies, a patient's knowledge was called by the medical sociologists as "patient perspectives, viewpoints and even beliefs" (as cited in Prior, 2003, p. 44).

The rising notion of the welfare state especially in the Western world has played an important role in the legitimation crisis of the scientific expertise as well as the theoretical shift from the patient knowledge to the patient expertise during the late 20th century (as cited in Prior, 2003, p. 43). The rising critique over the anti-democratic nature of the expert culture (Habermas, 1987) and the increasing desire for the democratization of knowledge (Turner, 2001) has changed the ways in which social scientists handle with and position the patient (as cited in Prior, 2003, p. 43). As the situated understandings (Lambert, & Rose, 1996, p. 80) of the lay people have been juxtaposed to the universalistic knowledge (Yearley, 2000) of the scientific experts (as cited in Weiner, 2009, p. 256), the hybrid concept of *lay expertise* emerged, which recognizes lay knowledge and experience as just as valid as scientific knowledge.

Recently, scholars have been focusing on the rising lay health groups, and the construction of lay expertise within the patient groups and/or organizations (Kelleher, 1994; Rose & Novas, 2004; Weiner, 2009). The research of Rabeharisoa and Callon (2002) on the French association of muscular dystrophy patients (AFM) and Epstein's (1995; as cited in Pinch, 2002) study of the AIDS organization ACT UP, which I discuss in this chapter in detail, are some of the most prominent examples of the research done on lay expertise of the patients, who became powerful not only in objecting to the way of doing science, but also taking part in it.

Rabeharisoa, Moreira and Akrich (2014) discuss the ways in which the evidence-based medicine has shaped the role of patient organizations and paved the path for a new concept, which they call *evidence-based activism*. Evidence-based medicine refers to the changes in medicine mainly in the second half of the 20th century, leading the clinicians to rely on controlled trials rather than case-control studies in order to increase the accuracy of their scientific research (Cochrane, 1972). The rise of evidence-based medicine led to highly standardized series of stages such as chemical composition analysis, in vitro tests, animal experimentation, and the successive phases (one through four) of human trials for testing and marketing of new drugs in transnational level (Dodier, 2005, p. 286 & 289). This leads to a shift from a clinical tradition, in which clinicians are considered the legitimate decision makers over the wellbeing of their own patients, to a *therapeutic modernity*, which encompasses the formalization of international ethical rules for experimentation and the universalization of healthcare after 1990s (Dodier, 2005, pp. 285-289). These alterations caused the scientific research for the approval of new drugs to take more time and increased the objections of patients suffering from especially fatal viruses or diseases and having no time or patience for waiting in hope. As I will discuss later in the case of ACT UP, some of the patient groups increase their lay knowledge and take part in scientific research. Evidence-based activism is a term, which covers the multiple forms of knowledge: the patient groups not only gather but also create, ranging from biomedical knowledge to health technology assessment, public health research or forms of judicial expertise (Rabeharisoa, Moreira, & Akrich, 2014, pp. 6-7).

According to Corbin and Strauss (1988), the primary aim of the patient organizations has been focusing on the illness trajectories of the patients (as cited in Rabeharisoa, Moreira, & Akrich, 2014). Increasing importance of self-descriptions of the patients about their disorder or illness has reshaped the concept of patienthood and the borders of expertise (Rabeharisoa, Moreira, & Akrich, 2014, p. 5). Patient organizations have served as the platforms where the social aspects of the illnesses are positioned and opened up for discussion. Based on the fieldworks of five different illnesses in different contexts, Rabeharisoa, Moreira and Akrich (2014) argue that patient organizations can no longer be considered as passive support groups relieving the patients only. In some cases, they can also serve as the hub where the experiential knowledge of the patients creates lay expertise (Epstein, 1995), which in one way or the other can shape and even interfere into the sacred space of the medical expertise (Rabeharisoa, Moreira, & Akrich, 2014).

According to Rabeharisoa and Callon (2002), there are three different models of lay expertise within patient organizations (as cited in Weiner, 2009). While patient organizations serving as the auxiliary association rely on the medical expertise, in the emancipatory model patients have the opportunity of challenging as well as questioning the medical expertise and the partnership model allows the patients to act as real partners on developing health solutions, and the patient organizations carry the purpose of being an intermediary (Rabeharisoa, & Callon, 2002; as cited in Weiner, 2009, p. 257).

2.3. Lay Expertise in ACT UP

Epstein's analysis of ACT UP, a well-known AIDS organization in the United States, is an example of an evidence-based activism. According to Epstein (as cited in Pinch, 2002), the thalidomide scandal has caused the Food and Drug Administration (FDA) to conduct more rigorous tests before approving a particular drug. Clinical trials, which consist of three separate, long and money-consuming phases, may lead to a drug approval after 6 to 8 years at least (Pinch, 2002, p. 130). The inefficiency of clinical trials as well as the lack of a possible treatment and prevention for the HIV virus in spite of the promises of the experts for finding its cure had created a serious discomfort among the patients, who could not bear to wait for their death. The grassroots patient organization ACT UP emerged as a platform of AIDS activists, who object to the loss of credibility (Epstein, 1995) of medicine and scientific experts for finding a cure for their illness. The importance of ACT UP in STS literature originates mostly from the success of the lay expertise of the patients, who not only have become as knowledgeable as the experts by creating their own dictionary of medical terminology for their disorder and studying it, but also have made the scientific experts and drug administration authorities listen to their lay expertise.

As Epstein (as cited in Pinch, 2002) argues, the turning of AIDS patients into activists through entering in the black box of the medical expertise has several motivations behind it. First of all, HIV can be a fatal virus, which causes the patients as a matter of course to run out of patience for recovery and fight for their lives while hearing about many deaths within their community. Secondly, and maybe even more importantly, AIDS means for the public more than a fatal disorder, as the risk-increasing factors for being infected are over-identified by having polygamist relationships and homosexuality, which in fact turn AIDS patients from pitiable, unfortunate victims into guilty people, who have to pay the price for their degeneration. According to Epstein (1995), the negative impression and stigma of "having AIDS" politicizes the patients, fighting for their stigmatized identity as well as for their sick body.

The long duration of the clinical trials testing the efficacy of drugs was not the only objection of AIDS activists. Patients, who have nothing to lose other than their own lives, competed with each other to attend the clinical trials, paying no attention to the possible side effects of the drugs. While each drug they try on themselves meant a new hope, they were quite suspicious about the possibility of taking the placebo rather than the drug. Some AIDS patients became so desperate that they opened up the capsules to discover whether the pill tasted sweet like a placebo, or bitter like AZT. Even though a company changed the taste of the placebo to make it bitter, patients were still not convinced and sent the drugs to local chemists for testing (Epstein, 1996, p. 204; as cited in Pinch, 2002, p. 137). Moreover, patients also turned to other countries where untested antiviral drugs are sold at quite lower prices.

What the AIDS activists proposed was not to destroy the medical expertise, but to allow the patients to choose among the risks, which is for some patients a "fair bargain" (Epstein, 1996, p. 189; as cited in Pinch, 2002, p. 132). An untested drug may have severe side effects, but still in some cases, patients might want to tolerate the side effects. Even though FDA aims to assure the safety of the drugs through clinical trials, losing time and hope for survival can cause more harm for the patients. Also some patient activists claim that there are other options for conducting clinical trials without using a placebo. With the support of some drug companies, community-based organizations in New York and San Francisco conducted trials for aerosolized pentamidine, the substance assumed to treat Phencyclidine (PCP). For the first time in 1989, the FDA permitted the use of aerosolized pentamidine based on the community-based trials without placebo groups (Epstein, 1996, p. 218; as cited in Pinch, 2002, p. 139).

Having spread throughout the U.S. quickly, ACT UP has become the most powerful patient organization for AIDS. Apart from the poisonous AZT, the medical experts have not come a long way for finding a possible cure for AIDS, dashing the hopes of the patients. Calling the FDA "federal death agency", AIDS activists in ACT UP considered AIDS a form of genocide due to the recklessness of the governments and medical experts. In order to change this, they aimed at organizing protests, forcing the FDA to approve drugs more practically, increasing the access to drugs, and changing the process of clinical trials towards a more achievable and beneficial testing (Pinch, 2002, p. 141).

Returning to the concepts of evidence-based activism and lay expertise, I see that AIDS patient groups, and particularly ACT UP as a patient organization, were fighting for creating a space for themselves in the decision-making mechanisms of the medical expertise. Moreover, they have been very successful in directly taking part in the research of their own illness and developing feasible and accurate treatments. While the success of the lay expertise of ACT UP and other similar patient organizations may sound very compelling in the sense of transforming the medical expertise, the democratization of scientific knowledge through lay expertise is not real for each and every patient organization. As O'Donovan (2007) argues, researchers on lay expertise have been studying mostly the radical and innovative patient organizations (as cited in Weiner, 2009). Researching on HEART UK, which is the biggest charity for inherited high cholesterol conditions in the United Kingdom, Weiner (2009) analyzes the hybrid professionalization of the patient organizations. According to Weiner (2009, p. 258), hybrid organizations like HEART UK act both as a patient organization, which represents people with a certain health condition, and as a professional association, which offers education, advice, and treatment guidelines, as well as networking and dissemination opportunities, to professionals. However, its hybrid structure, which brings the medical scientists and the patients together, does not necessarily refer to the democratization of health as well as science since these hybrids can be formed as a strategic move for both the experts and the patients and may reproduce the same lay-expert hierarchy (Weiner, 2009).

At this point, the important question is how could HIV patients at ACT UP as lay people convince the medical experts not only to listen to their opinions, but also to trust their medical knowledge? Considering the absence of the Internet and many communication technologies, which many patient organizations now have, how could the AIDS activists transform from patients to co-researchers of their own disorder? Did they destroy or on the contrary enter the medical expertise? In the next section, I will seek answers to these questions by analyzing the patient groups of trichotillomania in the light of ACT UP activists.

2.4. Analyzing Trichotillomania Patients: Evidence-Based Activism or Evidence-Based Trial-and-Error?

In this section, based on my online and offline fieldwork, I analyze how hair-pullers in the United States and Turkey organize themselves, and the ways in which the existence of a patient organization and the usage of social media affect the patients' lives and experiences of trichotillomania. In the U.S., hair-pullers organize through the Trichotillomania Learning Center as well as the online and offline support groups for sharing experiences and information. In Turkey, there is neither an official patient organization nor a support group and there are only online support groups on Facebook. My research is based upon participant observation at the annual conference of TLC in 2014 and semi-structured interviews conducted with hair-pullers in Turkey, as well as participant observation on online Facebook groups of the hair-pullers in both contexts.

Trichotillomania is not a lethal disease[6] like AIDS; however, hair-pullers are subject to stigmatization in their social environment. As trichotillomania starts mostly at a younger age, children or adolescents experience difficulties in hiding the bald spots and justifying their baldness. While suffering from a psychological disorder is itself considered a humiliating fact, harming oneself through hair-pulling or skin-picking causes mistrust in the person’s rationality. Trichotillomania patients may be considered unfortunate victims of their disorder as is the case in other disorders; however, lack of control of one’s own “abnormal” behavior makes the person look irrational, unpredictable and dangerous, resulting in a stigmatization similar to the experience of AIDS patients.

One of the main motivations of the hair-pullers in becoming a member of TLC is engaging in treatment activism and getting help through their illness. TLC plays an important role in raising awareness among the hair-pullers about trichotillomania and creating an environment for social support both within the organization itself and in contact with other online and offline support groups. The organization helps the hair-pullers in accepting their “disorder” through meeting and spending time with other hair-pullers at conferences and events organized by TLC and other sister organizations. Through TLC, hair-pullers can find out and reach the existing support groups near their neighborhood, personal blogs or video channels of the volunteers. The organization publishes a quarterly newsletter *InTouch*, which includes news from TLC’s scientific advisory board, volunteers and the whole trichster[7] community, and can be found online on the organization’s website. TLC hosts a special blog site on its website, in which trichsters share their personal experiences and suffering as well as achievements and motivational pieces. Moreover, TLC shares and advertises latest books, films, videos and any other kind of work created by trichsters about trichotillomania, while most of the creators of these works donate part of their copyrights or profits to the organization.

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[6] Even though trichotillomania as a psychological disorder is not lethal, some post-pulling behaviors may still cause death if not treated on time such as trichobezoars. Hairballs can develop in the stomach due to the swallowing the pulled hair and be fatal if not removed through operation on time (Penzel, 2003).

[7] “Trichster” is the nickname, which hair-pullers especially in the United States created and used to call themselves in slang.

During my fieldwork in the U.S., I noticed that while meeting with other trichsters and being a part of this community allow the trichsters to relieve themselves and to avoid feeling guilty, they also learn how to cope with the stigma of being a hair-puller and a hairless person, and increase their knowledge on hiding tactics for their bald spots. Apart from the received funding and collected donations for scientific research done in collaboration with the clinical expertise and the pharmaceutical industry, which aim to find the genetic or neurobiological roots of the repetitive hair-pulling behavior and to discover possible treatments, there are also businesses specializing on camouflaging the effects of trichotillomania and helping the trichsters in improving their social lives by meeting their beauty deficit. There are a number of hair care providers in the United States and Canada, focusing only on hair solutions for trichsters and some of these hair salons are among the sponsors of annual conferences and events of TLC, which allows them to reach many clients via these venues.

The children or adolescents pulling out their scalp hair are subject to bullying in the school or in their social environment. Using ordinary wigs is not a good solution for them since they look artificial and can also be a reason for being bullied by their friends. Furthermore, they are not suitable for actively moving and spirited children due to the risk of falling anytime. The wigs and other hair solutions provided by these hair care providers look more natural and are made more durable. Even though many children want to benefit from these services, the costs for such hair care are very high and not every family can afford it. While fake eyelashes and eyebrows drawn with permanent makeup are also other technologies for trichsters, there are also treatments for hair regrowth. What makes these places attractive for hair-pullers is being “trichster-friendly” by securing privacy and confidentiality.

Apart from the hair industry, there are trichotillomania pull-free kits, fiddlers, toys and balls to keep the hands busy and away from the targeted hair and to relieve the stress. Trichsters can buy these kits and toys online through the TLC website. Some of the ex-hair-pullers create their own pull-free kits and spread it on social media and video channels. Books written by the recovered patients are read by the trichsters. The stories of the ex-trichsters, what kind of challenges they faced and how they succeeded, create empathy and hope. Moreover, thanks to the latest developments in technology, there are plenty of mobile applications for recovering from trichotillomania. While self-CBT (cognitive behavioral therapy) applications target the trichsters, who are determined to change their habit, there are even hair-pulling games in which a cartoon girl appears on the screen and the game player pulls out her unwanted hair. Some of these applications are free and some of them are priced in the range of 3-11$. I find the experiences of the trichsters using these applications very important since they play an important role in turning psychological disorders into a self-tracked condition, decreasing the need for psychiatric experts and transforming the lay expertise. The field of self-CBT or self-help applications and online games require attention for further research, which are beyond the scope of this thesis.

It is not surprising at all that each and every illness or disorder leads to the formation of different industries or platforms as byproducts, ranging from the aims of treatment to social support. However, in the case of trichotillomania, the hair-care providers do not directly focus on treating trichotillomania, but on decreasing the stigma of being bald, which depends on the social categorizations of beauty. The Hair Club, as one of the loyal sponsors of the TLC's annual conferences, provides professional hair loss treatments for women and men, and offers free hair restoration services in a non-profit program to children between the ages of 6 and 17 (Hair Club for Kids, n.d.a). Below you see the photos of two children shared on the website of Hair Club for Kids. The first figure is the photo of Mikayla Hawkings, a 7-year-old girl who lost her hair at the age of 4 because of Alopecia Areata (Figure 2.1) and the second figure is the photo of Max Sherwood, a 10-year-old boy who lost his hair due to trichotillomania starting 3 years ago (Figure 2.2). Both figures show the before-and-after appearances of the children with and without their fake hair. Interestingly, both children are portrayed on their first photos as bald and unhappy, while in their other photos they have their wigs and smile. Moreover, there is an apparent make-up on their faces and Photoshop seems to be used to make the new appearance more "beautiful" and "happier", as the wound on the forehead of Mikayla does not exist in her second photo. Even the colors and types of the clothing they wear are different, the colors of pink and blue contribute to the positive impression created on their new photos. While in the advertisements they publish in newspapers or any other online/offline platforms, hair-care providers like every company may apply such tricks for women and men as well, I find it important to underline that even non-profit hair-providers like Hair Club for Kids reduce the repetitive behavior of hair-pulling and the depression or anxiety behind it to being bald and promise the “happiness” or solution for the trichsters through changing the appearance from outside.

Figure 2.1. The before-and-after photo of Mikayla Hawkings, 7 years old. Adapted from Hair Club for Kids, n.d.c, Retrieved April 15, 2015, from http://www.hairclub.com/hairclub-for-kids

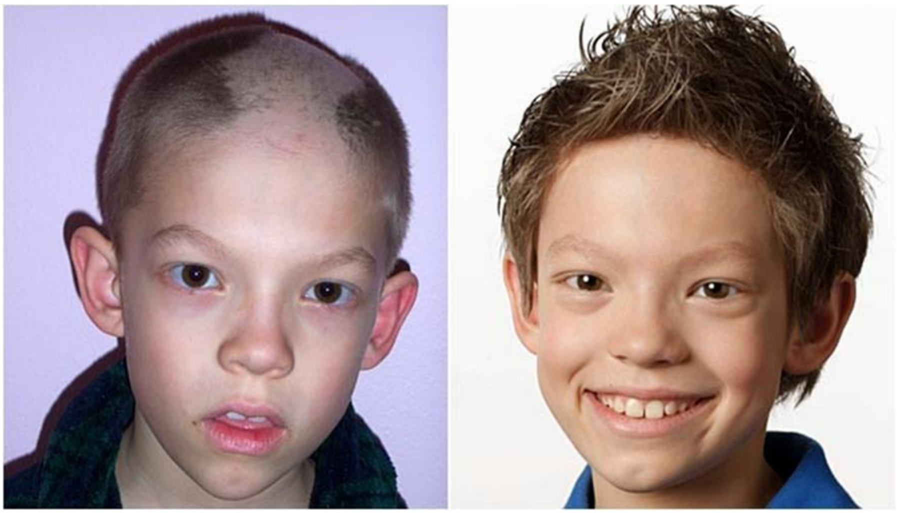

Figure 2.2. The before-and-after photo of Max Sherwood, 10 years old. Adapted from Hair Club for Kids, n.d.b, Retrieved April 15, 2015, from http://www.hairclub.com/hairclub-for-kids

As a person, who draws her eyebrows every single day with an eyebrow pencil for more than ten years, I am aware of the fact that it is hard for an individual to live with baldness, especially for teenagers and women. During the breaks at the TLC conference, the most crowded stands belonged to the ones of the hair care providers. However, this also shows that TLC and its sister non-profit organizations like Hair Club for Kids still take part in the old way of patient activism, which focuses on coping and hiding strategies of the hair-pullers rather than challenging the social categorizations of baldness as a factor of decreasing and/or increasing beauty on different parts of the body. During the annual conference of TLC, some of the hair-pullers, who are old in the community, were wearing "Trichster" written orange T-shirts with the drawing of a piece of hair on the front. But even though patients were using the picture of a pulled hair on their body as a symbol of their identity publicly, not many of them could take off their wig or wipe off their fake eyebrows during the conference.

Apart from their concern for their physical appearance, many trichsters suffer from self-stigma, which can sometimes exceed the stigma of their social environment. As I observed in my interviews with the hair-pullers and during my virtual ethnography, promising oneself to stop the pulling behavior and surrendering to the urge over and over again creates a feeling of self-hate. The trichsters, who care about their appearance, blame themselves for spoiling their beauty, which raises their anxiety and thus their pulling behavior in a vicious circle. Especially on online groups, hair-pullers express their self-hate and exhaustion for not being able to abandon their behavior over and over again. One day, in the Turkish Facebook group, a woman at the age of 22 wrote about how much she hates herself for breaking her promise for not pulling her hair again: "I don't know why God gives me this behavior. Why are you punishing me God? What did I do wrong to you? I wish that I either stop this shameful habit or God takes my life". The same woman, who pulls out her scalp hair, was wearing headscarf to cover her baldness in public. Interestingly, she was posting on Facebook her photos from a time when she did not have the disorder and had hair, pictures of graduation from her high school times, and writing how much she missed those days, in which she was freely wandering in public without covering her hair.

In addition to the previous research (Christenson et al., 1991; as cited in Mansueto & Rogers, 2012, p. 6) underlining the social aspects of the behavior, my fieldwork demonstrated that women more than men, young people more than the older adults, partnered individuals more than the singles problematize their pulling and feel the pressure of their weaknesses to stick to their promise of reaching pull-free state. As I managed to live pull-free for two years and my hair-pulling behavior was recurrent again, even though a person can stop hair-pulling for ten days, there is no guarantee of him/her not feeling the urge of pulling again on the eleventh day. I was surprised by seeing that a woman volunteering in TLC, who won the beauty competition in her state and has been pull-free for seven years, can still feel the urge of pulling out her hair, sometimes sharing it online with others. While meeting with others in the same condition through TLC helps trichsters accept that they are not the only ones who cannot control their urges even though they want to, the sense of failure is still recurrent each and every day.

At this point, online support groups play a substantial role in securing immediate help for trichsters in both Turkey and the United States. I observed in my virtual ethnography that as the end of the day involves disappointments for not reaching the daily goals, depressive moods due to the negative incidents happened throughout the day and the feeling of hopelessness for the next day, the urge of hair-pulling and anxiety level of the trichsters increase at night. Confidential support groups on social media are crowded mostly at night hours and trichsters can write about their negative feelings and personal problems, and can be cheered up with others' motivational and supportive comments. These social media groups can be even life-saving as some of the trichsters may have suicidal thoughts. In one example, a female hair-puller was threatened by her fiancé of splitting up if she did not stop her hair-pulling behavior and she wrote that this increased her stress and caused her to pull out her scalp hair on that day, creating bald spots, which was noticed by her fiancé the next day and she said she was hating herself so much and wanting to commit suicide. Especially, women with partners have the anxiety of being rejected by them. For instance, a Turkish female trichster at the age of 25, who was a member of the online trichotillomania support group on Facebook, stated that she has been hiding her trichotillomania from her husband for almost three years by hiding the bald spots on scalp with a bandana and is afraid of talking to her husband about it. However, the motivation of single men to stop trichotillomania is much more than men with partners. Nevertheless, in both cases, online support groups serve as valuable mood boosters and patient organizations like TLC indirectly contribute to the continuity of these groups by increasing the trichster network and bringing them offline as well.

Apart from securing an environment for emotional support, one of the important aspects of TLC is that it serves as a platform where patients share and receive information about trichotillomania. Trichsters not only benefit from each other's experience with medical experts and treatments they try on themselves, but also they can learn about the latest research on trichotillomania, raise questions to distinguished experts on trichotillomania from all over the world and consult them about the drugs they are using or any other issue. As it is not easy for trichsters to find an experienced and knowledgeable medical expert, through annual conferences and other events TLC organize, trichsters find the chance of networking with the clinical experts, psychiatrists, psychologists and other researchers and arrange appointments with them. Moreover, TLC announces the recent research on Body Focused Repetitive Behaviors (BFRBs) and call for volunteers to take part in these studies. From online surveys to pharmacological clinical trials, there are many studies that patients can take part in. This lessens the difficulties of the clinical experts in finding volunteer participants for their research. Therefore, TLC events and its networking facilities are also useful for the medical professionals, who claim to be treating trichotillomania and try to reach patients. So from this perspective, TLC events are valuable networking occasions for both patients and experts.

TLC aims to raise awareness among not only trichsters, but also medical experts. Since not so many psychiatrists and psychologists are knowledgeable about trichotillomania, skin-picking and other so-called BFRBs, TLC organizes workshops to educate clinicians and health care professionals on these behaviors. One of these intensive training programs is the Professional Training Institute, organized by the TLC's Scientific Advisory Board, which lasts three days. Attendants receive credits for the training and after the training they can still continue to consult to these experts over the problems they face during the psychotherapies and pharmacotherapies. In doing so, TLC fosters consciousness among the clinicians or other health care professionals, who have limited knowledge on BFRBs.

Drawing the attention of the medical experts to BFRBs brings certain advantages with itself. More clinicians studying BFRBs mean more research and information on these behaviors and this would divert the attention of the funding agencies to allocate funds for research on BFRBs. For instance, the increase in the number of the clinicians with sufficient knowledge on trichotillomania as well as in the number of the diagnosed patients would make trichotillomania a disorder having a high profitable and fundable research. Besides, the developing collaborations and network among the medical experts would distinguish trichotillomania as a separate disorder requiring adequate concern, which would increase the research facilities of TLC Scientific Advisory Board. The efforts of the TLC Scientific Advisory Board in raising consciousness over the diagnostic criteria of trichotillomania in DSM IV were successful and led to changes in DSM V. For these reasons, disease popularization among the patients along with the experts is one of the principal missions of TLC.

Apart from raising awareness among trichsters and clinicians, TLC also aims at increasing knowledge on BFRBs within the society. One of the ways for making this happen has been organizing awareness walks in October 2014 all over the world. These walks were not directly organized by TLC as an institution, but mainly by the TLC ambassadors, who are leading members and volunteers of the organization and want to raise the voice of the trichsters in their communities. Therefore, these locally organized walks were dependent on the efforts of the volunteers. TLC was rather helping them by announcing the awareness walks, supplying them with the brochures of TLC and other advertising materials, and supporting them if they face any problems. During these walks or other awareness events, T-shirts symbolizing trichotillomania have been used. Moreover, TLC creates short videos on trichotillomania and skin-picking, as well as spreading the amateurish or professional films or documentaries produced by the trichsters. Interviews with trichsters like Rebecca Brown, who took her photo every day and published her video of 6.5 years with trichotillomania online (Kirkova, 2014), and news about the celebrities with BFRBs like the Hollywood star Olivia Munn (Levy, 2012) turn to be useful materials to direct the society's attention to these disorders.

Creating awareness about trichotillomania or other BFRBs within the society makes the lives of the patients easier as they get rid of the anxiety of hiding their conditions. As a trichster myself, I can talk about how stressful it is still to hide from my parents and my best friend whenever I start pulling out my eyebrows again even though they know about my habit and I just feel anxious for making them sad. It is even more stressful for trichsters to hide their disorder from people, who neither know anything about trichotillomania nor about the fact that they suffer from it. The embarrassment of coming out as a trichster and the fear of being stigmatized by his/her social environment can become even harder than the self-stigma of the person himself/herself, just like in the case of LGBT people. Therefore, creating awareness among society and organizing "pride parades" help trichsters accept and even celebrate their identity without any fear.

While living openly with trichotillomania would relieve the hair-pullers to a considerable extent, I think that the self-opinion of hair-pullers on their own behavior can be conflicting in many aspects. For instance, in the online group of Turkish patients, I witnessed several times the discussion on how the lives of the hair-pullers would be if being bald was considered in society as a normal condition. As I was expecting to read positive comments over this utopic question, interestingly, many of the hair-pullers responded that the normalization of baldness would generate more harm for them rather than happiness since, according to them, this would result in the "normalization of their abnormality" and they "would not become aware of their disorder and therefore never get cured". Therefore, it is also important to underline that no matter how long a person pulls out his/her hair, the behavior can continue to be considered and stigmatized by the person himself/herself as abnormal.

2.5. Discussion

When compared to trichotillomania, HIV is a more stigmatizing condition, and since having HIV is mostly equalized with having homosexual relationships, a person with HIV is considered within the society as paying for what he/she did due to the stigmatized sexual orientation. Furthermore, as it has biological symptoms and affects a person's whole life from his/her relationships to the drugs he/she has to take to death, living with AIDS is something that is reminded to the person over and over again, along with the fear of getting sick and weakening of the immune system. Therefore, as a person, who cannot easily get rid of its stigma, an HIV patient has nothing to lose by becoming an activist in patient organizations like ACT UP.

Even though they also experience stigma by their social environment, the situation of trichotillomania patients is different. While some of the hair-pullers can become TLC ambassadors, call themselves as activists, post their bald photos on Instagram or other social media channels without being ashamed, the majority of the hair-pullers still consider their condition a temporary process even if they had been pulling out their hair for more than ten or fifteen years. For this reason, TLC and other patient organizations and support groups are the secret meeting places for them and these places serve as temporary shelters for many trichsters until they stop their pulling behavior and become pull-free. Even though there are activist hair-pullers, most of the trichsters try to conceal their disorder by hiding their bald spots in order to escape from the stigma of being a hair-puller rather than fighting against the stigma itself, which is the opposite of what HIV sufferers are doing. During the opening reception of TLC's annual conference, at the welcome desk, the applicants were required to state with a signed paper whether they want to be photographed during the conference or not. TLC was very sensitive about securing the anonymity of the attendants as long as they want it and they posted only the photos of the hair-pullers, who allowed them to do so.

My fieldwork demonstrates that being a member of TLC is more pragmatic rather than a passionate choice of patient activism as people use TLC not to be stigmatized. Therefore, hair-pullers at TLC have been following the old way of activism, which mainly focuses on the experiences of the patients rather than getting involved in evidence-based activism as the HIV patients have done. As the conflicting views of the patients towards their own disorder show, trichotillomania is still for many hair-pullers an abnormal and disgraceful condition, which should be stopped, and many of the patients want to hide it rather than fight for it. This characteristic can also be seen at the online support groups, where the members value their anonymity greatly. While some of the ex-hair-pullers, who have overcome trichotillomania, do not exit TLC and become leading volunteers within the community, many of the pull-free ex-hair-pullers prefer to exit the community as soon as possible. In the Turkish online support group for trichotillomania on Facebook, there had been a couple of examples of especially women, who after overcoming trichotillomania wrote a post of farewell, in which they thanked everyone and apologized for leaving the group since they do not want that their boyfriends, fiancés or husbands to find out one day that they were hair-pullers. Even though they have stopped their behavior and can freely share their experiences within the community with more courage, previous weaknesses and so-called abnormalities still serve as stress factors for them. I think that this way of feeling about one's past is not very different from the situation of ex-prisoners, who for a certain amount of time remained in the jail and got out of it one day, but continued to carry its stigma. In a similar manner, many ex-hair-pullers get out of the community or leave the online support groups in order to turn over a new leaf in their lives by breaking off from the community. Therefore, it can also be claimed that not everyone considers and internalizes living with the trichster identity similarly.

TLC serves as a data hub, which brings the medical experts and patients together. TLC bridges the gap between the medical expertise and lay expertise just like an NGO secures the connection and communication among society, the private sector and the state. However, we can hardly claim that each and every hair-puller can benefit from TLC since many of its services are costly for the patients. Annual memberships, conferences, events, self-help kits and many products and services cost a lot. Moreover, TLC's website is very crowded with the word "donation" or the commands like "donate now". TLC also encourages the patients and volunteers to organize fundraising events or to donate part of their profit from their copyrighted work on trichotillomania such as their books or films.

TLC's obsession with generating hope and also money for future research even in such controversial cases is an important example of the economy of hope

(Novas, 2006). Experts at the TLC’s Scientific Advisory Board mentioned during the conference many times the lack of funding for researching on trichotillomania and they claim that they themselves have funded many of their research. By sticking in the trichsters’ minds “more money=more research” equation, the scientific experts within the organization make the trichsters donate for the hope of getting cured with future research. As I mentioned in the previous chapter, during the TLC conference, Jon E. Grant as the Chair of the Scientific Advisory Board of TLC, announced the launch of the Body Focused Repetitive Behavior (BFRB) Precision Medicine Initiative (BPM) by TLC, which was later publicized in more detail on its website.

As BPM is advertised almost in every part of TLC’s website, it is stated that this project is expected to cost $4.5 million and only $500 thousand have been collected so far, much of which have been gathered through the payments of the patients for annual conference participation costs (Trichotillomania Learning Center, 2014b). TLC uses on their website smiling photos (Figure 2.3) of the children suffering from trichotillomania and the medical experts, who are members of their scientific advisory board, for the purpose of persuading the potential donators to the possibility that how important and useful the results of BPM research will be, which neither has reached the sufficient funding, nor will its results be apparent in a short amount of time. However, the uncertainty of the future of the research on trichotillomania and skin picking disorders does not discourage the patients from investing both their money and hopes in it.

Figure 2.3. Photos used for the announcement of Body Focused Repetitive Behavior (BFRB) Precision Medicine Initiative (BPM) on TLC's website. Adapted from Trichotillomania Learning Center, 2014a, Retrieved April 14, 2015, from http://www.trich.org/research/re-bpmnews.html

The low number of researchers on trichotillomania and other BFRBs as well as the nonexistence of any particular remedy for curing these disorders make the patients helpless and they appreciate the efforts of the TLC's Scientific Advisory Board for sacrificing their time and money for the research of their disorders. Patients at the TLC's conference were many times crying for the financial, professional and personal efforts of the medical experts researching BFRBs. In my fieldwork, I observed that TLC is very successful in convincing the hair-pullers that medical experts in TLC do their best all the time and are not responsible at least partially for the possible failure of their research so far. During the annual conference of TLC, Professor Jon E. Grant and other experts many times blamed the indifference of the pharmaceutical industry and funding agencies for not providing money for researching trichotillomania and other BFRBs on the basis of the inadequacy of their scientific findings. They successfully construct the image that there are "good scientists" and "bad scientists" in the eyes of the patients, for whom the members of the Scientific Advisory Board in TLC belong to the former, who know about BFRBs, care about the patients, advocate for them, just as they have been battling for the revision of the DSM IV and succeeded. They convince the patients that they are activist experts, who do their work for the social cause, not for profit. Therefore, no challenges from the patients to the medical experts at TLC have been raised. They are the only hope of the trichsters for rescue, and their failure stems from the mistakes of the bad scientists and pharmaceutical industry, which are not concerned about the BFRBs and people living with them. These experts are not seen by the patients as the part of the negligent medical system and the state, contrary to the situation of HIV patients, who believe to be subjected to the medical and social exclusion. Moreover, by being part of TLC, patients consider the member experts as companions of their illness, fighting together for the same cause.

Another reason for the lack of evidence-based activism at TLC is that patients of BFRBs are not as motivated as the AIDS patients since these disorders are not fatal like AIDS. For HIV patients, each and every day is valuable and the slowness of the clinical trials, as well as the failures of the previous research, is frustrating and annoying. Therefore, HIV patients have no choice other than becoming the experts of their illnesses and fighting with the medical expertise and the stigma within the society and the state. In the case of the patients of trichotillomania or other BFRBs, the treatment activism is conducted on behalf of them by the medical experts in the Scientific Advisory Board of TLC, thus we cannot see a conflict between lay expertise and medical expertise, and war-on-diseases take place within the psychiatric expertise.

The fact that trichotillomania is a mental disorder plays an important role in the reluctance of the patients in challenging the medical expertise. As I mention in the first chapter on medicalization in detail, the agency of a person with mental disorder is always questioned. In HIV groups, doctors, who caught HIV, might play an important role in spreading the lay knowledge and mobilizing others for taking part in evidence-based activism since with their illness, their medical expertise is not threatened even though their morality can be bombarded. In other words, having a biological illness, as the name implies, is biologically caused and the patient is still considered a rational person, whose knowledge and agency can be trusted. However, individuals suffering from a mental disorder are treated as unreliable and dangerous people, whose actions are unpredictable and irrational. Therefore, medical experts having trichotillomania cannot easily become a driving force within the trichster community, while medical experts with HIV can raise awareness among the HIV patients.

Since AIDS is a biological illness, overcoming the disorder or at least minimizing the symptoms depend on the treatments the person has been receiving along with, for many people, to his/her destiny. However, for trichotillomania and other BFRBs, the uncertainty of molecular treatments proves that each and every person responds to the treatments differently, which is directly dependent on the agency of the person and his/her determination to overcome his/her disorder. Therefore, "quitting" a mental disorder is still more of a personal success and from the perspectives of both the patients and the experts, an ex-hair-puller's expertise and knowledge on trichotillomania can be reliable, providing insights into how the problem is mentally solved. There are many other trichsters, who write about their illness, life stories and how they became pull-free, and publish self-help books.

I think that one of the most important and interesting details of the patients' view of their hair-pulling behavior in both contexts is how they name themselves. Surprisingly, in both Turkey and the United States, hair-pullers use a specific name for themselves. In Turkish, hair-pullers call themselves "trikdaş", whereas in English hair-pullers use the word "trichster". "Trik" in Turkish can be considered an equivalent of "trich" in English and the usage of the similar name in both contexts independently of each other is a remarkable indicator of how hair-pullers construct their disorder not only as a medical, but also as a social and political identity. Advocating for their identity and disorder, hair-pullers within the TLC or independent ones in both contexts see each other as companions to the same life and similar problems. Suffering from the same disorder makes them life-fellows and constructs the identity of trichster or trikdaş.

As I claimed before, different than the HIV patients, trichsters or trikdaşlar are subject to evidence-based trial-and-error rather than evidence-based activism. Weiner (2009) suggests that patient organizations do not necessarily change the lay-expert relations and the case of ACT UP is one of the rare examples of lay expertise and evidence-based activism. I argue that TLC as a patient organization serves as a proof for Weiner's argument. While trichotillomania patients in TLC do not get involved in challenging psychiatry and the medical experts, they also do not see themselves as reliable and reasonable agencies. Only ex-patients, who had recovered from trichotillomania, are considered as the experts of their disorder. As they do not try to change and challenge the medical categorization of trichotillomania, trichsters cannot be considered as evidence-based activists. On the contrary, thanks to TLC, they learn about many uncorroborated but promoted treatments for trichotillomania and apply them to themselves, such as taking the amino acid of the N-acetylcysteine. Interestingly, as I discussed in my first chapter in detail, hair-pullers in Turkey, where there isn't any patient organization for trichotillomania at all, have acquainted themselves with the latest research on N-acetylcysteine and have tested it on themselves through cough syrups without asking for a doctor's advice. It is apparent that the (non)existence of a patient organization does not necessarily change the destiny of the patient groups as the information and communications technologies (ICTs) can be much more effective in spreading latest information and research on trichotillomania and strengthening the lay expertise of the patient groups.

As Weiner's research (2009) on HEART UK shows, the patient organizations are subject to hybrid professionalization and serve as the hubs for bringing the patients and the medical experts together. As non-profit charity organizations, these institutions are involved in strategic partnerships between experts and patients in order to serve for the same purpose of making the disease known and drawing the attention of the pharmaceutical industry to the disorder. It is apparent that at TLC, the activism of trichotillomania and other BFRBs by both patients and experts play a substantial role in disease-popularization, which seems to benefit both parties.

Regardless of the contexts, online support is one of the most effective tools for trichotillomania patients. While in Turkey, the absence of TLC is filled with the information provided by patients who conduct tr(ial-and-error)eatments on themselves, trichsters in the United States are subject to tr(ial-and-error)eatments through the guidance of TLC's Scientific Advisory Board. TLC and its sister organizations like Hair Club for Kids are successful mostly in finding solutions for changing the physical appearance of the patients and bringing the patients together in annual events. From the perspective of medical professionals, TLC is also very useful for reaching patients and other experts in order to build research collaborations as well as to improve their knowledge on trichotillomania through workshops. However, the hybrid nature of TLC does not necessarily lead to a scientific cooperation of patients and experts in conducting research on trichotillomania and other BFRBs. Hair-pullers still construct their lay expertise by circulating their knowledge and experiences in both online and offline platforms and trying untested treatments on themselves. Regardless of the existence of medical expertise in both contexts, the ongoing ambiguities in the research on trichotillomania lead to evidence-based trial-and-error rather than evidence-based activism.

CONCLUSION

Throughout my M.A. thesis, I analyzed the medicalization and pharmaceuticalization and molecularization processes of trichotillomania, and the patients' activism and support in Turkey and the United States. My fieldwork demonstrated that in both contexts, patients are subject to tr(ial-and-error)eatments rather than treatments. Trichotillomania is medicalized differently based on its diagnostic criteria, which depend on social norms as well as subjective standards set by both the experts and the patients rather than relying on the universal and scientific categorizations. The behavior is also pharmaceuticalized by the psychiatric experts, who encourage the hair-pullers to try unproved pharmaceuticals such as NAC, whereas the hair-pullers in Turkey learn about these untested medications through the Internet and try them without consulting a doctor. Even though it remains as a relatively unknown psychological disorder, trichotillomania is molecularized and tried to be understood and analyzed by the medical experts at the molecular level, which focuses on the genetic background and the "normalcy" of the neurochemical balance in the brain of a particular person. Furthermore, different from other patient organizations like ACT UP, which get involved in evidence-based activism, Trichotillomania Learning Center (TLC) takes part in the old way of activism, which serves as a platform of social support among the patients rather than a patient group challenging the psychiatric expertise and conducting scientific research on their own. TLC also engages in the political economy of hope by generating optimism among the hair-pullers for the success of the future scientific research on trichotillomania along with the other BFRBs, and calls for donations to be spent for scientific research by the medical experts especially within the Scientific Advisory Board of TLC. Since the Internet serves as an important tool for increasing and spreading lay knowledge regarding the disorder, patients in Turkey and the United States benefit from online groups on Facebook for trichotillomania.

From the co-productionist perspective of STS, my thesis showed that trichotillomania as a psychological disorder is co-produced by the medical expertise of the researchers, TLC as a patient organization, patient identities around the world, who interact with each other through online and offline tools and also the Internet as the socio-technical medium, where the patient identities, scientific representations, and discourses are reproduced, interact and circulate. Moreover, in this co-production, psychiatric disorders, especially the contested ones, lead to many controversies in diagnostic criteria and treatments. The behavioral aspect of trichotillomania and its psychological stimuli behind makes the situation more complicated for the experts. As a psychological disorder analyzed at the crossroads of psychiatry, genetics and neurochemistry, research on trichotillomania requires more financial resources, for which creating public awareness on the disorder as well as attracting the medical experts and the pharmaceutical industry is a must. At this point, Trichotillomania Learning Center, the biggest patient organization around the world based in the United States, plays an important role in calling for donations and organizing events, in which both medical experts and patients especially from the United States and Europe come together. The Scientific Advisory Board of Trichotillomania Learning Center serves as the expert representatives of the hair-pullers within the medical field and their only hope for generating possible treatments in the future.

My thesis research had several limitations. When I problematized my own experience with my behavior of hair-pulling as well as the others', I started with focusing on the coping and hiding strategies of the hair-pullers and their understanding of their behavior compared to the experts' categorizations. As I decided to start a support group for hair-pullers in Turkey, I noticed that each person's relationship with his/her behavior is more diverse and it is not easy and feasible to bring the hair-pullers together and organize focus-group meetings on the basis of their homogeneity. For instance, while some of them are very keen to talk about their behavior, many of the hair-pullers do not want to meet in person and do not let their voice be recorded even if it is for academic research.

My fieldwork with the psychiatric experts in Turkey was as difficult as the one with the patients. While most of them did not respond to my e-mails or return my phone calls, some of them, who responded, were unwilling to meet at the end and had prejudices against the social science perspective of my research. Moreover, it was very hard to find psychiatric experts, whose specialization in psychiatry encompasses trichotillomania or at least is closer to the body-focused repetitive behaviors.

My research on the patients and experts in the United States was based on the annual conference of Trichotillomania Learning Center, which lasted only for two days. The conference was very eye-opening for me since I could obtain the latest information from researchers and medical experts ranging from psychiatrists to animal behaviorists, whose work specifically focus on trichotillomania, and talk to many hair-pullers attending from all around the world. During the conference, I noticed that trichotillomania is a more complex disorder, and embodies more actors than patients and experts alone. From pharmaceutical companies to the hair industry, trichotillomania can be analyzed in many dimensions and it was hard for me to pick one among those.

The virtual ethnography I conducted in online groups on Facebook had both advantages and disadvantages. While online interactions with the patients anonymously gave me significant clues about their relationship with their hair-pulling behavior more than the interviews could have, the richness, collectivity and spontaneity of the data I gathered online resulted in a more fragmented, partial, dispersed and at the same time superficial analyses for many aspects, sometimes even causing me to deviate from my research question. Moreover, while the online platforms are valuable tools for analyzing especially identities, which are subject to stigmatization, it also puts forward the ethical concerns of fieldwork and privacy issues. Should the researcher take the permission of conducting online fieldwork when he/she enters the group or should he/she secretly conduct virtual ethnography for the purpose of preventing bias in the interactions with the patients? What if the online identities are not real, should we always approach the online qualitative analysis with skepticism? While these questions do not have a single answer, I still regard the virtual ethnography as one of the most valuable qualitative methods for understanding the stigmatized identities.

Due to the reasons I stated above, neither can my thesis research be regarded fully comparative between Turkey and the United States, nor are my findings representative of the medical experts and patients in these two contexts. For an M.A. thesis, it is not feasible to analyze these complex processes comparatively in detail, and therefore, instead of focusing on just one specific research question, I preferred to open up trichotillomania for discussion through the concepts of medicalization, pharmaceuticalization, molecularization, inherent illness, the political economy of hope, lay expertise and the evidence-based activism in STS. The significance of my research originates in the fact that it is the first academic paper problematizing trichotillomania through the sociological lens.

In the future, a more comprehensive cross-cultural research should be done to understand the social, medical and economic dynamics behind trichotillomania and other so-called body-focused repetitive behaviors such as skin picking. Furthermore, more specific research questions can be analyzed in depth by working closely with the medical experts and patients for a longer period of time. For instance, the neuroimaging research of trichotillomania and other body-focused repetitive behaviors can be examined alone in the laboratory environment of the experts. Moreover, the neurochemical analysis of trichotillomania on the molecular level can create new research questions and broaden the discussions of social scientists over the contemporary psychiatry. In my chapters, I mentioned the rise of the precision medicine especially in the United States and how it is planned to be applied for treating psychological disorders like trichotillomania as well. I think that in the future, the ways in which the so-called tailor-made treatments promised by precision medicine, which integrates genetic and neurochemical analysis together for curing a particular illness or disorder, shape the molecularization process of psychological disorders can be analyzed in detail. Along with the invasion of psychiatry by the precision medicine, the role of patient organizations in generating the political economy of hope among the patients in order to collect funding for research and in constructing the lay expertise can be explored. As my thesis suggests, psychological disorders like trichotillomania are co-produced by patients, experts and the material world, all of which are affected by the economic, social, cultural and political context. I believe that future research can focus on the co-production of psychological disorders by analyzing interactions among these dimensions.

Apart from the STS perspective, trichotillomania can be analyzed in the future from many diverse aspects by other fields of the social sciences as well. As a both behavioral and psychological disorder, hair-pulling is somatic, mental, abnormal, subjective, social and even political, all of which and many others contribute to the construction of a trichster or trikdaş identity. I think that the future sociological or anthropological research on trichotillomania do not necessarily have to handle the identity of a hair-puller as a patient and can focus on the formation of the hair-puller identity with its “abnormalities” and both its inclusion and exclusion in everyday life in different social and cultural contexts. I believe that comparing and contrasting the hair-pullers with other medicalized identities such as LGBTs or disabled people, who are stigmatized within the society for owning different or “abnormal” bodies and generate a social movement, will open up new questions and discussions for the social understanding of the patient, health and illness in the contemporary world.

To conclude, my thesis research on trichotillomania has introduced the body-focused repetitive behaviors to the scholars of STS as a new field for research and added new question marks to the debates of the co-production of the diseases, molecularization of the psychological disorders and the lay expertise of the patients and/or patient organizations rather than trying to give full answers to them.

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