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# "They Told Me The Pills Were Safe"

Understanding the Experience of Iatrogenic Injury from Psychiatric Treatment

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#### **Abstract**

Iatrogenic injury resulting from psychiatric treatment represents a critical concern within the healthcare system and causes great harm to the afflicted individuals. This study delves into the multifaceted dimensions of iatrogenic harm attributed to psychiatric treatment, with a focus on the interplay between trust, accountability and recognition, and the social and relational experience of receiving treatment that ends up causing harm. The erosion of trust in psychiatric medicine on part of the individual, stemming from instances of iatrogenic injury where professional and systemic accountability was perceived as inadequate, challenges the foundation of the relationship between individual and treatment provider as well as the relationship between the individual and the psychiatric system. To mitigate this erosion, it is imperative to understand the factors that contribute to the individual's lack of trust, in order to promote open communication and informed decision-making in psychiatric treatment. In that sense, being afflicted with iatrogenic injury is an inherently social experience. Furthermore, central to this study is the emphasis on recognizing the individual narratives of those who have experienced iatrogenic injury, as each individual's unique circumstances and personal stories offer valuable insights into the human impact of medical maltreatment, and centering their experiences can contribute to a broader discourse on psychiatric care reform. This study underscores the need for a holistic re-evaluation of psychiatric treatment practices, where recognition of the individual's experiences and open discussions on the limitations of psychiatric treatment are at the forefront. Ultimately, this study aims to contribute to the ongoing dialogue surrounding iatrogenic harm and the need for different pathways that improve the safety and quality of psychiatric care by focusing on the individual's inherent right to control the process of undergoing psychiatric treatment and the right to not be harmed.

**Keywords:** iatrogenic injury, iatrogenesis, medical harm, medical sociology, critical psychiatry studies

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# Introduction

Psychiatry has been surrounded with a continuous critical debate regarding the consequences of modern psychiatric treatment, from the antipsychiatry movement in the mid-to-late 20<sup>th</sup> century, to the United Nations offering continuous criticism on the use of psychopharmacological treatment (Puras, 2017:13) and the World Health Organization criticizing its global human rights abuse (World Health Organization, 2021:3). Furthermore, psychiatric treatment has been linked to increased disability rates (Whitaker, 2010:5) and people have written autobiographies telling their stories about the injuries they sustained in treatment (e.g., Fisher, 2009; Åkerman, 2020), while the British Psychological Society (2007) have suggested that the current diagnostic system does more harm than good and should be rendered obsolete. In addition to this, discourse on social media as well as within psychiatric and psychological practice have slowly moved towards conceptualizing trauma as relevant to understand emotional suffering.

This is part of a longstanding, ongoing debate about what 'mental illness' really is, as well as on the negative ramifications of psychiatric treatment and of using psychiatric diagnoses to measure wellbeing. This debate has been furthered by a diverse group of researchers whose work is linked with the loosely defined umbrella of critical psychiatry studies. Prominent figures include Thomas Szaz, R.D. Laing, Erving Goffman, Joanna Moncrieff, David Healy, and Nikolas Rose. Furthermore, in medical sociology, researchers such as Ivan Illich and Deborah Lupton have described the social constructionist aspects of creating diseases, which includes viewing mental illness as part of larger societal processes of medicalization, as well as discussing how power structures shape medicine, arguing that medicine often is associated with values such as nobility, good intentions, and expectations of evidence-based treatment protocols resting on scientific rigor (Lupton, 2012:83-84,109). Furthermore, seeking medical treatment aligns with a cultural understanding of health as a moral imperative for the individual to strive for (Cederström & Spicer, 2015:30). However, medicine is not always benign (Illich, 1976:9), nor does treatment exist independently as divorced from social interaction or relations of power that may affect marginalized communities negatively (Lupton, 2012:105).

In this sense it is far from a given that psychiatric treatment is experienced as beneficial for every individual, or even for entire populations. On the contrary, it seems that common diagnostic and treatment protocols leave some individuals disabled and disenfranchised in ways they were not before they entered treatment (Whitaker, 2010:3), meaning that they now

suffer from the effects of iatrogenesis – an injury or illness caused by medical treatment (Illich, 1976:6-9). This is not something that is widely recognized and discussed among lay people, and the limitations of contemporary treatments and diagnostic tools are not usually communicated by treatment providers to their patients (Rose, 2019:193), leaving the afflicted individuals in a precarious position.

This precariousness can be observed in various online communities where recipients of psychiatric treatment congregate to find support for their experiences of trauma (iatrogenesis) caused by psychiatric institutions. Labelling themselves as survivors of psychiatry, the participants in these communities bare witness to the experience of serious injuries and trauma, and raise concerns about the psychiatric system and its treatment regimens that are often viewed as the primary solution for individual, emotional suffering in contemporary societies. They object to predominant understandings and ideals of modern psychiatry from the perspective of their concrete lifeworlds and biographies, often revealing how the injury they experienced pertains to social issues of trust, accountability, recognition and power, as well as clinical medical trauma. This thesis accounts for these communities and experiences as its object of study.

#### **Research Aim and Research Questions**

The aim of this study is thus to understand the experiences of iatrogenic injury that is attributed to various forms of psychiatric treatment by participants in online communities. It studies the experience of iatrogenic injury as a phenomenon that occurs within a social and cultural context where medicine as an institution is often afforded a gracious amount of trust based on its scientific and altruistic ideals, and in which specific ideas of what being treated fairly in a medical setting should entail are being promoted. In this sense, it examines the experience of the individual's interaction with the psychiatric system in relation to the development of iatrogenic injury, focusing on issues pertaining to trust, accountability and the need to have one's subjective experiences recognized, and raises the following research questions:

- 1. How do the informants describe the injury they have experienced?
- 2. How do the informants characterize their relationship with psychiatry?

# **Defining Introgenic Injury**

latrogenic injury is not merely a sociological construct, but also something which is researched and debated within the field of medicine. While this thesis primarily focuses on the sociological aspects of the *experience* of iatrogenic injury, there is a material, medical side to it that needs to be considered to fully acknowledge this experience. It concerns the effects of physiological and psychological injuries, and the constraints these pose on the every-day lives of the afflicted. To understand the phenomenon of iatrogenic injury, it is important to have an idea of what these injuries entail. As such, this section presents some clinical diagnoses that are of relevance for this study pertaining to injury from psychiatric treatment, to enable the reader to have a fuller understanding of the physiological and psychological afflictions that frame the experience of iatrogenic injury.

One such diagnosis is *Post-SSRI Sexual Dysfunction (PSSD)*. PSSD is commonly defined in medical literature as having persistent sexual side effects once pharmacological treatment has been discontinued (e.g., Bala, Nguyen & Hellstrom, 2018), and typically encompasses cognitive and emotional impairments. According to the diagnostic criteria, PSSD symptoms may include a loss of sexual desire, erectile dysfunction, inability to orgasm, genital pain, emotional numbing, depersonalization, sensory problems and cognitive impairment (PSSD Network, 2022).

Another common injury that is caused by psychopharmaceutical treatment is *akathisia*, which is defined as a neurologically caused psychomotor restlessness and agitation that can result in intolerable suicidal or aggressive thoughts (Liebert & Gavey, 2009:1882). Similarly, *tardive dyskinesia*, a medication-induced movement disorder that causes repetitive, involuntary body movements (Moncrieff, 2008:110), commonly occurs.

As well, iatrogenic injury can be caused by *Electro-Convulsive Therapy (ECT)*. ECT is characterized by the administration of electrical stimulation to the brain, carried out while the patient is under anesthesia, and common side effects include memory loss and learning difficulties (American Psychiatric Association, 2023).

Iatrogenic injury can also reside primarily in the psychological realm, as with the occurrence of being traumatized and developing *Post-Traumatic Stress Disorder (PTSD)*. The American Psychiatric Association (2023) describes PTSD as a

psychiatric disorder that may occur in people who have experienced or witnessed a traumatic event, series of events or set of circumstances. An individual may experience this as emotionally or physically harmful

or life-threatening and may affect mental, physical, social, and/or spiritual well-being. Examples include natural disasters, serious accidents, terrorist acts, war/combat, rape/sexual assault, historical trauma, intimate partner violence and bullying.

As can be deduced from this description, PTSD can occur from both non-pharmaceutical *and* pharmaceutical/biological interventions, as it encompasses emotional, social and physical harm. Thus, it can be attributed to such broad experiences as the negative effects of psychopharmaceutical treatment and/or ECT, the experience of force or isolation, as well as experiences within therapy. This means that an individual can, for instance, develop PTSD from the process of undergoing ECT treatment, or from being afflicted with PSSD, as well as from experiences which are perhaps more explicitly interpersonal at first glance.

Consequently, clinical iatrogenic injury encompasses a myriad of symptoms that can vary in their strength, from difficult to live with to debilitating and disabling. The experience of iatrogenic injury should thus be examined with consideration for the constraints that these symptoms pose, as it is a prominent part of the experience.

#### **Outline**

This thesis consists of five chapters. The first chapter contains an introduction of the topic, followed by a description of the research aim and research questions. The second chapter describes iatrogenesis from a sociological perspective, including both the theoretical underpinnings of the thesis and the current status of the field of research. The third chapter covers the methodological approach, where hermeneutical and phenomenological accounts of reality are considered, as well as the procedure of carrying out the research, including ethical considerations. The fourth chapter presents the results of the analysis. Finally, the fifth chapter is comprised of a concluding discussion where the results are discussed and suggestions for future research avenues are offered.

# Approaching Introgenesis from a Sociological Perspective

The infliction of harm through medical interventions, here referred to as *iatrogenic injury*, has emerged as a multifaceted concern that deserves both comprehensive understanding and meaningful engagement. Looking at the interplay between medicine and society, *medical sociology* helps illuminate the landscape of iatrogenic injury by showing how systemic factors, social norms and power dynamics converge to shape the occurrence and recognition of harm, as well as how it is responded to. In parallel, the lens of *critical psychiatry studies* guides the understanding of iatrogenic injury within the realm of mental health, illustrating how psychiatric interventions can result in consequences that exacerbate distress rather than alleviate it.

Fundamental to medical sociology and critical psychiatry studies alike is the acknowledgement of the social entanglement in constructing health and illness. Medicine doesn't exist outside of the social realm, and the processes which construct medical institutions are constantly produced and reproduced rather than fixed. As well, these processes are always intertwined with the experience of the individual within the institution. Hence, this thesis suggests a sociological framework that addresses the phenomenon of the experiences of iatrogenic injury in contemporary society as part of processes of institutionalization and meaning-making, something which raises questions about how these experiences relate to issues of institutional orientation, power, control, resistance, trust, accountability and recognition. Consequently, the thesis both draws on and adds to the way in which iatrogenesis has previously been theorized and approached within medical sociology and critical psychiatry studies.

In order to present the framework that will be applied in this thesis and discuss how it is related to previous research, the chapter will start by presenting the way institutions and meaning-making can be understood, drawing primarily on the social constructionist theories of Berger and Luckmann, and Foucault, as well as Illich's theory of medicalization and iatrogenesis. After this, an outline of important topics for medical sociology research on iatrogenic harm will follow, after which the same will be done for critical psychiatry studies. Finally, this study's contribution to the field will be considered.

#### **Approaching Society in Terms of Social Processes of Institutionalization**

When seeking to understand institutionalization processes one necessarily must look at the way institutions can be produced and what purpose they serve. To do so, it makes sense to depart from a perspective of social constructionism. Social Constructionism is characterized by its

critical perspective on taken-for-granted knowledge, its acknowledgement of phenomena as historically and culturally situated and of knowledge as being developed through social processes, thus positing that knowledge and social practices are entangled (Burr, 1995:2-4). A great contributor to this perspective is the phenomenologically oriented social constructionist theory of Berger and Luckmann (Burr, 2015:222), which helps explain how social order is produced and maintained via institutionalization.

As Berger and Luckmann (1966:47-48) theorize, institutions can be conceptualized as social structures that shape and maintain social order by providing individuals in a society with a shared set of values, beliefs and norms. As such, institutions are not fixed or immutable; institutionalization occurs when habitual activity on part of people in a social and cultural context becomes ingrained collectively, thus offering an anti-essentialist view of social constructionism wherein collective social practices shape how phenomena are produced and reproduced (Berger & Luckmann, 1966:70-77). This happens through three processes: externalization, objectivation and internalization, where externalization is the process wherein the idea of how something 'is' is first produced, whereas objectivation is when the discourse becomes ingrained in the social realm and eventually starts to exist beyond the individuals as an object of truth; it becomes an object of consciousness and is perceived as natural and factual. Then, the next generation internalizes this as part of their consciousness simply on behalf of being born into this society, and considers it a natural way of understanding the world (Berger & Luckmann, 1966:76-78). Consequently, phenomena are experienced as fixed and taken for granted despite being socially constructed.

This can be understood through what Berger and Luckmann (1966:174) refer to as *plausibility structures*:

Subjective reality is thus always dependent upon specific plausibility structures, that is, the specific social base and social processes required for its maintenance. One can maintain one's self-identification as a man of importance only in a milieu that confirms this identity; one can maintain one's Catholic faith only if one retains one's significant relationship with the Catholic community; and so forth. Disruption of significant conversation with the mediators of the respective plausibility structures threatens the subjective realities in question. (Berger & Luckmann, 1966:174)

In short, plausibility structures are intersubjectively upheld via practices and are important for meaning-making. The distribution of knowledge can be more complex, however, in the sense that when marginalized people congregate in groups in a long-term fashion, they can create counter-worlds that are based on their counter-identities, allowing for new plausibility structures to be formed wherein reality is understood through *counter-definitions*. This is exemplified by the 'leper colony', by looking at how people with leprosy and their children suffer *stigma* in relation to their disease and that, because of this diseased label, as individuals, their objective and subjective identities will be predefined by the institutional idea of what they are (Berger & Luckmann, 1966:185-186). Goffman further describes stigmatization as the "situation of the individual who is disqualified from full social acceptance" (Goffman, 1963:11), and defines stigma as an "attribute that is deeply discrediting" (Goffman, 1963:12) which reduces the stigmatized person to a tainted, discounted person instead of a whole, normal person (Goffman, 1963:11). Being stigmatized thus results in a lower status position compared to majority society, as was the case for the 'leper colony'. However, if the community of people with leprosy is large enough, then another socialization process can commence that in some ways counteracts this stigma, by adding a new plausibility structure according to this new group, wherein leprosy could be understood as divine election rather than disease:

At any early stage of such a process of change the crystallization of counter-reality and counter-identity may be hidden from the knowledge of the larger community, which still predefines and ongoingly identifies these individuals as lepers, and nothing else. It does not know that, 'really', they are the special sons of the gods. At this point an individual assigned to the leper category may discover 'hidden depths' within himself. (Berger & Luckmann, 1966:186)

The individual develops a privileged status within their own consciousness in relation to this new definition of reality, resulting in a separation of the larger community's internalized reality and their own self-identification:

He no longer is what he is supposed to be. He acts the leper – he is a son of god. If we are to push the example one step further, to the point when this cleavage becomes known to the non-leprous community, it is not difficult to see that the community's reality, too, will be affected by this change. Minimally, it will no longer be so easy to recognize the identity of those defined as lepers – one will no longer be sure whether an individual so defined identifies himself in the same way or not. Maximally, it will no longer be an easy matter to recognize anybody's identity – for if lepers can refuse to be what they are supposed to be, so can others; perhaps, so can oneself. (Berger & Luckmann, 1966:186-187)

As such, while reality is experienced as existing outside of the individual, i.e., it is "constituted by an order of objects that have been designated as objects before my appearance on the scene" (Berger & Luckmann, 1966:35), it is not mutable. The language helps uphold and produce the social order by offering a framework that makes sense of these objectifications and puts them in a context that makes them meaningful (Berger & Luckmann, 1966:36). As such, language,

as well as institutions, are part of the meaning-making that orient us. Reality is thus produced intersubjectively in the practices of every individual, with every-day life being characterized by the common-sense knowledge people share (Berger & Luckmann, 1966:37). The relationship between the social world as a product, and the individual as a producer, is thus always dialectical (Berger & Luckmann, 1966:78).

## Trust, Accountability and Recognition in Relation to the Institution of Medicine

As Berger and Luckmann theorize, institutions offer security and predictability insofar as they offer ways to make sense of reality. This idea can be linked to broader sociological discussions of trust, accountability and recognition in contemporary societies. For instance, it seems that processes of institutionalization would be crucial to manage what Giddens (1990:92-93) has referred to as ontological insecurity, namely the sense of continuity and stability individuals experience regarding their self-identity and the world around them. Ontological security as a concept reflects the need for stability in a complex world, and maintaining trust in institutions helps explain how individuals function in society. Giddens (1990:83-84) highlights the role of expert systems and abstract knowledge in the construction of trust in modern society: as society becomes more characterized by uncertainty, 'lay actors' often place their trust in experts, professionals, and institutions that claim specialized knowledge (Giddens, 1990:84-85), something which can be understood in relation to how the institutions of society, and the symbolic elements that make up our cultural and social universe, work together to create a sense of security and predictability for individuals (Berger & Luckmann, 1966:80). Trust is thus "filtered by the trustworthiness of established expertise" (Giddens, 1990:84), meaning that lay-actors trust expert systems, wherein the expert knowledge "creates (or reproduces) the universe of events, as a result of the continual reflexive implementation of that very knowledge" (Giddens, 1990:84).

While the trust primarily lies in the abstract system, however, the experts who represent the system are also expected to present with a demeanour that reassures the lay-person that the system is trustworthy (Giddens, 1990:85-86), as due to the complexities of modern society, individuals need to trust that experts are competent, seeing as the lay-person lacks the knowledge to themselves acquire all forms of knowledge necessary to get by in everyday life (Giddens, 1990:27-28). In relation to this, personal experiences can strongly influence trust towards specific abstract systems (Giddens, 1990:90):

The fact that access points are places of tension between lay scepticism and professional expertise makes them acknowledged sources of vulnerability for abstract systems. In some cases, a person who has unfortunate experiences at a given access point, where the technical skills in question are relatively low-level, may decide to opt out of the client-layperson relationship. (Giddens, 1990:91)

Consequently, lay-people can decide to take it upon themselves to handle the situation which requires expert knowledge, although this rests on the idea that they have the knowledge necessary to accomplish this (Giddens, 1990:91). Nonetheless, society depends on professionals and their expert knowledge for its functions, with healthcare being one such expert field (Giddens, 1990:27-29).

Other sociological scholars, like Piotr Sztompka (2003), have argued that for this trust in social institutions to be upheld, the presence of some kind of accountability on part of individuals and systems is needed. Accountability here indicates the enforcement of trustworthiness pertaining to the presence of agencies that sanction and monitor an institution, either in general or in the specific instances when trust has been breached. These agencies can be formal, such as standardization boards, ombudsmen or law enforcement, as well as informal groups. Accountability thus promotes trustworthiness because the threat of being held accountable adds an incentive towards acting in a trustworthy manner (Sztompka, 2003:87). Similarly, this also means that individuals are more likely to grant trust, because it functions as a kind of insurance towards potential losses, which means that creating institutions that promote trustworthiness is important in societies. However, it's not enough to simply rely on the presence of agencies of accountability as a deterrent, such agencies must also be able to act effectively, such as by having legal mandate to intervene (Sztompka, 2003:88). Importantly, accountability is not equally easily accessible for individuals, seeing as they may not have equal access to the institutions that deal in accountability, with the elites, the rich and the educated being more likely to make use of these, which can affect trust (Sztompka, 2003:128).

Consequently, lack of accountability from a systemic perspective can be understood as a lack of recognition towards an individual or a group. For those who are stigmatized within the plausibility structures of an institution, it is made apparent that not all individuals have access to either accountability or recognition for the injustices in terms of breaches of trust or lack of accountability that they may face within a societal institution. As Berger and Luckmann (1966:105,110) posit, recognition is understood in terms of the recognized legitimacy afforded to plausibility structures, and within them the status of individuals belonging to certain groups.

Institutions, as well as individuals, depend on recognition for orienting themselves and constructing meaning in situations, and Honneth and Farrell's (1997:20) research identified three modes of recognition pertaining to this. The first is characterized by unconditional concern, where the individual is recognized as having desires and needs that are uniquely valued by someone. The second mode concerns universal equal treatment, positing that the individual has the same moral accountability as others, while the third mode considers the individual to have abilities that are valued by a community (Honneth & Farrell, 1997:30). Recognition is thus typically understood in the realm of recognizing the moral worth someone has as a person (Sayer, 2005:956), and suggests that individuals strive for a life that is characterized by practices and ways of living that can offer recognition and self-respect (Sayer, 2005:948). These concerns for recognition are understood in relation to normativity and societal values of what is good and bad, how practices should be carried out, and ideas of how people should be treated by others (Sayer, 2005:949). Consequently, recognition also affects the development of identity and self, and it can be made apparent that some institutions and their plausibility structures thus frame certain populations as othered in terms of being stigmatized or less valuable (Berger & Luckmann, 1966:185-186). In relation to this, Fraser (2000:113) conceptualizes recognition as a question of social status, meaning that recognition entails making individual members of a group equal and full partners in social interactions. Misrecognition, in turn, would be equal to social subordination; of not being able to participate as an equal in social life. To understand the intricacies of the institutions of health and medicine, therefore, for this thesis it is important to consider how certain plausibility structures frame certain perspectives as more important and more true than others.

#### **Iatrogenesis, Medicalization and Power**

The primary institution needed to understand the occurrence of iatrogenic injury is the institution of *medicalization*. Medicalization is understood as the social processes whereby the lens of medicine becomes the lens through which people understand life events, something which gives precedence to the perspective of medicine over other perspectives. In a medicalized society, physiological and behavioral experiences become understood as medical problems, which are diagnosed and treated by medical professionals and medical interventions (Bradby, 2009:126; Conrad, 1992:211). One of the earlier conceptualizations of medicalization came from Ivan Illich who posited that the language of medicalization has changed the way people experience their bodies, by having these experiences framed by a language of "bureaucratic gobbledegook" (Illich, 1976:41), while suffering, healing, and mourning should

only occur within the 'patient role', demarcated as illness by professionals (Illich, 1976:41). The plausibility structures pertaining to medicine thus offer individuals a limited scope of experiencing their bodies in relation to the medicalization processes.

Medicalization and the occurrence of preventative medicine are usually understood as a manifestation of (bio)power, wherein the healthcare system and medicine work to enact practices that promote health (Foucault, 2010:139). As such, societal institutions and individuals collectively engage in practices which promote certain norms that are associated with health. Iatrogenic injury can thus be understood from the perspective of biomedical dominance and the subsequent medical innovations that characterize modern society. Consequently, one issue pertaining to medical harm is the inadmissibility of uncertainty in medicine. Biomedicine is promoted as a scientific, fact-based practice, and talking about iatrogenic injuries and/or ineffectiveness of treatments is interpreted as challenging the legitimacy of medicine. It is thus responded to with a reiteration of scientific facts, effectively excluding the views of people who try to challenge the paradigm, as the only people who have legitimate access to factual knowledge are those who have completed medical training (Bradby, 2009:184). This illustrates a strong institutional trust in medicine as science, as well as professional experts, and while this legitimacy to define illness can be challenged to a certain extent, especially with the media highlighting cases of malpractice and medical error, the institution itself is durable (Bradby, 2009:185), and one of its consequences is the occurrence of iatrogenesis (Bradby, 2009:1).

The theory of *iatrogenesis* was developed to describe illness/injury which occurs from medical interventions that are supposed to be curative, and which may affect either individuals or collectives (Bradby, 2009:1,6). First coined by Ivan Illich in the 1970's, iatrogenesis was conceptualized through the medical profession's jurisdiction to demarcate normal versus pathological (Illich, 1976:15,165), and subsequently the natural consequence of medicalization. The theory of iatrogenesis proposes that medical intervention itself is a cause for injury, in part because people have been divorced from their capabilities to shape their environment and to heal on their own (Illich, 1976:6-9).

Illich (1976) describes three levels of iatrogenesis; the clinical, the social and the cultural, where *clinical iatrogenesis* refers to injury inflicted at the hands of the doctor, i.e., damage caused by the supposedly curative treatment, such as side effects, the doctor's concern for avoiding malpractice suits and so on (Illich, 1976:27). *Social iatrogenesis*, on the other hand,

concerns the societal problem of overmedicalization, which promotes the practice of people becoming consumers of medical interventions, whether these interventions are environmental, industrial, curative or preventative (Illich, 1976:33). Finally, *cultural iatrogenesis* refers to how instead of being able to handle impairment, suffering and death, people become paralyzed because of the nature of medicalized health management, which outsources all impairments to medicine (Illich, 1976:127). Consequently, iatrogenesis isn't merely something that pertains to the de-facto medical treatment, as is often the case in medical literature, but also something which permeates entire cultures. As such, if the aim is to circumvent introgenic injury, whether pertaining to individuals or society, Illich (1976:10) proposes self-care as the solution. Selfcare, in this context, refers to the informal, personal way of dealing with illness and suffering outside the medicalized system, something which is made possible by politically and socially restricting the reach of medicine. Put another way: healthcare should be demedicalized (Illich, 1976:54). This does not mean that medicine should be abolished, rather the idea is to reach a point where "health is identical with the degree of lived freedom" (Illich, 1976:242) because "beyond a certain level of intensity, health care, however equitably distributed, will smother health-as-freedom" (Illich, 1976:242). Illich thus views iatrogenesis as a cultural phenomenon which should not be understood as the responsibility of the individual patient or doctor, but as a societal issue. From this perspective, medicalized medicine doesn't create functional trust in the institution to produce stability, it is a destructive force that obfuscates accountability and results in a dis-recognition of the needs of individuals and societies.

Similarly, Ashe (2021:255) argues that the entire medical profession is causing harm to patients because the profession has become corrupt due to the power structure medicine produces. Utilizing Illich's terminology, Ashe posits that medicalization has resulted in a growth in corruption and harm. She develops Illich's concept of the "iatrogenic spiral" in her autoethnographic project which shows how one iatrogenic catastrophe after the other could occur as her condition baffled the professionals (Ashe, 2021:258), in combination with disinterest from professionals and their ability to use mental illness as a justification for drawing on their epistemic power as experts and invalidating the patient, coupled with a lack of professional accountability (Ashe, 2021:260-261). For Ashe, the *dis-recognition* of the individual and the obfuscation of responsibility is built into the system of medicine, something which in turn causes harm to healthcare-seeking individuals, and she posits that iatrogenic harm, i.e., harm which is destructive and objective/systemic, but not intentional, leads to

iatrogenic violence, which is a form of violence that is actively destructive, subjective/agentic and intentional (Ashe, 2021:256,264):

The latter violences were different. Particular persons – doctors, the order-givers, and nurses and aids who compliantly fulfilled their civic responsibilities as the bureaucrats of torture – wilfully realised them, and they were directed toward and made immediate assault upon *me* and me alone. The worst of them unfolded behind closed, locked doors and were performed '*under doctor's orders*'. Thus these baroque transgressions were rendered unseeable, inescapable, and – most unbearably – *good*. This double aspect of corruption, as, on one hand, grave but apersonal harm escalated into volitional brutality and, on the other, that brutality dissembled itself as benevolence, is what made my violation in the internment centre so annihilative. (Ashe, 2021:266-267)

Ashe utilizes the term epistemic injustice to describe this process, pointing to the active exclusion and silencing of the patient experiences in favor of the medical perspective, something which is only possible in relation to the structural power afforded to medicine (Ashe, 2021:268). Here, medicine does not function as an institution that produces trust, but instead actively engages in practices that disempower individuals and break them down, with accountability simultaneously being obfuscated.

Comparably, Illich (1976:29-32) posits that the health industry has always worked to shift the blame for medical harm onto the victim, something which in pre-industrial times was conceptualized as an ethical problem, but which today is primarily understood as a technical problem that has been rationalized as a consequence of 'breakdown of equipment' or 'random human error'. Consequently, the responsibility of harm is obfuscated despite technically being attributed to the institution of medicine. From Illich's perspective it can be argued that, within the field of medicine, accountability becomes something the individual has to carry, rather than the institution and its representatives. The theories of medicalization, iatrogenesis, and Illich's view of institutions offers another way to look at the individual's agency in relation to institutions in contemporary society as compared to the overarching perspective of Berger and Luckmann. Where Berger and Luckmann view the social order as constantly produced and renegotiated in the interaction, this shift of responsibility that Illich describes frames the production process more as an instrument of power.

#### Governmentality and Responsibilization

This can be further examined in how the lack of accountability for the harm individuals are subjected to has been theorized in terms of the neoliberalization of society; while professionals have been given jurisdiction over the expert field of health, the process of *maintaining* health

has been trending towards individualization. The *individualization of health* refers to how individuals are expected to take responsibility for their health and engage in actions that promote health as a moral imperative (Cederström & Spicer, 2015:30). Rose (2000:337) further talks about the *responsibilization* of health, wherein personhood is understood through the idea of the individual as someone who can make choices and thereby shape their life, and who thus is responsible for their own life. Drawing on Foucault's theory of governmentality, Rose (2000:324-325) describes responsibilization as a form of governance that operates through the cultivation of individual self-discipline and responsibility, where the individual is conditioned to constantly improve themselves and constantly monitor their health.

There has thus been a shift from collective responsibility for health to a greater emphasis on individual responsibility, and individuals are increasingly seen as responsible for their own health outcomes, something which is reflected in policies and practices that encourage self-care, healthy lifestyles, and the monitoring of one's health (Rose, 2000:334). The process of accountability being transferred from the societal institution to the individual illustrates another side of the conceptualization of recognition, where recognition stops being about the ways individuals can be afforded agency as a worthy person in society. Instead of promoting equality and belonging, responsibilization can be understood as a strategy of cementing inequality, in the sense that it *dis*-recognizes individuals as having different positions and statuses that prevent them from having equal access to the lifestyle that is prescribed as proper conduct. Similarly, this strategy for governance also obfuscates political struggles of inequalities, including but not limited to poverty and marginalization, by dubbing its outcomes 'illness' (Rose, 2019:185-186).

The theory of governmentality thus becomes helpful for examining the institution of medicine. Foucault used the term *governmentality* to describe the various techniques, strategies, and practices that govern and regulate populations. Governmentality encompasses not only state institutions but also the broader systems and mechanisms through which power touches people's bodies and reaches into their being, inserting itself into their everyday lives, attitudes, actions and discourses (Foucault, 1980:39). The disciplinary mechanism of power encourages self-regulating practices by focusing on the things one *should* be doing (Foucault, 2007:68), rendering modern power disciplinary, as individuals internalize the gaze of authority and self-police their behaviors accordingly (Foucault, 1995:200-201). Institutions, from this perspective, reflect power structures, and can be understood through *biopower*, which is the application of strategies and technologies that serve to maintain and improve well-being and

productivity of entire populations; certain behaviors become normalized and deemed desirable, whereas others are characterized as deviant, and individuals learn to self-regulate in order to align themselves with these norms (Foucault, 2010:139-142). Here, behaviors and meaning-making pertaining to health are concerned with controlling the conduct of a population. From this perspective, the institution of medicine becomes an instrument of power.

Institutions can consequently be understood from a different perspective than that of providing stability and security, as has been theorized by Berger and Luckmann, Giddens and so on. From a Foucauldian perspective, the production of common-sense knowledge and the establishment of institutions are discerned by examining the relationship between power and knowledge, something which illuminates the construction of the institution of medicine not as a process of collective meaning-making that makes the experience of self and everyday life coherent, but as an exertion of power and subsequent governance that is exerted in the social interaction and in different relationships. Power isn't merely a repressive force, it actively produces discourse and norms, and it produces knowledge, and knowledge and power are thus intricately linked, with powerful institutions and authorities being able to define truths; knowledge is shaped by power (Foucault, 1980:93). Thus, the common-sense knowledge that operates within a culture is very closely linked to power, with power being embedded in everyday practices and norms (Foucault, 1995:26-27), something which connects the medicalization processes to the interests of the powers that be in a specific cultural context. The institution of medicine, from this perspective, does not only offer a way to make sense of reality; it also frames expectations of appropriate conduct.

As was the case with the 'leper colony' and its counter-defined, alternative plausibility structure, the ability to resist is similarly built into the concept of governmentality. Foucault (2007:268) refers to the resistance towards being governed as *counter-conduct*, positing that people can engage in various activities that challenge the dominant techniques of conduct (Foucault, 2007:259,265). Counter-conduct is not the process of violent, global revolution directed towards governments, but singular movements where the concern is to be 'conducted differently'; i.e., governed differently. Counter-conduct is thus always occurring in relation *to* something; to a power which comes with the original 'conduct' or form of government (Foucault, 2007:260,265). Foucault (2007:270) thus theorizes that counter-conduct struggles can take many different forms and have different standpoints, and it may be expressed through individual behaviors as well as in movements, but it is characterized specifically by the refusal to accept the current state of being governed, and the desire for a different conduct (Foucault,

2007:265). This is a different kind of resistance than that which comes from the creation of counter-defined plausibility structures because it assumes an inherent power conflict. Foucault's concept of counter-conduct goes beyond just reinterpretations of existing norms; it encompasses a wider range of practices, including resistance, subversion and non-conformity, within various institutions and systems of power. Thus, while both Berger and Luckmann's concept of counter-defined plausibility structures and Foucault's idea of counter-conduct explore forms of resistance and challenge to dominant social structures, they differ in their focus and scope. Berger and Luckmann's work centers on the construction of alternative meanings within existing structures, while Foucault's work delves deeper into the dynamics of power and knowledge in society and how they are contested.

Foucault as well as Berger and Luckmann are great contributors to social constructionist thinking (Burr, 2015:222), and their theories shine light on different aspects of the social processes of constructing institutions. Berger and Luckmann focus on the social processes of reality construction through everyday interactions and institutionalization (Burr, 1995:7), whereas Foucault emphasizes the role of power, knowledge, and discourse in the shaping of reality (Burr, 1995:43-44), but both theories emphasize the role of social processes in the construction of knowledge and meaning, and that what we know and how we interpret the world around us are shaped by social and cultural factors. Similarly, the significance of social institutions in the construction of reality and the importance of historical context in shaping social constructions are recognized, as is the centrality of language and discourse in the construction of reality. Different interpretations of trust, accountability and recognition allows for a complex understanding of phenomena as both producing stability and security for individuals as well as institutions, while simultaneously illuminating the critical perspective of this production in relation to power and governance. Consequently, a framework utilizing both perspectives offers a comprehensive insight that acknowledges institutions as multifaceted and mutable; institutions are socially constructed, and not divorced from either human interactions or societal norms, nor power, and the individual develops their common-sense-knowledge and meaning-making in relation to these structures, as well as partake in constructing them.

# Approaching the Problem of Introgenic Injury in Medical Sociology

The construction of health and illness as biomedical phenomena has been put forward by medical sociology as important for understanding medicalization and subsequent cases of iatrogenic injury, with social, historical, and political contexts influencing how disease is categorized (Lupton, 2012:86). Conrad (1992:223-226) describes the political process of

demarcating health versus illness by looking at how various conditions have been medicalized and de-medicalized, with this being a bidirectional process, where de-medicalization typically only occurs when medical definitions and control are challenged in some kind of organized movement, bringing up the gay liberation movement as a successful example of the demedicalization of homosexuality. As such, medicalization can cause harm because it allows for the decontextualization of social issues, such as that of social justice politics (Conrad, 1992:223-224). For instance, pertaining to the medicalization of childbirth, as well as the criticism of psychiatry as actively oppressing minority ethnic groups, the interests of medicine can be understood as harmful towards marginalized populations (Bradby, 2009:158). This can further be exemplified by how the medicalization of emotional suffering has been suggested to contribute to people with serious mental disorders being "trapped in cycles of power relations that perpetuate oppression" (Gosselin, 2019:8). As well, the practices of providing diagnosis based on stereotypes on what kind of person suffers from mental illness, of coercing and manipulating patients into drug treatment, and of working from a framework that idealizes individual choice and control without considering limitations contribute to this oppression. Consequently, medicalization can be understood as a contributor to injustices placed on marginalized people (Gosselin, 2019:8).

General judgements towards patients, categorizing them as 'good' or 'bad', as well as in relation to socioeconomic status and other structural factors, play into what kind of diagnosis and treatment the patient may receive (Lupton, 2012:128). Thus, health disparities regarding iatrogenic injury can be understood in relation to other systems of oppression. Nazroo, Bhui and Rhodes (2020:270) found that black people are at least twice as likely to be institutionalized or diagnosed with psychotic illness, while also having "more negative pathways through care, poorer access to effective interventions, and poorer outcomes" (Nazroo et al., 2020:270). Similarly, black people, as compared to white people, are more likely to be prescribed injectable antipsychotics, as well as placed under court-ordered outpatient treatment and involuntary hospitalization, something which can be attributed to less resources and lower quality services in socioeconomically deprived areas, and which may result in less engagement with the healthcare system due to injurious experiences (Nazroo et al., 2020:270-271). This is posited to be the result of "interacting and interdependent structural, interpersonal and institutional racisms" (Nazroo et al., 2020:271). Supporting this, Greenwood, Hardeman, Huang and Sojourner's (2020:21196-21197,21199-21120) research on labor and delivery mortality rates found that black newborns and black birthing mothers have higher mortality

rates than their white counterparts, attributed to institutional racism and accompanying bias, as well as racial and ethnic disparities.

These disparities clash with the idea of medicine as an objective science and a clinical practice wherein altruistic ideals prevail. The ability for medicine to be autonomous, self-regulating, and dominant developed in relation to the understanding that medical professionals use their expertise for the benefit of their patients, without concerns for personal gain (Bradby, 2009:153), but, as has been shown, outcomes are affected by socio-economic status (Bradby, 2009:153). This can occur because the medical professional has an epistemic advantage, placing the patient in a position where their experiences can be disregarded in favor of the perspective put forward by the doctor (Ashe, 2021:268; Bradby, 2009:154), which can result in iatrogenic injury (Ashe, 2021:268).

Consequently, power has always been an important concept for medical sociology, going back to the earliest thinkers who theorized the role of the doctor as arbiter or gatekeeper. In the 1950's, Parsons (1951:285) theorized that if people are sick, they need a legitimate excuse to not participate and perform their roles in the functional system that he theorized society to be. He conceptualized this position as *the sick role*, which is a concept used to explain how when an individual is incapacitated from participating in society due to illness, they can be exempt, *if* they are deemed legitimately sick, with doctors being the gatekeepers who confirm this status. Once recovered, the individual goes back to participate in society, but in the meantime, there will be no stigma for the lack of participation because the sick role is itself a legitimate position in this system. Parson's conceptualization of the sick role underlines the doctor's position of medical expertise and authority.

Meanwhile, the patient carries the responsibility of doing everything they can to recover, which is accomplished by following doctor's orders (Parsons, 1951:312). Medical literature traditionally rests heavily on the idea of compliance, which assumes that patients are supposed to comply and adhere to the treatments the doctor prescribes (Lupton, 2012:115). As such, there exists a power imbalance between patient and doctor, which favors doctors. However, access to medical knowledge via the internet and the rebranding of patient into consumer has been argued to somewhat shift this dynamic (Bradby, 2009:158, Lupton, 2012:114), as has the notion that the patient is the one with the power to first seek out treatment (Lupton, 2012:115). Individual, cultural, social, and institutional factors thus affect whether a patient will be treatment-compliant, as does the relationship between patient and doctor, and that between the

individuals and the healthcare system; language barriers, educational background and cultural ideas about health and treatments influence whether the patient will exercise resistance or compliance (Lupton, 2012:114-117). Consequently, patients can find strategies to resist medical dominance (Lupton, 2012:76), and express their experiences in terms that make cultural and psychological sense to their lives outside of medicine (Lupton, 2012:88). Nonetheless, medical sociology has extensively described how hospitals are experienced as repressive environments wherein agency and normalcy are often removed, going so far as to label the hospital a 'total institution' (Lupton, 2012:95), and doctor's themselves operate under a system where the institutionalized norms within medical practice are that the doctor takes control, something which the patient too expects and desires (Lupton, 2012:121). Importantly, there is also an inherent belief that medical providers are trustworthy actors (Lupton, 2012:107,158).

Fears of being subjected to iatrogenic injury has led to people seeking out *complementary and alternative medicine (CAM)*. CAM espouses a holistic view which contradicts and offers an alternative to the biomedical model of illness and encourages the individual to become empowered to take responsibility for their own health, as well as offering a strong focus on the inner self and personal meaning as compared to orthodox medicine (Lupton, 2012:127-129). Critics argue, however, that CAM also promotes medicalization because by bringing these aspects into treatment, it expands medicine's jurisdiction even further into the private life of the individual, which carries the risk for further iatrogenic injury. The industry also contends with fraudulent practitioners, who risk causing harm to the person seeking treatment (Lupton, 2012:130-131). In relation to this, Kennedy (2017:312) posits that it's important to gain a good understanding of iatrogenic effects, because facing risks to one's health, whether somatically, socially or psychologically, may result in an avoidance of healthcare treatment and subsequent worsening health outcomes.

#### Approaching the Problem of Introgenic Injury in Critical Psychiatry Studies

One of the first to draw attention to iatrogenic injury within the psychiatric system was Thomas Szasz (1977:122), who posited that mental illness, conceptualized as organic pathology, did not exist, and that treatment could be harmful, going so far as describing involuntary psychiatry as "an evil like slavery" that should be abolished (Szasz, 1977:126). For Szasz (1977:138), psychiatry was a means for social control rather than curing disease, and bore responsibility for the injuries it caused by labeling people through diagnosis (Szasz, 1977:135) and subjecting them to stigma (Szasz, 1977:90). Similarly, his contemporary, R.D. Laing, criticized the

biomedical model of mental illness for being reductive as diagnoses were made from observing behaviors and from the perspective of the clinician only, and posited that the experiences the ill individuals describe are as true as anything else, and that by not recognizing this experience harm is done to the patient (Laing, 1969:52-55,67-68). While Szasz focused primarily on the harm of having one's freedom and rights removed, Laing approached suffering from an existential viewpoint of having one's experiences and one's self discarded.

A third, not entirely dissimilar perspective came from Goffman. In his study on asylums, he illustrated the asylum as a total institution wherein the patient's identity is stripped, and their behavior reshaped, as the patient is subjected to a highly regulated and controlled environment (Goffman, 1961:203,206). Within the total institution, the patient is to be remade into the standardized individual that fits within the frames of the institution by what is referred to as the *mortification of self*, where the patient conforms and adapts to the norms and the roles that are available within the institution, resulting in the loss of agency and identity (Goffman, 1961:19-21).

Szasz, Laing and Goffman developed their theories in the 1960's and 1970's, alongside the Survivor's Movement that primarily operated in the coastal USA and Northern Europe. In the 1970's, this movement primarily focused on the harm caused by coercion and force in psychiatry, dubbing itself a liberation project, similar to other social justice movements (O'Hagan, 2003:2). Force and coercion have nonetheless remained within contemporary psychiatry, and survivors still speak out against its harmfulness and violating nature, as well as direct criticism towards the harm caused by the biomedical model's reductionist and negative explanations of 'madness', and the lack of agency afforded to survivors (O'Hagan, 2003:2,9).

Contemporary critical psychiatry studies thus continue to dissect how reducing mental distress to mere chemical imbalances in the brain neglects the broader social, psychological, and environmental factors at play, resulting in people seeking medical care instead of looking towards political solutions for their problems (Moncrieff, 2008:215; Rose, 2019:52). This has been argued to be the result of biomedical psychiatry. Biomedical psychiatry is characterized by the idea that psychiatric diagnoses are organic anomalies (Rose, 2019:169), which includes the serotonin theory of depression (e.g., Rose, 2019:151), of mental illness being hereditary (Rose, 2019:27) and so on. These diagnostic conceptualizations, however, have not been scientifically established, and psychiatric treatments have thus often been oppressive towards the users in the sense that there is dishonesty about its supposed curative nature, and that it

neglects to consider social and environmental aspects of suffering (Rose, 2019:187-191). Harm is thus understood in relation to how medicalization of suffering conceals social ills, specifically pertaining to the insincerity in prescribing therapy and medication for problems which are beyond the scope of medical treatment. This includes, but is not limited to, poverty, marginalization and global inequalities (Rose, 2019:185-186), and leaves people without adequate support to deal with challenges like discrimination, social exclusion, trauma and violence (Rose, 2019:148).

Similarly, Boisvert and Faust (2002:247-248) suggest that treatment is provided in a context where the language system makes clients think that therapists have access to special knowledge and know more about the client than the client themselves do. This primes clients to accept the framework posited by professionals who use pejorative labels which suggest that the client is flawed, something which risks contributing to injury, as well as present specific ideas about the causes of suffering and how to treat it which may contradict the clients' experience. The diagnostic process risks causing unnecessary pathologization, and clients may internalize diagnostic metaphors and interpret their behavior through this framework and start to consider themselves 'mental patients', which may lead to injury due to self-defeat, internalized stigma and so on (Boisvert & Faust, 2002:252). Similarly, Horley (2011:127,131) posits that labeling people can be iatrogenic. By diagnosing a person, it will affect their entire life, as it frames how they should think, feel, and act. Furthermore, even if the person in question rejects the label, "they might still have to live with the consequences of the labelling process through social reaction to publication of the particular name" (Horley, 2011:131).

The damage of the labeling process is illustrated in O'Connell's auto-ethnographic research study on being in treatment for anorexia. O'Connell (2023:264-265) posits that anorexia treatment is inherently iatrogenic, and that the lens through which anorexia is conceptualized in treatment can lead to the sufferer re-examining past experiences through a 'pathological lens' rather than as 'normal experiences'. This makes them understand normal experiences as symptoms of anorexia in retrospect, resulting in an unnecessary and thus potentially harmful medicalization of their experiences (O'Connell, 2023:270). Furthermore, treatment teaches patients to 'do' anorexia correctly, which leads to worsening health as acting in an 'anorexic manner' becomes an affirming experience for the individual. This in turn results in the individual becoming more and more removed from normal life, which makes the diagnosis and its assigned practices more appealing, and the increased partaking in these practices thus

validates more restriction and coercive measures in treatment, resulting in a cycle of ever-increasing injury (O'Connell, 2023:271-272,275).

Psychiatry further has the added element of practicing coercive medicine. The experience of utilizing mental health services and subsequently always being under the threat of compulsory detention results in a culture which is plagued by fear and domination, something which can be understood in relation to affective support of psychiatric power, in the sense that this disempowers the people in question as they defer to psychiatric practices (Crossley, 2004:172; Lewis, 2010:3). Stigma also increases for people who have been forced into civil commitment, and this stigma in turn also legitimizes coercive measures to a further extent (Dallaire, McCubbin, Morin & Cohen, 2000:692). Interestingly, iatrogenic injury has been presented as an unavoidable consequence of psychiatric treatment. In an article about systemic failures within the NHS, Beale (2022:18) posits that there exists a culture of exclusion toward people with mental illness due to stigma, discrimination and lack of resources, which in turn causes iatrogenic harm to patients: "Some of our processes seem almost designed to harm; the ways in which institutional factors have an impact on specific aspects of people's illnesses Kafkaesque" (Beale, 2022:18). Furthermore, in a psychiatric case study pertaining to suicide, iatrogenic injury was accepted as unavoidable in suicide-prevention (Burrin, Daniels, Cardinal, Hayhurst, Christmas, & Zimbron, 2021:6).

Contemporary critical psychiatry studies also focus on the harm of pharmaceutical treatment, arguing that the preference for psychopharmaceuticals is heavily influenced by pharmaceutical interests in psychiatric research, and that this can lead to downplaying the negative effects of medication while overemphasizing positive effects (Dillon, 2011:152; Healy, 2004:226-227; Timimi, 2011:94). Similarly, the pharmaceutical industry has had a major impact on the widespread use of psychopharmaceuticals and construction of disorders (Cosgrove & Krimsky, 2012:2-3; Healy, 2004:226), which not only carry the risk of substantial side effects but also risk individualizing social problems. This puts efficacy in question, because if the problem is not medical in the first place, then treatments will be ineffective, although they can still be harmful. Furthermore, psychopharmaceutical treatment has been linked to stigmatization, in the sense that people experience using psychotropic drugs as resulting in stigmatization and suffer from it (Bussing, Koro-Ljungberg, Noguchi, Mason, Mayerson & Garvan, 2012:98), and psychopharmaceutical overmedication has been shown to produce iatrogenic drug-dependence disorder (Khullar & Coughlan (2018:275).

Much attention has thus been directed to the harm done by psychopharmaceuticals, drawing heavily on the lack of proper research into the effects of medication and the above-mentioned dominance of the pharmaceutical companies:

It seems extraordinary in the twenty-first century that people should be forced to take drugs which profoundly alter their bodily functions, their emotional life, their behaviour and personality, and that the institutions that instigate and enforce this 'treatment' have no interest in the range of effects the drugs produce and how they make people feel. The misrepresentation of the mental and behavioural modifications produced by psychoactive substances as the targeted reversal of underlying diseases has produced a scientific blind spot that means the full pharmacological effects of psychiatric medications are not properly investigated or appreciated. This ignorance means that the psychiatric community has been historically slow to recognise the serious medical complication that its drugs can produce, as we saw with the emergence of tardive dyskinesia. (Moncrieff, 2013:151)

Rose (2019:128-129) refers to this as the psychopharmaceutical paradox, specifying that while we know that the drugs do *something*, we don't understand *why* they do what they do, but we do see that the research points to the long-term effects of psychopharmaceutical treatment as likely harmful. For instance, taking antipsychotics is associated with higher mortality, as well as tardive dyskinesia, brain shrinkage, obesity, metabolic syndrome, stroke and heart disease (Moncrieff, 2013:167-169), and it's been theorized that psychopharmaceutical interventions for psychosis lead to worse outcomes compared to those who received no intervention, and that recovery from psychosis can occur without psychopharmaceutical treatment (Moncrieff, 2013:126-129), while long-term use can lead to chronicity and dependency (Dillon, 2011:154; Moncrieff, 2013:217).

It has been posited that to avoid being harmed within psychiatry, patients need to be given the space and encouragement to assert epistemic authority (Gosselin, 2019:23), and medical staff need to be transparent about the limits of psychiatric science, and the subsequent decisions made for the patient's treatment, as this impacts how people within psychiatry and their kin construct mental illness (Dixon & Richter, 2018:338). Similarly, Rose (2019:171-172) proposes an alternative framework where 'mental disorders' can instead be understood as 'social adversity disorders', underlining the importance of body and environment as holistic rather than separate from one another. This means that social and cultural factors are an inherent part of mental health issues, making the current biomedical, 'brain disorder' paradigm moot because you cannot separate the patient from their environment and their experiences.

Anecdotally, in a special issue of the journal *Psychotherapy and Politics International* concerning the lived experience of therapists, under the headline '*Notes From The Frontline*',

psychotherapist Erin Stevens (2020:3) suggests that iatrogenic injuries travel down generations. She examines intergenerational iatrogenesis by drawing on her own experiences as the daughter of someone iatrogenically harmed. The dehumanizing treatment afforded to her mother by medical professionals also extended to her, as her mother's child, and the shame shaped her entire adult life, making Stevens question psychiatric labeling and diagnosis-focused treatment as oppressive and harmful both to the individual and intergenerationally (2020:4). As such, recognizing phenomena as interconnected, contextual, and emergent is important when one seeks to understand iatrogenic effects. It's not simply the case of a reductive model where a treatment causes adverse effects in a linear causality (Brito, Joseph & Sellman, 2021:273).

#### The Contributions of This Study

While medical sociology focuses on the overarching structures that shape the occurrence of iatrogenic injury within the medical system, relatively little attention is given to iatrogenic injury as caused by psychiatric treatment. In critical psychiatry studies, on the other hand, a discussion on the occurrence of harm is almost built into the paradigm, seeing as the premise is that the science of psychiatry is inherently flawed, resulting in malfunctioning treatments. This study primarily adds to this already established knowledge by further illuminating how injuries occur in a social context while giving insight into the meaning-making assigned to this process. By outlining the process of losing trust in the institution of psychiatry while utilizing the concepts of accountability and recognition in tandem, it can further the understanding of iatrogenic injury as a process that is ongoing and illuminate how individuals attempt to handle it.

# Method

To understand the experience of being afflicted with iatrogenic injury, this study will explore the dynamics of the individual's personal experiences and attempt to offer a nuanced and contextualized portrayal of the informants' lifeworlds, by looking towards qualitative perspectives that explore meaning-making and experience; especially phenomenological ones. More specifically, the Interpretative Phenomenological Analysis Model (IPA) has served as an inspiration for this exploration, although it has been adapted to fit the method and data material used for this study, which somewhat diverges from the material and methodology that is orthodoxically aligned with IPA. The chapter will thus begin with describing IPA and how it will be utilized, as well as its relation to meaning-making and lived experiences. Data collection and the iterative process of coding and thematic synthesis will then be described.

# **Interpretative Phenomenological Analysis**

To understand and describe the lived experiences of individuals from a first-person perspective, the methodology has been inspired by IPA, which is an experiential method that has its theoretical underpinnings in hermeneutics, phenomenology and idiography (Smith & Nizza, 2022:6). IPA offers an approach that acknowledges the inherently subjective nature of human experiences while recognizing the importance of context and cultural influences (Smith, Flowers & Larkin, 2009:3), something which allows for contextualizing and situating the experiences of the informants in relation to the institutions they operate within while recognizing the unique perspective of the individual. With its hermeneutic epistemology, IPA positions informants as sense-making beings, meaning that the way individuals explain their experiences also inform how they make sense of these experiences. The access to an experience is thus contingent on the information the informant shares, as well as the researcher's interpretation of the informants' account of the experience (Smith et al., 2009:3). Consequently, IPA involves a double-hermeneutic, where the researcher makes sense of the accounts of the participants, who themselves are making sense of the phenomenon (Smith et al., 2009:35). Both the researcher and the participants thus draw on "everyday human resources in order to make sense of the world" (Smith et al., 2009:36), but the researcher only has access to the second-hand account and understands this through their own perspective. This means that the meaning-making on part of the informant is 'first-order', while that of the researcher is 'second-order'. IPA further combines hermeneutics based on empathy and questioning; the researcher wants to see what it's like to be in the shoes of the participant, while also wanting to ask questions and analyze the account of the participant (Smith et al., 2009:36).

The hermeneutical foundation of IPA is suitable for the interpretative process, utilizing the hermeneutic circle which is characterized by its process of looking at the parts to understand the whole, and the whole to understand the parts (Smith et al., 2009:28). By utilizing an idiographic lens, IPA further illustrates the individual narratives that collectively provide the basis for shared meanings within a specific context (Smith et al., 2009:29). Furthermore, as a phenomenological method, IPA is designed to help acquire an understanding of people's lived experience, and how this lived experience is made sense of in the specific context that is their personal world and their social world (Smith & Nizza, 2022:3). IPA is thus concerned with understanding people's subjective experiences through analyzing their stories and thematizing them (Smith, Jarman & Osborn, 1999:220), and has been used to study medical phenomena such as receiving a diagnosis, living with mental illness, as well as experiences pertaining to emotions and issues with identity (Smith & Nizza, 2022:4), which makes it a good point of departure for this study. Participants are deemed 'experiential experts' pertaining to the specific phenomenon being studied, with the focus being on what they think and feel about the experience, as well as their actions pertaining to it (Smith & Nizza, 2022:6), something which is especially important when studying an experience that condradicts common-sense knowledge of a phenomenon.

#### **Data Collection**

In need of a qualitative data collection method to accurately capture the complexity of the embedded, lived experience, the choice was made to utilize qualitative surveys. Qualitative surveys allow for a wide-angle lens on phenomena and is good for studying lived experiences and actions (Braun, Clarke & Gray, 2017:8), which makes it fitting for a phenomenological study. Qualitative surveys can be used to gather data that represents opinions, attitudes, and beliefs, and are beneficial because they allow for an in-depth understanding of complex phenomena, by helping us understand experiences and how reality is reproduced (Braun et al., 2017:23-24).

In qualitative surveys, a series of open-ended questions are used, offering the participants the freedom to answer according to their own wants, allowing for the participant's perspective to come through, with participants being able to express their experiences and thoughts in their own words and at their own pace (Braun et al., 2017:15,23-24). Consequently, for the purpose of studying iatrogenic injury, which is a sensitive subject, using a qualitative survey had the benefit of allowing the sampled group to talk about their experiences in a comparatively non-invasive manner, as they were already participating in online communities where these

experiences are discussed, and it also had the benefit of making it easier to talk about sensitive experiences, as the face-to-face interaction was missing (Braun et al., 2017:19). Similarly, it had the advantage of allowing the informant to step away from the survey as needed (Braun et al., 2017:15), although the survey did not save their data in the meantime. Furthermore, the participants remained anonymous, and it facilitated contact with a marginalized group/population that would otherwise be difficult to reach (Braun et al., 2017:19).

## **Constructing the Survey**

Constructing qualitative surveys requires substantial preparation (Braun et al., 2017:6), and utilizing it posed a challenge in that there would be no engagement with the population in a face-to-face dynamic. Consequently, the questions needed to be very precise, because there was no opportunity to ask clarifying questions (Braun et al., 2017:26).

The survey also needed to be adjusted for the challenge of reaching out to a marginalized group as the researcher could be viewed as a representative of the medical system by the informants, something which can affect the way they respond to prompts (Radley, 1999:23). When constructing the survey and recruiting participants, a choice was made to use terminology which positioned the study as critical of the system (see Appendix), something which aligned with the theoretical framework. There are different ways to position oneself regarding research when it comes to marginalized groups, and Landry (20:16-17) argues that it's important to retain a critical perspective that pushes back against hegemonic psychiatric and biomedical discourse, and to center the experience of survivors as active, capable agents as well as promote the need for social change while doing so. Similarly, Costa, Voronka, Landry, Reid, McFarlane, Reville and Church (2012:90-91) argue that while some researchers tend to claim that they study the lived experience, they are quick to speak over actual survivors and frame research in terms of 'managing them', which is ethically questionable behavior. Having been inspired by these perspectives, online research was done prior to constructing the survey, to learn how to best center the experiences of the population. Different online communities were therefore surveyed for several months before participants were recruited, to help understand the topics that were continuously brought up by users, which in turn shaped the way the survey questions were constructed.

To further gauge the survey's potential, three pilot studies were conducted, to find out whether the questions were possible to answer in a satisfying matter, offering the opportunity to alter them accordingly in the process (Braun et al., 2017:32). The answers from the pilot studies were not used in the analysis.

#### **Sample Selection**

Informants were strategically recruited from online communities that outrightly took a critical stance towards psychiatry, specifically asking that the informants identified as having experienced iatrogenic injury and/or maltreatment themselves. This choice in recruitment was partly done for ethical reasons — the potential informants were already actively engaging with the topic and were discussing their adverse experiences in an open forum. As such, the risk of re-traumatization, in comparison with recruiting from a forum where the informants may not be actively engaging with their traumatic experiences, could realistically be reduced.

Furthermore, IPA is generally characterized by a homogenous sample, and thus purposeful sampling is often used to find the group who is most likely to find the research question significant (Smith & Osborn, 2003:56). The purpose of a homogenous sample is to find the best access to a phenomenon, although the definition of homogeneity may differ depending on the phenomenon being studied as well as the study itself. For instance, a homogenous population sample could be working-class women from a specific geographic location, but it could also be everyone who's experienced psychotherapy (Smith et al., 2009:49-50). In spirit of the latter definition, a strategic sampling selection was made because the aim was to reach out to people who had suffered introgenic injury, a topic which the online communities overwhelmingly engaged with.

In total, 51 informants responded to the survey, representing eight different countries and five continents. A little more than half of the informants were from the USA, while the others hailed from the United Kingdom, Australia, Canada, Germany, Brazil, Morocco, and South Africa. 30 informants identified as women, while 17 informants identified as men, and 4 informants identified as non-binary. Their ages ranged from 18 to 75 years old. While this was a homogenous sample in that the recruitment focused on iatrogenic injury, it was clearly heterogenous in terms of demography. As such, the accounts of the informants were embedded in many different institutional relationships that would be impossible to fully disentangle. When possible, research was conducted to understand the specific, situated context of the individual pertaining to the societal institutions and norms which were present in their accounts, but the written survey combined with the heterogenous sample made a rich

understanding of all institutional relationships impractical. An effort was nonetheless made to tease out the similarities and differences in the informants' accounts and to contextualize these.

Furthermore, when constructing the survey, a choice was made to only include basic demographic data; i.e., gender, age and location, which means that additional information that may have been important was excluded. Unless the informants discussed it in their answers, nuances regarding race/ethnicity, (dis)ability, sexual-and-gender identities and socio-economic status, and how these may have affected the informants' experiences, weren't available. The reason to exclude such data from the survey was not because it was deemed unimportant, but for strategic reasons; in a global context, navigating potential cultural barriers regarding different power structures require complex knowledge. More importantly, it also served to declutter the survey, making it clearer and more precise (Braun et al., 2017:25-27). However, based on the informants' responses, future studies should consider intersectionality to further the understanding of iatrogenic injury.

#### **Distributing the survey**

The survey was distributed in six different online communities on the social media platforms *Reddit* and *Facebook*. These communities focused on peer support and critical discourse toward aspects of psychiatric treatment, such as therapy, medication and living with specific injuries, or the existence of contemporary psychiatry, making them appropriate places to find people whose experiences resonated with the research questions (Smith, 2007:56). Two of the communities described themselves outrightly as 'anti-psychiatry', while a third community identified as having a critical perspective. A further fourth community was concerned with the damage done by therapy, while the fifth community focused on iatrogenic harm from psychopharmaceuticals. While these five communities were selected for, one community moderator distributed the survey in one sixth community, making it not actively selected for. Therefore, this community was surveyed, to find whether it aligned with the selection criteria (offering peer support while taking a critical stance against at least one form of psychiatric treatment), which it did.

In practice, the actual process of recruitment for each individual informant remains obscured; a consequence of using an online survey which is publicly accessible. However, the choice to publish in these open communities was made based on the aforementioned ethical considerations, because infiltrating a community that would be understood as and expected to be private by the participants would negate the process of informed consent (franzke,

Bechmann, Zimmer, Ess & the Association of Internet Researchers, 2020:7-8,69). For similar reasons, the choice was made to avoid small communities, as it would further promote anonymity. The smallest community thus had a little over 100 members, while the largest was in the 8000s.

On Reddit, approval was sought from moderators before posting the survey, whereas on Facebook it was not, because different platforms have different cultures (franzke et al., 2020:17). On Facebook, getting in touch with moderators involves contacting them on their personal accounts, whereas on Reddit it is done via community boards. On Reddit, furthermore, moderators remain anonymous, whereas on Facebook, their personal accounts and real identities are on display. Moderators on Reddit moreso thus functioned as a form of *gatekeeper* (Taylor, Bogdan & DeVault, 2016:49), in that getting their stamp of approval promoted additional trust from the community itself.

#### Interacting with Potential Informants

Another aspect worth considering is the interaction with potential informants. While some people, expectably, reached out privately to ask questions about the study, mostly about whether they were eligible to participate with their specific experiences, a surprising number of people reached out either on the discussion board or privately to share their thoughts on the study and their personal experiences in more general terms. This sometimes required finding ways to acknowledge and validate their experiences while also discouraging them from sharing personal details. As such, even though the data collection process didn't require personal interactions with the informants in the way that interviews do, interaction with some potential informants still occured. However, none of the responses could be identified as belonging to any specific person, so anonymity was still upheld.

#### **Coding and Analysis**

IPA doesn't prescribe a specific method for the analysis but promotes an analytical perspective that is characterized by the desire to understand how participants make sense of their experiences (Smith et al., 2009:79). The material was therefore first interacted with by reading through all the answers received, without making notes, while trying to keep an open mind and getting an idea of the material and trying to find patterns or narratives (Smith et al., 2009:82). Then, a tentative coding process began, consisting of writing down preliminary descriptors while also writing memos and notes. In IPA, this process is described as an almost free textual analysis where making comprehensive, detailed notes and comments on the data is in focus.

This included descriptive comments which focused on the content itself, linguistic comments that focused on the language used, and conceptual comments that engaged with the material at a more conceptual and interrogative level (Smith et al., 2009:83-84). In the conceptual annotating, pre-understanding and professional knowledge was drawn upon as part of the process, while simultaneously engaging with the new understanding the material provided (Smith et al., 2009:89). The next step was looking for emergent themes (Smith et al., 2009:91), where quite some time was spent arranging and rearranging these code words and phrases into different categories, starting from intuitive divisions based on the content of the codes, to developing mind maps where the chunks were categorized into themes, eventually establishing three overarching themes in accordance with the research aim and research questions.

#### **Ethical Considerations**

Researching a sensitive subject such as iatrogenic injury warrants reflection in terms of its ethical implications. The experience of dealing with health issues in general inevitably raises questions that concern morality and ethical questions about how one should live, and answering questions about one's health has the person having to consider these questions, what their current health status is and how they have coped with suffering (Radley, 1999:25-27). This experience could be traumatizing, which is why potential informants were discouraged from participating in the survey if they were not in a good place emotionally and/or socially at the time of recruiting (see Appendix). Because of the sensitive nature of the subject, being available for questions was important, and if a potential informant expressed uncertainty about partaking in the study, they were thanked for showing interest but ultimately advised against participating. While the risk of traumatization was thus taken seriously, it can further be argued that the benefits weigh in favor of conducting this kind of study; to shed light on the phenomenon and the injuries the informants have sustained. The need for recognition is a focal point in the experience of injury according to the material, and this suggests that although there may be a risk of retraumatization that should be taken seriously, the greater risk expressed by the informants is that the phenomenon remains unadressed.

Precautions were also taken to uphold anonymity, as has been touched upon previously. Most personal data was anonymized in its inception, as the survey only asked for age, gender and country of origin/location. However, some answers contained potentially identifying data, such as the mentions of specific locations, people or time periods. This information was removed in the event that a quote was utilized in the presented results. The data material itself was stored on an encrypted, password-protected external hard drive, meaning that no other person ever

had access to any potentially identifying information. In the results, the informants were given pseudonyms to more compellingly present the material, but these were randomly selected from the most common names of their age group, gender and location. The main concern pertaining to anonymity was the aforementioned contact with potential informants, but no individual informant could be identified from their responses.

The study adhered to the Swedish Research Council's Principles of Ethics (see Vetenskapsrådet, 2002), which includes informing participants about the purpose of the study and how the process of giving consent worked. Since this was an online-based research project, it's important to note that ethical standards are not cross-culturally universal, which poses a problem in internet-based research as the researcher must deal with ambiguity, uncertainty and disagreement should an ethical dilemma occur (franzke et al., 2020:6,7,15). Therefore, it was especially important to make the information letter as clear-cut as possible.

The data collection process also adhered to the General Data Protection Regulation (GDPR) law (Regulation (EU) 2016/679) on the protection of natural persons with regard to the processing of personal data and on the free movement of such data. Potential informants were informed about which data would be collected and how it would be utilized and stored. The data collection was done via REDCap, a platform which operates in accordance with the GDPR law, and during the analytical proceedings, the original data was stored on a secure, encrypted external hard-dive. At the completion and publication of the study, all original data was permanently deleted. The informants were provided with the above-described information by accessing the study (see Appendix).

# **Results**

As has been established, societal norms, discourses and personal experiences shape our ideas of how we are going to be treated. The informants in this study describe seeking treatment within a context where the psychiatric profession is understood as belonging to the institution of medicine, where being treated benignly and altruistically (Bradby, 2009:153; Lupton, 2012:109), and being offered curative or therapeutic medical interventions (Lupton, 2012:109) is expected. In relation to this, the understanding is that one should be able to *trust* treatment providers as professionals and representatives of medicine, and that if providers fail to uphold their end of this perceived 'contract', there exists some process of professional and systemic *accountability*. Furthermore, the expectations include that the right to be treated as an individual whose inherent worthiness and right to not be harmed will be *recognized*. Departing from these expectations, the experience of being afflicted with iatrogenic injury, as described by the informants, is inherently social, as it is situated within a contextual, normative structure that expresses what being treated fairly and curatively in a medical setting entail. The analysis will attempt to show that it is in the failure of these expectations to materialize that the social facet of iatrogenic injury is made visible.

Three main themes were identified in the analysis. The first theme covers the informants' experience of being transformed into a non-subject in the encounter with psychiatry. This theme illustrates how the system is often experienced as a place where one's lived experience, agency and dignity are disregarded. This process is inherently social, because it occurs in the interaction with professionals, and leaves a lasting imprint. The next theme concerns the experience of losing trust in the psychiatric system. This allows for a deeper understanding of how the process of acquiring injury occurs within the social interaction that is shaped by power imbalance and power structures within medicine. The third theme considers the lack of accountability and the need for recognition and covers what happens when the informants must come to terms with being injured and having their trust in the psychiatric system erode.

## I. Being Transformed into a Non-Subject

One core experience of iatrogenic injury that is being brought up by the informants is the experience of being undermined and transformed into a non-subject, in contrast to their expectations of being able to trust the treatment provider, of accountability being upheld, and of having their worth as humans recognized. Instead of this materializing, the informants describe their interactions within the psychiatric system as being characterized by having their status as subjects undermined in various ways. Mainly, they describe a power disadvantage wherein they are prejudged and stereotyped according to a diagnosis; to being 'mentally ill'. This could be understood in relation to the proposed idea that psychiatric diagnoses are established as part of larger processes of medicalizing misery (Rapley, Moncrieff & Dillon, 2011:2) that risks reducing psychiatric conditions to mere biomedical phenomena, which carries the risk of naturalizing their condition, and subsequently boost the experience of injury.

This theme will begin by describing how the transformation into a non-subject is experienced by examining how the informants feel *violated* and *infantilized* in the interaction with treatment providers, experiences that occur in relation to the overarching process of *being pathologized*, which is covered in the second half of the theme.

### **Being Violated**

The verb 'violate' has several definitions; one which concerns the act of being treated with irreverence, and another concerns the literal definition of being assaulted or raped. For the informants, being violated was often a bodily/carnal experience, making both definitions applicable as a surprising number of informants drew parallels to being raped when they wanted to explain experiences during hospitalization, which were characterized by a perceived power imbalance and the subsequent feeling of being assaulted in physical interactions with staff. Similarly, the analogy is used to describe being injured by psychopharmaceutical treatment, something which too affects the body. For the informants it presents as a way of attempting to have their experience of bodily violation recognized and acknowledged. In their narrative, the treatment provider is characterized as an aggressor, and their methods an invasive physical procedure which violates bodily integrity, hence them being treated as non-subjects. Thus, in the interaction, the informants perceive themselves as victims of assault rather than recipients of medical treatment. Kyle, Megan, Riley and Rebecca's stories will exemplify this.

Kyle, a 32-year-old man from Canada, was suffering from anxiety, body dysmorphia and low self-worth when he first asked for help. Kyle thinks that his suffering was situational and that

he should have been offered therapy, as he attributes his suffering to previous trauma. Instead, he was prescribed SSRIs<sup>1</sup>, and developed side effects which, four years later, persist. When trying to find treatment and recognition for the side effects, and in particular the sexual dysfunction he has developed, Kyle says that nobody believes him. Kyle states:

I genuinely feel similar to a rape victim, in that I was abused through an imbalanced power dynamic, and then told it was my fault, that I'm to blame. I will never get my sexuality back, there is no cure, I have noone to turn to. no laws, no place to go to report, no one who cares, no one who will help or listen.

In sexual assault discourse, there has been a strong focus on *believing the victim*, which illuminates how the experience of not being believed can be understood as a form of violation. Similarly, the analogy encapsulates the experience of *blaming the victim*, which in Kyle's case concerns the experience of the treatment providers insisting that he needed treatment because he was sick with depression. The rape analogy he uses thus seems to serve not only to illustrate the experience of violation, but also works to point to a greater contextualization wherein the right to bodily autonomy and need for reparations are invoked. Kyle says: "my life is horrible post psychiatry. they stripped everything I was. the pills destroyed my personality, my sexuality, any ability to feel joy and purpose." Kyle thus expresses how the violation of bodily autonomy itself is a traumatic experience, and in relation to the lack of recognition for what happened, the violation continues to occur post-trauma.

The rape analogy is also used by the informants to describe violating experiences which appear more akin to the actual act of sexual assault. This is often described in the context of inpatient treatment, wherein using bodily restraints are a relatively common and accepted practice. When Megan, a 47-year-old woman from the USA, describes being hospitalized she says: "It was rape by hospital staff with 2 male policemen watching. I was severely traumatized." Megan didn't voluntarily agree to hospitalization, hence the police presence, and the process of being detained, held down and forcefully subjected to treatment didn't and doesn't align with Megan's understanding of what 'hospital staff' and 'police' are supposed to do; the *male* police officers *watched* while she was *assaulted and detained* against her wishes. Like Kyle, Megan expresses that this traumatizing event was not recognized as such by the treatment providers, and because of that, she now fears them, as well as the police.

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<sup>&</sup>lt;sup>1</sup> Selective Serotonin Reuptake Inhibitors, a class of drugs commonly referred to as antidepressants.

While Megan was *involuntary* committed to the hospital, Riley, a 38-year-old non-binary person from the USA, describes how they decided to go to the hospital because they felt like they needed professional intervention:

went to seek treatment be a steroid shot caused mania. was not aggressive or a danger to myself or others. was tied down for 14 hours with a bed pan under my back the whole time causing serious issues as I have a serious back issue, and was tied w legs spread a part and no underwear on and lots of people walking past the bottom of my bed able to see my intimate parts. I was ignored and not believed or listened to at all.

In this statement, Riley first expresses that they did the responsible thing by seeking treatment for a self-identified, worsening medical condition, something which in relation to them not being aggressive had them expecting to be treated with dignity and care. Instead, Riley experienced humiliation and bodily violation. The kind of violation of bodily integrity that Riley experienced goes against the understanding of what having one's worth as a subject recognized entails. As well, it goes against the common-sense understanding of the 'good patient' who does things correctly and therefore is treated well. Therefore, it perplexes Riley that their experience of being forcefully tied down while naked is characterized as medical treatment, when they instead feel violated. As can be seen in Riley's statement, it isn't only the bodily violation that is experienced as injurious, however, it is also the effects of being treated as less than human, of being exposed, ignored and disbelieved.

Rebecca, a 42-year-old woman from the USA, also describes the injurious experience of being exposed and violated while receiving inpatient treatment:

My traumatic experiences were mostly in hospitals. You are treated rudely by staff. You have all you belongings and free will stripped. You are also literally stripped searched. One time I had to take all my clothes and stand there completely naked while turning around. I have flashbacks of it to this day. You go to then hospital for safety from yourself but are out in unsafe situations. One time I was put on a unit of only men. I was the only female.

The experience of having one's clothes removed is something which the informants highlight as particularly traumatizing. The contrast of trusting the hospital to be a safe place where healing occurs, but instead experiencing it as an unsafe environment where one is 'literally' strip searched like a prisoner makes it difficult for informants like Rebecca to understand why this is not universally recognized as a violation of their human rights.

Furthermore, Rebecca brings up something that several informants who identify as women or non-binary have described; feeling inherently unsafe in a mixed-gender environment, wherein the very hospital setting is experienced as threatening and in violation of their rights to a safe space. While the hospital has been shown to be experienced as a vulnerable and alienating place (Lupton, 2012:95), the psychiatric inpatient unit has the added component of being a locked ward that checking into is often much easier than checking out of. To understand the experience of being violated as expressed by the informants, it's thus important to understand the coercive measures that often align with inpatient treatment which relates to the removal of rights that are normally afforded adult subjects, such as holding on to one's belongings, being able to move around freely and being able to stay clothed and decline physical contact with strangers.

Being exposed and left unprotected in various ways is experienced as a very vulnerable position. Typically, sexual assault is recognized as a form of violence that affects one's identity and one's existence on a fundamental level, and the experiences the informants describe can be understood in a similar fashion, with their entire understanding of themselves and the psychiatric institution being rocked by the violating treatment. This can further be understood in relation to the feeling of having their own needs and comfort disregarded in favor of the needs and comfort of the treatment provider. In that sense, the experience of violation can be understood as a betrayal of trust, something which will be further discussed in the subsequent themes.

When being hospitalized for the first time the informants thus describe expecting to be kept safe and given treatment for their condition, but instead of having their suffering recognized, they describe being placed in unsafe situations. Rebecca, who willingly decided to go to inpatient treatment because she feared she would harm herself, says: "I expected to be kept safe and treated as a human. But I was treated like a criminal who had done something wrong."

### **Being Infantilized**

Another side of the experience of being transformed into a non-subject is being treated like a child. As an adult, the expectations of being treated with respect and dignity include being treated as competent, knowledgable and capable. However, paternalism has always existed in medicine to some extent, and interactions with healthcare professionals are typically characterized by a power imbalance. In psychiatry, this also speaks to a context where, historically, treatment was characterized by the idea of the psychiatric patient as too disturbed to care for themselves. The informants' experiences thus must be understood in relation to this ongoing stigma and their experience of being coerced to accept treatments for 'their own good', even when they themselves have different ideas of what they need. Michael, a 25-year-old man

from Canada, describes being infantilized and objectified as a defining part of his experience: "Being treated like a child constantly and consistently. Once you're slapped with a label be it even depression, you have almost zero rights left."

Jade, a 23-year-old woman from Australia, describes being infantilized while she was being "sectioned, placed under the mental health act", and being told she was psychotic and delusional when she reported that she was experiencing PSSD. She asked to be taken off the medication that was making her sick, and the treatment provider responded by upping the dosage instead. Jade had expected that she and the treatment provider would jointly work to improve her health, but instead she felt her own experience went unacknowledged and dismissed as a symptom of the diagnosed disorder that, in the eyes of the treatment provider, rendered her childlike. Jade explains: "I felt powerless, unheard, silenced and dehumanised. I am highly educated, intelligent person and I was treated as if I had an intellectual disability. Like I was a moron that doesn't know my own body." In Jade's experience, the interaction with the psychiatrist positioned her as incompetent and unknowledgeable of her own body, giving the psychiatrist an epistemic advantage that rendered her powerless.

Dakota, an 18-year-old non-binary person from the USA, describes entering psychiatric treatment as a child, and immediately registering it as similar to being 'disciplined'. This feeling persisted as Dakota grew older and felt like they wanted to influence the treatment process in a different direction than the treatment provider did:

Complaints about medication were met with "they're working [read: suppressing emotion], and you said you were okay with trying it [years ago, when you were 8, with no info about effects], so you're not allowed to change your mind now". I wasn't given a chance to influence anything else either - it was presented to me as "you have to change these things about you to be a good person", and if I objected the response was the same as it'd be for a kid that, say, didn't want to take a bath or go to school.

For Dakota, treatment was not experienced as healing or curative, but instead part of a social interaction wherein they were expected to obey a certain set of directives, like one would expect a child to in the culture Dakota was raised within. Failing to obey would result in punishment, something which made it difficult for them to decline treatments that were experienced as injurious.

The experience of being infantilized can also mimic previous adverse experiences that the individual sought mental health treatment for in the first place. Hayden, a 43-year-old non-

binary person from the USA, describes how being infantilized in therapy worsened their mental health, as it acted as a trigger concerning previous traumatic experiences:

Early in therapy, I got recommended a book on self-compassion. The book was using a lot of soft, pastel language, advising people to pet themselves like a cat and call themselves "poor darling". It also had the author talking about her self-compassion on the pain of having a disabled son. I am a disabled person with a bad history of being infantilized. This book backfired hard and put me in a very bad mental state.

As Hayden describes, their treatment was re-traumatizing rather than healing, because it amplified their pre-existing emotional pain. Hayden's story thus also touches on something important; the informants' need for recognition of their past experiences and their lifeworld. In Hayden's case, this is particularly significant as they are a marginalized person and carry the specific trauma that follows their particular marginalized identities. Hayden felt that the therapists interacted with them from the perspective of offering parental guidance and healing the injuries of being abused and neglected as a child, and for Hayden, this was interpreted as infantilization:

I grew up in a healthy family home, and was exposed to a pattern of systematic institutionally-imposed infantilization and control, combined with traumatic medical procedures, dating back to infancy. So a lot of the attempts to show warmth and caring that were possibly appealing to people who never had a nurturing parent felt like I was horribly trapped in special education again. I think a lot of psychologists and other therapists are not equipped to understand and adapt to this, and unfortunately are sometimes ideologically biased against believing this is even the real problem. My therapist persisted in looking for nonexistent family dysfunction while re-enacting the infantilization and paternalistic control that was actually damaging.

Hayden's statement illustrates how the lack of acknowledgement for people's unique experiences and narratives can be experienced as injurious. They express that the treatment provider was drawing on stereotypes about mental illness to figure out what the suffering person needs without considering the context, which in Hayden's case backfired.

Consequently, the informants describe the importance of the treatment provider's awareness of suffering as situational, and that the solutions hinge on understanding the individual's unique circumstances. Concerning therapy, the informants talk about seeking treatment to overcome symptoms which they attribute to past traumas, but instead of having such symptoms relieved, they experience more trauma. As Hayden illustrates, the informants expect the treatment provider to be able to understand and adapt to their unique circumstances, and when they experience the opposite, this is part of the process of acquiring iatrogenic injury, either in the form of re-traumatization or, as was the case with Dakota, having side effects of medication

ignored, illustrating how the social interaction, especially in terms of *dis*-recognition, is important for understanding the experience of developing injuries. The experience of being infantilized is thus an important aspect to consider, as the individual feels that they cannot influence the treatment process in relation to the perceived power imbalance.

## **Being Pathologized**

The experience of being transformed into a non-subject can thus be understood in relation to the lack of concern for holism and contextualization, wherein the individual feels reduced to a medical problem by having their experiences and personhood medicalized instead of recognized. The informants paint a picture of how the psychiatric diagnosis frame the interaction with the treatment provider as one where they are at a disadvantage. As has been illustrated, they describe being *talked down to* instead of being *talked to*, as well as having their thoughts and feelings on a given subject matter disregarded in favor of the treatment providers' preferences, something that at its worst results in bodily violation. The experience of being pathologized is thus a vital part of experiences of maltreatment within psychiatry, with pathologization being experienced as a form of prejudice which disregards their humanity in favor of interpreting experiences through the lens of their diagnoses.

Many informants look back on their experiences in treatment as having been characterized by the treatment provider describing them as 'delusional' or as 'suffering from cognitive distortions'. Clara, a 25-year-old woman from Germany, describes how her therapist didn't listen to her when she tried to explain that she had lived through adverse experiences, including being bullied throughout her school years, which in turn affected her mental state negatively. As Clara describes, the therapist didn't recognize her experiences but instead accused her of suffering from cognitive distortions that made her interpret things incorrectly due to her mental illness.

Also when I described several traumatic things that happened to me, such as being ostracized by everyone around me for years, listening to classmates describe detailed fantasies about how they would kill me, telling me I was not human, calling me an "it" instead of "she" to humiliate me. The therapist just said "this is a cognitive distortion and it never happened the way you are describing."

Clara experienced the therapist's treatment method as a strategy for the therapist to disregard Clara's narrative in favor of the narrative of their own, which aligns with medicalized perceptions of the brain as malfunctioning. In doing so, Clara's thoughts and feelings were understood as pathological, when what Clara wanted was for the therapist to acknowledge her

suffering as a reaction to a harmful environment. Instead, Clara's experience is that the therapist dismissed her as mentally ill, and because of this illness, deemed her to be an unreliable narrator.

The experience of being dismissed and considered unreliable because of the psychiatric diagnosis is something which the informants say extends to the entire healthcare system, where their complaints of physiological issues are often dismissed as symptoms of their psychiatric diagnosis; the healthcare professionals gatekeep their access to somatic healthcare, something which they not only feel is unfair, but which also compel them to alter their behavior in order to protect themselves from being stereotyped and discriminated.

Fiona, a 40-year-old woman from Australia, describes how the prejudice has affected her:

As there is so much stigma around mental health and I have seen psychiatrists for 30 years there is always a negative crossover. Your psychiatric notes are linked with your general doctors notes so I'm often prejudged when I see a new health professional. They read the notes on their computer while silently pretending to not be shocked by what's written but I always know. Unfortunately it makes it hard for a fresh start as the psychiatrists notes are like a paper trail that follows me wherever I go. I have had doctors afraid to prescribe medication and nurses mistake a high heart rate for anxiety instead of tachycardia. Social workers doubting I could be a good mother if I have depression. Every time they are reading the same notes [...]

Fiona experiences her wellbeing as threatened based on the 'paper trail' of previous psychiatric diagnoses and treatments that follows her around. Every interaction is experienced as characterized by the need to prove herself, to show the professional that she is as reliable as any other adult, in a never-ending story. Fiona not only worries that being prejudged based on her 'psychiatric notes' can result in wrongful treatment protocols for her somatic health concerns, she also feels that her status as a mother is questioned based on her diagnoses, and that being in contact with authorities presents a risk toward her homelife.

Because of such experiences, some informants elect to take precautions to prevent these risks from materializing. This is the case for Lucy, a 32-year-old woman from the UK. Where Lucy lives, most medical treatments occur within the National Health Service, the NHS, which is a tax-funded healthcare system. Lucy, however, has elected to pay out of pocket for private care, because she fears that if her psychiatric treatment is on record with the NHS, she will be discriminated against by other medical providers: "I stick to private care to keep my psychological history out of NHS records. Generally, if you have significant psychiatric

history, GPs are more likely to attribute reports of symptoms and requests for investigations to psychological problems."

Doing so, however, puts Lucy's mental health treatment providers outside the boundaries of accountability agencies, something which Lucy considers to be a contributing factor to the maltreatment she has experienced:

It's possible that if I had not felt the need to keep my therapeutic history from my primary care practitioner, I would not have been subject to the whims of private therapists operating without oversight. Having therapy within an institution like the NHS, where there is accountability and a formal complaints process, is probably safer.

In Lucy's case, the attempt to mitigate risks of injury due to her distrust in the system has effectively resulted in iatrogenic injury because of the lack of formal accountability.

In the USA, keeping one's records confidential is less of a chore, as the system is decentralized, with the patient often being responsible of transferring their medical records to the newest provider. Crystal, a 37-year-old woman from the USA, states that unless she is seeing a mental health professional, she does her best to conceal her diagnoses to avoid being discriminated and dehumanized:

Also, I have learned that doctors won't take you seriously or listen to your concerns if they know you have depression, anxiety, or autism. They don't think people with mental illnesses are human and treat people with mental illnesses like animals. This is why I try not to let anyone know the autism and complex PTSD diagnoses unless they are a counselor that I am seeing.

As Crystal describes, she must hide vital information that affects her overall wellbeing status when seeing a doctor. This is not because Crystal rejects her diagnoses, rather it's a protective mechanism to maximize her chances of receiving adequate healthcare according to her needs, as she doesn't trust the treatment providers to look beyond the stigma these diagnoses entail.

As has been illustrated in the cases of Fiona, Lucy and Crystal, informants not only struggle with pathologization within psychiatric treatment; they also struggle with desiring holistic treatment in terms of not having their somatic complaints recognized due to their psychiatric diagnoses. Pathologization thus extends beyond the therapy session, or the meeting with the psychiatrist, and experiencing inherent distrust from providers make the informants reluctant to share their full medical history.

This experience of stigma and prejudging thus must be understood in relation to the informants' observations of being *labeled* and having their experiences essentialized in terms of their

diagnosis. The informants typically seek psychiatric treatment because they want to have their suffering alleviated, desiring to cultivate resilience and self-worth. This is a reasonable decision within the cultural context and plausibility structures they operate within. However, instead of being uplifted, they describe being harmed by the constant exposure to various kinds of defeatist discourse coming from the treatment providers; they tell stories of being presented with a narrative which, in one way or the other, suggests that their future is bleak because of their 'terminal diagnosis'. Logan, a 33-year-old man from the USA, who himself works as a recreation professional within the mental health system, describes entering treatment because of a traumatic event which resulted in him developing mania, that after psychopharmacological treatment developed into psychosis. Logan now has a psychiatrist whom he likes, but he describes the first years in the system as demoralizing. The contrast between what he expected and what actually happened was stark:

I thought I would receive treatment or help or something. instead, I was left to fend for myself when I was alone, confused, and couldn't navigate what was happening to me. my self esteem plummeted as I was presented with this expectation that how things were then was as good as they were going to get and that I would amount to nothing. they were wrong, but even now I find myself living with self doubt.

Logan and the other informants paint a picture of interacting with authority figures who are experts concerning their particular brand of suffering, and being told that they are chronically ill and unable to change this. For informants like Logan, this is experienced as being held down, and even when they are far removed from these negative influences, they still struggle with differentiating between the judgement of the previous treatment providers and their own assessment of their wellbeing. Part of the treatment process, as described by the informants, is internalizing a *deviant* identity, not because of the emotional suffering, but because they learn to identify as a *psychiatric patient*. Logan describes himself as successful now, but he still doubts if he *really* is because he was continuously told he would never get better. The labeling process is thus experienced as a demarcation process where the informant is dubbed pathologically different. Megan, a 47-year-old woman from the USA, summarizes her experience: "I was given pills "for life", told I had a "chemical imbalance" and declared to be "Bipolar"." This also illustrates how the experience of being transformed into a non-subject indicates that something occurs on an identity level as well as on an emotional level, and how being deprived of subjectivity thus can be understood as a form of social-emotional damage.

Clara, a 25-year-old woman from Germany, similarly describes her experience of being diagnosed with autism:

Certainly when I was diagnosed with autism and the therapist told me that I was unable to communicate, unable to ever live independently, and unable to ever make friends. And they began treating me like a dog that needed to be trained after that.

For Clara, the diagnostic process didn't serve to help her understand herself as the diagnostic process ideally should. Instead, it instilled hopelessness and a self-image which professed her to be less-than compared to her peers. Furthermore, if she had listened to the professionals, who she felt were trying to 'train her like a dog', it would have meant giving up on trying to do basic, human things, such as cultivating friendships and independence, because these did not align with the professionals' expectations.

Thus, as Megan, Clara and Logan express, *dismissing* the predictions of their treatment providers put them on the path to a better life. However, the process of doing so wasn't easy, and even now it is important for them to underline that they *are* capable of living 'normal' lives and that they are *not* pathologically damaged:

By the time I saw a psychiatrist months later, the first medication I was given induced psychosis and caused seizures. I was always covered in bruises and cuts from fainting for several years. When I stopped taking medication that caused that, I was labeled noncompliant. I was labeled noncompliant again when I refused to quit my job and give up my son. I was also labeled "lack of insight" for believing that I could get better. it still comes up on charts from time to time, though it was 7 years ago and since then I've advanced in my career, bought a house, served on nonprofit boards, and kept my son. (Logan)

Logan describes refusing to accept the defeatist message he was presented with, and in turn, managing to turn his life around. However, for Logan, this required going against the medical narrative of being 'a good patient', and to place himself in the position of being rejected and looked down upon. Furthermore, Logan illustrates the ongoing struggle that many informants describe surrounding the dichotomy of being a 'regular person' and a 'sick person', where the treatment they have received labelled them the latter, and where it's important for them to show that they are (or strive to be) the former. This further helps to underline how the experience of being pathologized within interactions with professionals can be internalized, and how the language of normativity can be used by informants as a tool to reclaim their humanity compared to the label that positions them as 'less than'. This is interesting, seeing as anti-stigma campaigns focus strongly on the opposite — on the diagnosis functioning as a liberating force, and identification with the diagnosis being something positive. For many informants, however, the experience of having been told that they will never have a normal life due to the nature of their diagnosis has often fostered hopelessness, as well as dependence on the system, which they in hindsight regret. As they describe it, the process of being convinced that they are sick

with incurable disorders that need lifelong treatment made it difficult to resist ineffective treatments. As Logan explains, resisting is understood as risking being labeled as non-compliant and being met with resistance and hostility in return. Thus, if the label seems inadequate, or if the treatment is not working, going against it requires self-reliance, something which is illuminated in how Logan still doubts himself despite having recovered. Realistically, however, most people who seek out mental health treatment probably don't feel particularly self-reliant. As much is true for the informants, who describe seeking treatment while being in a position where they feel neither self-reliant nor strong. Maximilian, a 21-year-old man from Germany, sums up the feeling of the more critical portion of the informants on this by stating: "I find that psychiatry more dangerous as it's able to harm an individual on a very deep level when he's in his most vulnerable state."

The experience of being transformed into a non-subject is characterized by having one's unique life circumstances neglected, as well as not having one's treatment preferences and autonomy respected. Furthermore, the process of being transformed into a non-subject illustrates how the experience of treatment isn't characterized by a journey from illness towards normalcy or health. Instead, the processes of violation, infantilization and pathologization undermine the subject status of the informant and reduces them to something less-than; they become an object for *medicalization*, something which results in a *dis*-recognition of their unique circumstances, resulting in injury. The informants further experience a lack of *power* in the interaction with their treatment providers, where their own interpretation of their health and their needs are second to that of the professional. In the context of medicalization, this can be attributed to the conceptualization of medical interventions and medical science as an overarching power, making the label of 'mental illness' something tangible which actively shapes the way interactions play out. The informants describe being acutely aware of this and elaborately discuss their attempts to manage it by adjusting their behavior accordingly in various ways, sometimes at the detriment of their overall experience of health. However, their (in)ability to act must be understood in relation to the context the interaction occurs in: the way the medical system is set up, their emotional state as well as the level of autonomy they are allowed to exercise within the environment affect their strategies and opportunities to potentially resist treatments which they find damaging. This is something which is especially tangible when looking at the informants' experiences of being violated, something which typically occurs in a context where the power balance is particularly skewed due to the structure of the hospital environment. Consequently, the ability to act is constrained by the plausibility structures and

structures of governance surrounding the institutions of medicine and psychiatry, while it also converges with other plausibility structures in the informants' specific cultural and social contexts.

## II. Losing Trust in the Psychiatric System

While the former theme discussed how the subject is undermined, and the damage this causes, it also somewhat illustrated the damage done to the informant's relationship with the treatment-provider and, by extension, the psychiatric system. The experience of being violated particularly illustrates this erosion of trust. This theme will continue to focus on this damage by attempting to illustrate how the breakdown of the therapeutic relationship results in a loss of trust in the psychiatric system, specifically by examining coercion and force. The informants universally express that their experiences of psychiatric treatment have contained elements of coercion which erodes trust, as they experience disempowerment and betrayal instead of healing and benevolence. In the understanding of individuals as consumers of medical intervention, and in relation to the surveillance individuals themselves exercise when they decide to seek help, injury can thus be contextualized as occurring in complex situations where the exertion of power is present but not always visible.

This theme will explore various levels of coercive interactions which undermine the trust in the psychiatric system. Starting with the experience of *forced treatment – being subjected to court-orders and the medical-judiciary system*, the outright coercive elements of treatment and its relation to injury will be examined, as well as the complexity of consent. The second half of the theme will concern *betrayal of trust*; outlining how the experience of trusting the professional and the experience of being coerced by deception relate to the experience of losing trust in the psychiatric system.

Forced Treatment – Being Subjected to Court-orders and the Medical-Judiciary System In psychiatry, professionals are given a legal mandate to override the individual's right to decline treatment if it is deemed necessary, something which is administrated via the court system (Moncrieff, 2013:18). Here, medicalization is expressed as 'mental disorders' justify invasive procedures for the individual's 'own good'. This kind of treatment also reveals the intersecting relationship between psychiatric power and judiciary power, with such coercive measures only being made possible because of the involvement of the justice system. Forced treatment can include interventions such as involuntary hospitalization and community court orders, as well as the utilization of physical restraints, and so it's not surprising that informants whose treatment has been court-ordered experience this as forceful and oppressive. This in itself can be characterized as injurious (O'Hagan, 2003:2), and in combination with somatic injury from the treatment regimes, the court-order-related injury is experienced as an especially hard pill to swallow.

Every informant who describes being on the receiving end of involuntary hospitalization share stories of having their wishes overridden and of being physically restrained, something which occurs only after they have attempted to decline treatment in some fashion. Megan's story will help illustrate the experience of court-ordered treatment and its relation to iatrogenic injury. Megan, a 47-year-old woman from the USA, spent six years in a court-ordered outpatient program, where she was subjected to daily observations to make sure she was taking the prescribed medication as ordered, something which made her own home feel like an unsafe space. Megan further describes how the outpatient treatment was punctuated by involuntary hospitalizations, where she, on and off, went from being forcefully medicated in her every-day homelife, to being placed in a psychiatric ward. This added to Megan's experience of treatment as traumatizing, because it included physical elements of coercion; police officers would come to her house, to bring her to the hospital, something which can be standard procedure when the hospitalization process isn't initiated by the treatment recipient; she was one of the informants who described the traumatizing effects of involuntary treatment by utilizing the metaphor of sexual assault, describing a specific hospitalization process as "rape by hospital staff with 2 male policemen watching." Court-ordered treatments include invasive bodily procedures that are non-negotiable for the recipient, which explains why Megan experienced the process of being hospitalized as a violation. The continuous experience of not being in control of the medication regime also added to Megan's experience of treatment as injurious, as she felt like she had no control over what was being done to her body.

Megan goes on to describe the long-term effects that the involuntary hospitalizations have had on her life: "I am now terrified of police entering my house on a whim and taking me away". For Megan, the treatment, which was presented to her as a way of keeping her safe and as healthy as possible, has instead resulted in an erosion of trust not only towards psychiatry, but also towards the police. Despite the court-order being lifted, she now lives in fear of having her right to make decisions regarding medical treatment removed again, and she doesn't feel safe anywhere because of it: "I am off the Court Order but its damage is done. I am effectively a vegetable poisoned by monthly injections and humiliating daily forced pills in my own home, which effectively became a prison." Certainly, Megan describes the treatment as causing harm rather than healing, and in addition to her clinical injuries, Megan now experiences the psychiatric system as inherently threatening; she characterizes treatment providers as potentially malevolent actors who at any time may invoke their power to alter her life by initiating the involuntary hospitalization process.

This feeling of powerlessness also extends beyond the psychiatric system. Fiona, a 40-year-old woman from Australia, describes how her experiences with involuntary hospitalizations have resulted in her avoiding medical care altogether, including when she is suffering from somatic illness:

The trauma has caused me not to go to hospital to seek care for life threatening conditions as I'm scared a psychiatrist will get involved. I'm always scared if a medical hospital enquires about my mental health a psychiatrist will decide I should be locked up in their hospital. I fear them that much now.

Like Megan, Fiona describes being traumatized by being involuntarily hospitalized, and the diagnoses she has received, as well as any displays of emotional suffering, are understood by Fiona as potential weapons that professionals can choose to wield on a whim to take away her freedom. As Fiona puts it, she would now rather risk dying than risk being subjected to the treatment that she experienced while involuntarily hospitalized.

The descriptions of injury as related to court-ordered treatment also include the experience of being isolated from one's ordinary life and support network while involuntarily hospitalized. The informants describe a particularly vulnerable state of being trapped in a physical, restricted space wherein the power imbalance between professional and informant is pushed to its limit. As the informants describe it, they have no recourse on their part if it turns out that they are unhappy with the treatment they've been prescribed, something which is terrifying in a closed off environment that they legally are not allowed to leave. Aaron, a 31-year-old man from the USA, frames the hospital as a place that only functions to isolate the individual and take away their rights. He describes how even though he had access to a support network, being hospitalized meant he wasn't allowed to interact with them, while he also wasn't allowed to check himself out of the hospital, thus effectively experiencing it as an act of forced social isolation:

One of the most defining moments was 2013 when I was hospitalized for about 6 weeks and a friend had to lie and pretend to be my boyfriend to get HIPAA<sup>2</sup> access rights to come in and see me and help me get out.

As Aaron describes it, the staff not only prevented him from leaving the hospital, but also prevented him from being in contact with his friends against his wishes. He describes wanting to check himself out of the hospital, but not being able to do so without the aid of a friend –

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<sup>&</sup>lt;sup>2</sup> The Health Insurance Portability and Accountability Act of 1996, which is federal law in the USA and concerns the protection of sensitive patient information from being disclosed.

who had to be willing to lie and scheme to visit him and have access to his medical information. This made Aaron feel powerless, and his eventual homecoming became framed as an escape rather than a healing process which eventually results in being discharged from the hospital. Thus, instead of being a safe place to heal from illness or distress, the hospital is experienced as a hostile, closed-off, secluded space where the informants are at the mercy of the staff and where they have no choice but to submit to the treatment process and learn to go along with the rules that apply within the confinement of those walls. This experience doesn't cultivate trust; it cultivates fear.

The informants also experience the psychiatric ward as a place where the treatment providers implicitly coerce them into agreeing to treatment, as they feel that the alternative is having their stay converted to indefinite involuntary commitment or prolonging the court-order. Thus, they may acknowledge that *on paper* they voluntarily agreed to specific treatment regimes, but in practice, they explain that they had to play along because they were afraid of the potential consequences of resisting.

### Zahra, a 61-year-old woman from the USA, describes:

I knew and know I could not influence the treatments I received. I am really a very smart and kind and educated woman. I knew I had to fake it to get out. Take their pills. And thank them for helping me.

In Zahra's case, learning to play the game was the only path she could see out of the psychiatric ward. Internally, she resisted, but outwardly, she moulded herself into the 'good patient' so that she could 'escape'. Thus, Zahra may be perceived as a successfully treated patient who benefited from and accepted the treatment offered, but in her own experience she was coerced into complying and now feels betrayed.

While Zahra describes internalizing the coercive structure of the inpatient unit from her own previous experiences with involuntary hospitalizations, other informants learned the ropes by secondhand exposure, by witnessing coercive measures directed at other patients. Joanne, a 50-year-old woman from the UK, describes picking up on this immediately when she decided to voluntarily seek help and check herself into a psychiatric ward:

On the first night in hospital another patient was distressed and violently assaulted and forcibly injected with medication. That meant I knew from the start that even though my admission was voluntary I had no realistic ability to refuse treatment. This meant I did not believe I could refuse ECT.

Joanne didn't have to experience force herself to learn to abide by the rules that dominated the psychiatric ward. She deduced, from the social environment she had been thrust into, and which didn't align with her expectations of what hospitalization would entail, that she would best navigate the situation by complying and subsequently avoid being assaulted, like her peer had been on that first night. Joanne thus considers the ECT she received while hospitalized to be forced treatment. She now suffers permanent memory loss, something which has severely affected her quality of life, and no longer trusts that treatment providers or regulatory bodies can counteract or even recognize injurious treatments.

## **Betrayal of Trust**

The experience of having been subjected to coercion can also be identified by the informants post-treatment. The informants who chose to undergo treatment without feeling like they were under duress in the moment, and developed injuries from said treatments, look back on it with regret and express that they did *not* give informed consent; if they had been given all the information about the risks involved, they would have made a different choice. While some describe asking the treatment provider outright about potential risks at the time of treatment and look back on the responses as deceptive, others simply did not question anything, because they trusted that the treatment provider was well-educated and well-intentioned. In short, they put their trust in the expertise of the professional.

George, a 45-year-old man from the USA, explains that he never thought to question the doctor who first prescribed him Zoloft<sup>3</sup>: "I just did as I was told. I trusted my doctor". George ended up developing PSSD from the treatment, and has been suffering from permanent, debilitating symptoms for 15 years. Caleb, a 22-year-old man from the USA, similarly describes trusting his doctor to be an expert: "I believed they knew everything they prescribed and were aware of the potential side effects". As Caleb saw it, a doctor is a person who promotes health, and therefore their prescribed treatment would be a healing agent. Like George, however, Caleb unexpectedly developed PSSD, and he now feels strongly that psychiatrists themselves don't understand the treatments they prescribe.

Like Caleb, some informants first encountered psychiatry while very young, having had little to no experience of previous medical treatment. This was the case for Thomas, a 27-year-old

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 $<sup>^3</sup>$  An SSRI (antidepressant) which in 2020 was the  $12^{th}$  most commonly prescribed medication overall in the USA according to ClinCalc

man from the UK, who sought help because he was having trouble sleeping due to work stress. Thomas describes:

I felt like the GP gave me medication with minimal explanation of what sides could occur and why I was being given an SSRI in the first place. I never had health issues in my life so I didn't have much experience with going to the doctors as I never needed to hence why I didn't question it.

Thomas assumed that the doctor would inform him of the potential risks of the anti-depressant that he was prescribed, and that it would be the best way to treat his sleep issues. In hindsight, Thomas is baffled as to why medication was prescribed in the first place, but at the time he trusted the doctor because he had no reason not to; after all, doctors are supposed to be well-meaning and well-educated.

Liam, a 22 year old man from Australia, describes an overarching trust in psychiatrists as something which permeates society and which is the reason people agree to treatments: "I think in general people may not realise all the possible damage psychiatry could do as they trust that psychiatrists are professionals and would not give them an unsafe drug which I do not believe to be true". Similarly, Joseph, a 60-year-old man from South Africa, states: "The laypersons believe that what psychiatrists say is truth as they are "doctors"," and Drew, a 30-year-old man from the USA, agrees that: "yes, everyone in my family seems to understand and believe that the doctors are infallible because they went to school.". In terms of being subjected to coercive treatment, thus, it's not just that the individual informant trusts the professional and the medical science that gives them this aura of authority; they also have family and friends who express this belief, making it an institutional truth. Thus, the informants describe operating within plausibility structures where common-sense knowledge states that medical professionals can and should be trusted.

Trusting the professional may also offer certain benefits to the informants, something which further compels them to trust the treatment process, even if they later come to regret it. Laura, a 75-year-old woman from the USA, describes how she not only trusted the professionals to be working from a position of being the bearer of expert knowledge, but that they also provided a scientifically legitimized framework which essentially worked to tell her how to live her life:

I looked on psychiatrists/therapists as the experts, the people I could look to tell/show/ or otherwise indicate the way I "should" be. That gave me a feeling of security, too, as long as I did as they suggested and looked on them as the experts.

Laura had struggled with anxiety since adolescence, which she now attributes to trauma and which she firmly believes shouldn't be understood within the framework of medicine. Previously, however, internalizing the identity of the 'mental patient' worked as a way for Laura to escape challenges in life and of coping with anxiety, similar to how dieting and engaging with compulsions did. In the turmoil that was Laura's life, she was happy to find a setting where somebody focused only on her, and she expected that if she looked inside herself, felt her feelings and talked about herself, then she would get 'better'. The treatment provider also offered a sense of approval and validation, as long as she was compliant with their advice. Laura held onto this view of therapy as something she needed whenever life became challenging until about 10 years ago, not because she got better but because she had internalized a worldview where therapy was always good, helpful and successful. Now, however, Laura expresses that therapy harmed her, and she regrets having put her life in the hands of professionals.

The experience of coercion by deception can thus be understood in relation to the idea of therapy as something that always works and is always benign, something Lorena, a 29-year-old woman from Brazil, also experienced. Lorena now struggles with rejecting therapy in a societal context where most people who don't share her experiences view therapy in the way that she and Laura also used to. Lorena states:

People who haven't gone through the mental health industry are completely clueless as to how it operates. They have their own, imagined beliefs of what treatment looks like. It's all fantasy. They think therapy always works, for anybody, for anything, and refuse to recognise that therapists are capable of doing harm.

Lorena's own experience says otherwise, but she had to live through the injurious experiences to realize that this paradigm wasn't true, because this 'truth' was so ingrained in her social setting. Even now, she feels like she must defend her position to other people, as they still promote therapy as a good and necessary treatment choice for her.

As the informants look back on their experiences with injurious treatment, the societal view of psychiatry and psychology as scientifically sound practices are constantly being contrasted with their own experiences. This illustrates how it's not only within the interaction with the treatment provider, but also in the interaction with their peers, that this trust is cultivated, and how this makes the individual less likely to feel that they can decline treatment. For the informants, it's not until injury occurs that this trust becomes eroded. When injury does occur,

however, the informants experience it as deception and betrayal, and as having been tricked or manipulated. Craig, a 23-year-old man from the USA, explains:

My psychiatrist relied on my trust and used it against me. He gave me an explaination of how ADHD influences the brains chemical balance. A theory which I realize now is outdated. He pretended to listen to my concerned while subtly pushing me in the direction he wanted all along. I had very little real input.

Craig, like most informants, started out trusting in the expertise of the professional. Now, Craig thinks that his psychiatrist weaponized his trust and used it to trick him into choosing a treatment which he now understands to be un-scientific. Instead of the interaction simply being about passively trusting the doctor and complying, Craig describes it as a process of manipulation, wherein the doctor utilized their professional status to make him agree to being medicated. Craig continues:

I expected to receive treatment for my actual condition. Instead my psychiatrist decided to perscribe his favorite drug without considering consequences. No discussion of side effects or drug interactions took place at the psychiatrist's appointment, no mention was made of how the drug could induce serious withdrawal symptoms. It was only pushed that these drugs were safe and effective and had minimal side effects, especially on a low dose.

Craig blaming the psychiatrist for prescribing 'his favorite drug' can be understood as a way of making sense of this deception, because attributing it to self-gain offers a framework that fits with Craig's cultural understanding of why a doctor would do such a thing. Craig expresses that he himself managed to do his own research on the risks of his treatment, and thus attributing his psychiatrist's action to ignorance makes no sense, as he feels the psychiatrist – who is a highly educated professional - would be more than capable of doing the same research. Cluelessness regarding risks and benefits on part of the professional does not fit into the plausibility structure that many informants operate within, and hence they experience it as having been manipulated for the benefit of the individual treatment provider.

Some, like Drew, a 30-year-old man from the USA, see this as a malicious act: "anyone whos experienced psychiatry first hand knows that they are not only, just people, but people who have an inflated sense of authority and prejudice, and use their knowledge to manipulate everyone and everything". For Drew, it's unthinkable that this is a systemic error afflicting the treatment providers in the same way that it afflicts the patients. Instead, treatment providers are understood as malicious and actively harmful. Others, such as Maximilian, a 21 year-old-man from Germany, take a less person-centered approach, suggesting that treatment providers are

not acting maliciously but instead are themselves manipulated by a greater, corrupt system. This doesn't negate the experience of deception, but it offers another framework to make sense of it. Maximilian states:

But still I'm not sure whether they know how they can do harm and I'm sure that they're not doing it super consciously as the information they get was partly created by the pharma industry which is to blame in my opinion.

Attaching blame to the pharmaceutical companies was not an uncommon response for the informants when finding out that psychopharmaceutical treatments could be harmful. This illuminates another layer of iatrogenic injuries as something socially curated. While Drew expresses that his psychiatrist manipulated him, Maximilian suggests that the psychiatrist themselves are being manipulated, both of which are social actions that result in clinical consequences for the informants. It's further visible in that this is being described as a top-down practice, where manipulation is unilaterally directed downwards, as an exertion of power. While the treatment providers thus may very well act with good intentions, that is not how the informants see it.

Several informants further describe having been outright lied to by their treatment providers, rather than subtly manipulated. Pam, a 65-year-old woman from the USA, explains:

I was given a prescription for Navane, described to me as helpful for "stress" to deal with this incident. It was not communicated to me that I was perceived as having hallucinated the entire incident as "things like that don't happen in the beautiful country USA"

Instead of being told the truth by the treatment provider, Pam says that it was her roommate who told her that Navane was "an antipsychotic". This experience made Pam feel betrayed, because not only did she see it as the treatment provider dismissing her as a liar by claiming that she was hallucinating, she was also upset that she was going to ingest a drug she no longer recognized as beneficial and hadn't consented to taking.

Pam and her treatment provider had fundamentally different explanations for what she was going through, and while withholding information may be rationalized as in the individual's best interest for a treatment provider, to Pam and the other informants in her position it is experienced as fraudulent behavior and coercion by deception. The informants unanimously express wanting to be able to make an informed choice: they want to know about potential harms and benefits and *then* make the decision for themselves. When injury occurs and they

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<sup>&</sup>lt;sup>4</sup> Also known as neuroleptics, antipsychotics are typically used to treat symptoms of psychosis

see themselves as having been cheated out of this, the informants feel betrayed, because instead of getting the help they asked for and wanted, they feel trapped in a state of injury that is often described as worse than the original malaise they sought help for. Bailey, a 20-year-old woman from the USA, describes her experience of living with injury from psychopharmaceutical treatment with great regret: "The two most humanly parts of living was taken from me because I didn't want to be sad anymore.." As Bailey sees it, something vital has been stolen from her, and to understand her experience of injury, it's important to understand that the suffering she ascribes to her previous issues with depression and social anxiety, and the suffering she ascribes to treatment side-effects, are not one-in-the-same. For Bailey, the un-treated depression she used to suffer from is preferable to the 'lasting PSSD' she developed from being treated with anti-depressants, anti-psychotics and benzodiazepines<sup>5</sup>. Bailey states: "I wish I never did it. I felt normal being depressed and anxious".

That Bailey characterizes the former state as 'normal' illustrates the subjective nature in demarcating the normal and the pathological. As Bailey describes it, she suffered greatly before she was medicated, being unable to function in social settings and finding one-on-one conversations terrifying. Yet, in hindsight, she describes feeling 'normal' compared to postinjury.

Andrew, a 28-year-old man from the USA, similarly describes how his life was much better before treatment:

My state of mind was a lot better compared to now. I initially went in for anxiety and some depression symptoms. [...] I have minor anhedonia where I have trouble feeling emotions. I also experience brain fog, and minor sexual dysfunction. My quality of life has been ruined. So I feel stuck.

Like Bailey, Andrew expresses that the side-effects from treatment were worse than the suffering which he hoped to have treated in the first place. The informants thus describe a state of regret that aligns with the loss of trust in the institution. They feel like they were coerced into treatment, albeit indirectly. As Sarah, a 27-year-old woman from Canada, puts it: "People are not being warned about the dangers of psychiatric medication and it is a very big problem. Informed consent is practically non-existent within psychiatry as well as modern medicine."

The experience of losing trust in the psychiatric system must thus be understood in relation to the institutional power afforded to psychiatry. There are several layers of this. As the

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<sup>&</sup>lt;sup>5</sup> Tranquilizers that are known for their highly addictive properties, typically indicated for anxiety and insomnia

informants describe it, the treatment providers are able to draw on this medical power – they can utilize the legal system and they can force treatments upon any individual at their own discretion without consequences. By drawing upon the scientific knowledge psychiatry operates from, it's possible to effectively coerce individuals into treatment, as well as convince them that a treatment is gainful. On the other side of the equation is the individual, who has a desire and need to trust the treatment provider, and whose understanding of psychiatry starts out with the knowledge that certain problems need to be treated in the realm of psychiatric and psychological medicine. Having identified a problem, the individuals typically voluntarily seek out medical care to treat it because they understand their lack of ability to sleep, their anxiety or their depression, as medical phenomena. This process of internal surveillance, where their understanding of their experiences is framed by medicalization, and where they feel responsible for taking charge of their health, occurs to the extent that political issues such as a difficult workplace become understood as a medical problem. This perception only changes after the individual has acquired injury, at which point it is too late to change what happened. However, this results in a loss of trust in the psychiatric system, because of the lack of openness about the limitations and potential harms of the treatments, as well as the lack of recognition for the individual's needs and their humanity, as was more thoroughly examined in the first theme. This loss of trust results in a paradigm change for the individuals, where they recognize themselves as having been harmed and start to look for accountability from the psychiatric system. This is also when the individual becomes aware that rejecting the normative, protreatment paradigm renders them deviant, as compared to their social circle. And for some, the fear of being subjected to treatment again becomes so debilitating that they alter their lives in any way they can to avoid it.

## III. The Lack of Accountability and the Need for Recognition

The informants' stories about being injured are told from the perspective of having processed and recognized that injury has occurred. To understand their experiences of iatrogenic injury, therefore, the experience of *living* with injury becomes important. Those who suffer from clinical injuries wish for curative treatments, but pertaining to the social realm, the experience of living with injury is – above all else – characterized by the desire for acknowledgement and recognition; to have their experiences accepted as truthful and to be understood. Furthermore, for the informants, recognition also represents an avenue for developing potential treatments for clinical injuries, as well as an avenue to avoid future injuries. More importantly, it occurs to the background of a lack of accountability on part of the psychiatric system pertaining to the injuries they have sustained.

This final theme will consist of two parts, where the first will cover the issue of the informants feeling like the psychiatric system doesn't take accountability in the event of injury, as well as their experience of having to re-negotiate their relationship with psychiatry. The second part will outline how the informants attempt to (re)claim their story and find their voice in relation to *the critical community*.

### The Lack of Accountability

The informants who voluntarily sought out psychiatric treatment all describe doing so with the expectation of the treatments being curative or at the very least offer relief, as well as having the ability to decline treatment at their discretion and being treated with care. When they were faced with medical maltreatment, they therefore describe looking to their treatment providers and the overarching psychiatric system for answers, but finding themselves wanting.

Many informants specifically describe having reached out to a treatment provider to alleviate physiological injuries attributed to psychopharmaceutical treatment or ECT. This can be illustrated by Jade's case. Jade is a 23-year-old-woman from Australia, and she developed PSSD from psychopharmaceutical treatment and now describes her current life as "the most miserable, torturous, and gruelling experience of a human life". Looking back at her experiences of being afflicted with PSSD, Jade says that she feels like the pills were pushed on her and that she was told she would never recover without medication. However, this completely backfired and left her in what she considers to be a far worse position with no hope for improvement:

I was expecting there to be a much better safety net for if something went wrong. That's the issue with psychiatry..... there's no safety net. If you develop permanent PSSD, chronic protracted withdrawal, akathisia, neuropathy or tardive dyskinesia, then there's no treatment. All of the illnesses that I have just lifted a far worse than any kind of psychiatric illness, and anyone who argues otherwise has never experienced any of them. if there is a risk of a heart attack, then we have treatments for heart attacks, if there is a risk for a rash, then we have treatments for rashes... but if you develop permanent PSSD, there is no doctor in the world that can fix your sexuality. There is no doctor in the world who knows how to restore sensation in your vagina so that you don't feel like a blowup doll during sex. there is no doctor in the world who can restore your emotional feelings.

For Jade, the lack of accountability primarily exists in the realm of being sold a treatment that has very real, possibly permanent side-effects which were concealed, and then developing these side-effects and finding that there is no curative treatment. Not only is there no treatment, however, there is no protocol at all to invoke in the event of its occurrence, making her feel like she has been abandoned by the medical system that harmed her. Furthermore, Jade expresses that no one takes her seriously when she asks for help with the PSSD, and that what she has been through should be acknowledged as human rights abuse, underlining her need for somebody to take accountability for what happened to her and recognizing her right to not be harmed in the first place.

Hayden, a 43-year-old non-binary person from the USA, experienced injury from therapy rather than psychopharmaceutical treatment, but their experience of not being taken seriously when trying to report it resonates with Jade's:

There is a widespread tendency to disbelieve and/or blame clients. Clients who report harmful therapy are treated as less credible than clients who report other kinds of interpersonal harm, and many people, including therapists and many participants in pro-therapy mental health communities, will assume the problem couldn't have happened that way and the client must have done something wrong. And clients are often blamed for not knowing more, not doing more, and not finding the right phrase to make the therapist do their job well. The trauma of harmful therapy is worsened by the intensity of disbelief and blame.

In Hayden's experience, other treatment providers as well as higher-ups are deferential to the perspective of the therapist, and instead of being listened to when trying to report maltreatment, Hayden themselves became stuck with the blame because nobody would believe them. As they describe, this creates shame, which in turn exacerbates the experience of injury. Furthermore, Hayden expresses that even in supportive mental health communities, the blame is usually placed on the 'client' rather than the professional, meaning that their 'peers' are unsympathetic and fail to recognize the pitfalls of the system. Hayden feels that in all interactions, they are forced to shoulder the accountability of something that was beyond their control.

It's when trying to make sense of this perceived systemic failure, where the individual is left injured without recourse *and* left shouldering the responsibility of the situation, that the informants describe finding support in what this thesis conceptualizes as *the critical community*. The critical community refers to various online communities whose one common ground is that they reject some form of psychiatric and/or psychological treatment. For the informants, the critical community functions as an antidote to the forced accountability they themselves have needed to shoulder to keep moving forward, something which will be discussed further in the second part of this theme. For now, we merely acknowledge that Joy, a 30-year-old woman from Canada, describes the critical community as vital for her as she kept looking for help within the same system that damaged her, and whose representatives for the most part refused to take responsibility for the harm.

[The critical community] saved my life as I was repeatedly throwing myself at an abusive system in the hopes that that abusers will actually help me heal. That insanity is like throwing yourself at your rapist in the hopes of getting respect.

Joy describes spending six years trying to overcome trauma by going to therapy, but instead of finding relief, she experienced more trauma in the interaction with therapists, essentially replicating the abuse she had previously experienced and sought help to heal from. As a person of color, she also experienced racist discrimination from treatment providers, which in itself was traumatizing. For Joy, accountability from treatment-providers would have included being protected from racial discrimination, or at the very least having the treatment providers who discriminated her sanctioned. However, it also would have included having the treatment providers advise her to stop seeking therapy, because the system and its representatives only ended up causing more harm. As she sees it, "they often don't help and the power imbalance + lack of transparency covers racism, discrimination and just utter abuse from providers. "Safety" isn't really for you but really just to enforce judo-Christianity beliefs." Therefore, in Joy's case, accountability from the representatives of the system would have meant acknowledging that the treatment providers lacked the ability to help her, as well as taking accountability for structural *isms* which were continuously upheld within the treatment system. For Joy, the lack of accountability occurred on both a systemic and individual level.

While Joy has staunchly taken a stand against treatment because of this lack of accountability, other informants handle the eroded trust in the psychiatric system, and the expectations of this experienced systemic lack of accountability, by explaining that it's still important to seek

professional help. However, to do so, one must be ready to take on the responsibility of being fully informed about the risks of potential treatments, because the treatment providers might not be. Consequently, these informants suggest that accountability is shifted onto the user to navigate successfully. Gavin, a 22-year-old man from Australia, discusses how normally people will trust psychiatrists because they are experts, and that therefore psychiatrists would not prescribe drugs which are "unsafe", something which Gavin realized is untrue after his own damaging experience of being prescribed SSRIs for anxiety. Gavin states that this experience has permanently altered the way he views psychiatry, and that he has developed "extreme social problems that I never had previous to psychiatry that bring me a lot of distress" from the SSRI treatment. Nonetheless, Gavin represents a group of informants for whom the injury is not something which has discouraged engaging with psychiatry, and who still feel that psychiatric treatment can be gainful, *if* the person seeking help does not blindly trust the professional. Gavin says: "listen to your doctor but also do your own research I think they can be misinformed often".

Similarly, Andrew, a 28-year-old man from the USA, talks about how he developed PSSD from SSRI-treatment and expresses that his "quality of life has been ruined". Nonetheless, Andrew still thinks that psychiatric maltreatment can be avoided for the treatment-seeking indiviual, and that people should continue to seek help within the psychiatric system: "I'd say be careful with medication. And pick a psychiatrist that is will work with you accordingly. Psychiatry isn't bad... I just want people to be careful and not go in blind like me." For Andrew, the adverse experiences can be utilized to make informed decisions while still benefitting from treatment. He trusts that knowledge is power, and that circumventing injury is possible.

Many informants, however, disagree. Charlotte, a 32-year-old woman from the UK, expresses worry regarding the insufficiency of critical opinions on psychiatry in the specific critical community she participates in, suggesting that this continued reliance on the psychiatric system is something which can further harm people. For Charlotte, it has been important to protect herself from additional injuries by trying to distance herself from the system, and she considers this an insight born from "a positive place of freedom and self-actualisation". Charlotte suffers from PSSD and doesn't think that healing will be found within the same system that damaged her, and she worries for the people within her community who are still looking for answers from psychiatry:

It makes me sad when I see younger people in the patient groups for PSSD ask what psychiatric drug they need to take for their PSSD, or still expect their psychiatrist to be the one with the answers. There are so many naive and vulnerable people in the patients groups. It worries me that they are going to have to learn the same lessons I did the hard way – and not everyone is as strong-willed as I have been.

Whether one positions themselves as Gavin and Andrew, or Joy and Charlotte, however, one thing is true for all informants: their trust in psychiatry has been eroded, and the lack of trust for treatment providers to be held accountable persists whether they keep seeking treatment or not. In addition to this, they experience having been made responsible not only for the injuries they sustained, but for any potential injuries that may occur in the future. Whether this responsibility has been shouldered by the informant or forced upon them, the resulting iatrogenic injury subsequently also becomes their responsibility, as they describe clinicians and agencies of accountability failing to shoulder the responsibility for the injuries they sustained, and the subsequent disabilities they must live with. In relation to the individualization of health (Cederström & Spicer, 2015:30) and the responsibilization of the individual (Rose, 2000:325), the informants experience a lose/lose situation, where even if they express having done all they can to take responsibility for their health, they are simultaneously also blamed for becoming sick from the treatment that they were told they needed. This, in turn, worsens the injury, because not only do they experience a lack of treatment options for the injuries they have sustained but they also express that shouldering the blame is emotionally difficult. This can be conceptualized as a dis-recognition, not only of their experiences with injury but of their worth as a person. Meanwhile, they all struggle with finding ways to live with the injuries they have acquired, and of finding ways to relate to and understand their own stories. In part, this struggle plays out within the critical community, and, as Charlotte touches upon, there is a need for the critical community to offer acknowledgement and recognition when society doesn't.

## **Recognition and the Critical Community**

The various critical communities the informants participate in function as support groups for a heterogenous assembly of people who express that their lived experiences pertaining to psychiatric treatment differ from their peers, making them feel marginalized. The critical community is a place where they feel like they can escape the normative rhetoric that promotes the overarching umbrella of mental health treatment as generally desirable and effective, and where others recognize and acknowledge their experiences as something beyond a medical mishap or a delusion.

Finding the critical community, however, is a bittersweet experience. While it offers a new

framework to understand and have their experiences recognized, it also invokes regret, because it represents a counter-defined, alternative plausibility structure where they realize they could have made different choices regarding treatment. Sarah, a 27-year-old woman from Canada, explains: "I wish I would've found a community against psychiatry before being harmed by it." Sarah describes being disabled and unable to work due to anti-depressant withdrawal syndrome, as well as having been harmed by therapy, and she is now grieving the life she feels she has unecessarily lost. For Sarah, the critical community offers a contesting framework to the medicalized narrative of psychiatric treatment being a necessity when one suffers emotionally, and she no longer believes that mental health issues can be treated by medical institutions.

This contesting framework, or counter-defined plausibility structure, can also be experienced as empowering, as is the case for Maggie. Maggie, a 51-year-old woman from the USA, first entered treatment at 13 years old, guided by her parents, and continued to seek treatment until she was in her late 40's. She describes how, up until her last therapy endeavor, she was trying to do what she had learned was expected of her as a patient, which was finding another treatment provider when yet another treatment had failed to make her feel better. Maggie expresses that it was the critical community that allowed her to reclaim a sense of self-worth after learning to doubt herself over the years in therapy. "The [critical community] saved my life. My therapist made me question my worth because how she treated me. Then I read the posts in this sub and realized I was ok." For Maggie, rejecting the normative treatment in favor of engaging with the critical community and finding other avenues to improve her situation was a way of reclaiming control of her own life. Essentially, Maggie expresses that she no longer wants to be governed in accordance with the psychiatric knowledge structure, and the dismissal of this is a form of *counter-conduct*. She describes how changing her behavior and outlook has led to an improvement in her overall disposition:

Therapy caused me to be suicidal. I'm not suicidal anymore and I'm finally my normal self. My life has improved dramatically. I sleep well and exercise. I made a personal commitment to never see a therapist. As long as I stay outside of the system then I am safe. My power belongs to me.

Like many informants, Maggie contrasts the 'pathologized' self with the 'normal' self, attaching a preference to the latter. The critical community adds another layer to this by expanding normalcy beyond having a 'normal' lifestyle to include describing adverse experiences within psychiatry and feeling justified in talking about maltreatment. Instead of

embracing the stigmatized identity of the sick person, the narrative is rewritten as reclaiming agency and power over one's life.

While Maggie took to the critical community in a relatively immediate manner, other informants describe a longer process of being exposed to different ideas. Laura, a 75-year-old woman from the USA, was fifteen when she first entered treatment. Ten years ago, she started to participate in an online community that for the most part held the normative view of therapy as benign, but which also had the occasional debate on whether this was an absolute truth. Laura describes how over time she was able to engage more with these ideas and read about other people's negative experiences and viewpoints. This helped her critically think about her own experiences and develop a different framework to understand them: "[...] the other people's ideas and experiences on the forum began to lead me to use my own (usually pretty good) thinking process to examine my therapy experience, too." For Laura, this process resulted in the acknowledgement that the help she needed didn't exist within any medical institution. Laura explains that "This community has allowed me to see myself as a human being and not a mental patient." Resisting the medicalized narrative allowed for Laura to finally recognize herself as equal to her peers, rather than seeing herself as maladjusted and *othered*.

The most important aspect of the community, as described by the informants, is the recognition and acknowledgement that it provides regarding their experiences of maltreatment. Clara, a 25-year-old woman from Germany, thinks that psychiatric treatment functions as a way of blaming societal problems on her as an individual, and feels that the treatment she received had nothing to do with making her feel better but only served to change her behaviors for the convenience of others. Even so, she found that she was doubting her experiences, because the societal message she received was that she needed to keep going to therapy and keep trying another therapist. Clara views the critical community as a place where her story could finally be heard and where she could find support to make choices in her own best interest, according to her gut feeling. She states: "I finally found validation that the things that happened to me were real, and that it's okay not to feel pressure to go to another therapist after being traumatized by therapy."

Similarly, Crystal, a 37-year-old woman from the USA, describes how the critical community helped her to learn to trust her own version of events:

I'm realizing that I'm not crazy for thinking that some of the things that I have been through were bad or in some cases abusive. I have also realized that so many years of gaslighting is why I question my judgment when I am treated badly.

For Crystal, who was institutionalized as a minor while in the care of the state as a foster child, trusting her own judgment would have been particularly challenging. Crystal spent her teenage years in therapeutic boarding schools and identifies as a victim of the Troubled Teen Industry (TTI), a phenomenon specific to the USA where for-profit treatment centers operate and focus on rehabilitating wayward teenagers. This industry has been massively criticized by survivors in the last couple of years, and several informants describe their injuries specifically in relation to this treatment setting. Crystal expresses that both her time in TTI and subsequent psychiatric treatments have resulted in a lack of trust in herself. However, engaging with critical voices within the critical community has helped her understand her background and acknowledge that she, and other children like her, suffered systemic trauma within the psychiatric system.

Thus, acknowledging the systemic effects of what happened to them has been important for the informants. They describe the significance of finding a forum where they can have their experiences recognized, and where it can be acknowledged that what happened to them is part of a greater picture rather than an anomalous experience. The critical community thus becomes a place for counter-conduct, something which goes beyond the counter-defined plausibility structure in the sense that it is an active resistance *against* the *power* of the institution of medicine. Charlotte describes how she started out thinking "my symptoms were so bizarre and disparate that I was the only person on the planet to have them - so why bother talking about it??" Finding a community with people who suffered similarly gave her a framework for understanding her symptoms and finding new avenues to treat them, as well as acknowledging herself as part of something bigger. Despite having been part of many other patient groups previously, it was joining this critical community that sparked an interest in advocacy and raising awareness for Charlotte, and she describes this as a very positive experience on both a social and personal level:

I have made friendships all over the world and have spoken on the phone to other sufferers who have also suffered for many years. I thought I'd never make friends with anyone again, but again, joining the PSSD community has allowed me to understand myself and others in a way I did not before.

For Charlotte, being part of the community not only entails recognizing the systemic issues that have resulted in harm; it also means actively working to make things better for fellow sufferers.

Tensions in the critical community often relate to ideological differences in terms of what the community should be and how critical one is. Rebecca, a 42-year-old woman from the USA, experiences the community she participates in as unnecessarily negative and reductive at times. While Rebecca feels that the psychiatric system is broken, she thinks there is room for more nuance when discussing treatments and potential outcomes:

I am not anti medicine so it bothers me when people on the forum ask lay doomsday and say that if you take medicine, you are going to be miserable for the rest of your life even if you get off the medicine.

Nonetheless, Rebecca appreciates the community as a place where others can relate to her experience and where she can find others who recognize the systemic issues which cause harm. Aaron, in contrast, describes psychiatry as "literally disgusting, which I know puts me on the extreme end of viewpoints". Aaron, a 31-year-old man from the USA, identifies as a psychiatric survivor and describes himself as very involved in these circles, as well as in Mad Pride and Mad Studies, so for Aaron, the critical community experience extends well beyond participating in an online forum. When asked about community experiences, he states: "The worst thing I experienced recently was within the psychiatric survivor community. Someone I thought was my best friend did not accept my antipsychiatry views." For Aaron, having his critical psychiatry-viewpoint accepted and reinforced by others is a necessity, and the inability for a friend and fellow survivor to do so thus becomes a dealbreaker.

While the cases of Aaron, Charlotte and Rebecca illustrate that there is internal disagreement in various communities regarding the extent of critical opinions, they also illustrate the deep need for recognition and belonging, and how the critical community is experienced as a place to have these needs met. Being bothered by disagreements underline this, as the diverging opinions can be understood as threatening to the counter-defined reality they have come to depend on. Many informants express having no social support for this alternative framework outside of the critical community, and even if they do, they describe that no one else can really understand what they have been through:

[...] is that I can only compare this community as to the soldiers who have been to war. People outside of this cohort will only see the romanticised or 'selected' version of psychiatry. It's like the difference between

watching Apocalypse Now at home on your sofa with some nice snacks, and actually having fought in Vietnam. At the end of the day there are no words or two-and-a-half hour movies or 30-second TikToks that will ever make someone outside of this understand. (Charlotte)

For the informants, the critical community - potential conflicts notwithstanding - is a safe space where their experiences won't be questioned and dismissed. It can be understood as a place where they might be inspired to reclaim a lost sense of agency over potential treatment choices and health behaviors, and it can spur political activism. Even if outsiders are sympathetic, which is far from always the case, the ability to be oneself within the community, and to (perhaps temporarily) shed the *primary* view of themselves as diseased and disordered, is something that is highly valued. This also illustrates how even if the informants attempt to shed the pathologized identity, the pervasiveness of medicalization remains; resulting in the need for a context where this viewpoint is actively rejected in interactions.

The critical community thus serves an important function for the informants in relation to the social aspect of iatrogenic injury, because the experience of acquiring injury is shaped by the social interaction, and so is the aftermath. Participating in critical communities is experienced in relation to the injury sustained, and the social acknowledgement of the community not only interconnects with the way the informants understand their experiences of suffering injury, but it also helps illuminate the socially injurious aspects of treatment that the informants struggle with. Consequently, the critical community can be understood to function as a way for the informants to work together to re-humanize themselves in relation to the non-subjectification they experienced from the psychiatric system, something which becomes all the more important when they have been made responsible for the injurious outcomes of these treatments.

Since the 1990's, support groups that focus on self-help and activism have flourished on the internet, with people sharing information and offering emotional support, going from consumers of health to producers of information, thus opening up for the potential to challenge medical dominance (Lupton, 2012:132). The counter-defined, alternative plausibility structure for understanding 'mental illness' that the informants are exposed to and themselves produce offer a different kind of reality which for the individual informant can be experienced as life-changing. In relation to this, the critical communities represent a resistance – an expression of counter-conduct – against the governance of psychiatry and against the plausibility structures of psychiatry as an institution. These communities can be understood as a resistance project

that develops in relation to how the informants, as patients, are *labeled* and *othered* and, in relation to this, stigmatized. The community gives them a framework and space to renegotiate the stigma of being seen as less reliable, as responsible for the wrongdoings of the psychiatric system and so on. Instead of being pathologized when they tell their stories, the community offers a narrative of being a group who has "peeked behind the curtain" and realized that the common-sense narrative of psychiatry is an illusion. This positions the informants as a group of people who have insider knowledge that others lack. In terms of counter-defined identities, the informants can transform themselves from being sick, from being an unreliable narrator, from being a non-subject, and so on, to being wise, perceptive whistle-blowers who are, within the context, *normal people*. This not only offers a different plausibility structure but also the recognition from a community where they can be regarded as equals status-wise. In short, the community offers an alternative version of reality that fits with the informants' experiences.

The critical community can thus be understood as a resistance project in terms of fighting epistemic injustice and re-politicizing suffering via counter-conduct, but it doesn't necessarily need to be understood as thoroughly critical of *all* aspects of psychiatric and psychological discourse, rather it seems that the informants carefully select for the theories and conceptualizations of suffering that are meaningful to their own experience and context. For many, the resistance does encompass the desire for the complete destruction of psychiatry, but more important is the need for recognition of its limitations and consequences. The fact that many informants are physiologically injured further complicates the experience, because they do desire a cure for the iatrogenic injuries they sustained, and they are aware that such cures would be developed in accordance with the same system that harmed them. Similarly, the discourse surrounding injury often reproduces a medicalized discourse, with the trauma they sustained being conceptualized as akin to disorder. This illustrates the complexity in the phenomenon that is iatrogenic injury, and how it is experienced on a somatic, emotional, and social level alike.

# **Conclusions and Discussion**

The results of this thesis illustrate that the informants describe and experience injury as something relational. In this study, the experience of iatrogenic injury and the relationship between the informant and psychiatry has been showed to be intertwined, as the informants describe how being afflicted with injury results in losing trust in the psychiatric system. Injury is described in relation to social interactions with treatment providers, where some social aspects of the treatment process are experienced as injurious, such as being reduced to a nonsubject by having one's bodily integrity violated, being treated like a child or having one's experience reduced to pathology. Furthermore, injury is experienced in relation to forced treatment, where the informant doesn't have a say in how the treatment plays out, or as betrayal, where the informants express that they were not given adequate information to consent to treatment or were manipulated into consenting. Consequently, although iatrogenic injury is often described in clinical terms, something the informants also partake in by utilizing labels such as PSSD or PTSD, these afflictions are understood by the informants in a social context. The development of such disorders is connected to the experience of having the true nature of psychiatric treatments concealed from them, which in turn affects the informants' ability to trust the psychiatric system. Thus, when social-emotional injury occurs, trust suffers, and this lack of trust can be further cemented when there is a lack of accountability on part of the psychiatric system pertaining to acknowledging such injury. Similarly, this too applies to clinical injuries, where the lack of acknowledgment also encompasses the lack of available cures for clinical iatrogenic disorders.

For the informants, this dynamic also results in a lack of trust in their own ability to define and interpret their experiences. This lack of self-reliance has been expressed in relation to how the informants describe the representatives of the psychiatric system as having been given the mandate to define their experiences, and the informants subsequently describe their relationship with psychiatry as contentious. The critical community seems to help the informants recover some trust in themselves to a certain extent, by sharing their stories and having their experience recognized. However, the opposite enforcement seems to occur regarding the lack of trust in the psychiatric system, where the critical community instead emphasizes the informants' understanding of psychiatry as something that needs to be approached with caution. The informants thus describe the psychiatric system as untrustworthy to various extents, ranging from the need to pre-emptively research treatments to avoid being injured, to seeing it as inherently threatening to their freedom and agency.

This thesis illustrates that this progression, where most informants go from trusting psychiatry as a medical institution to losing trust in it based on the experience of injury, transcends continental boundaries. There is a remarkable similarity in the narratives put forward by the informants, considering their heterogenous backgrounds. This might be a consequence of the online communities, where certain structures of understanding injury may be dominant, but it may also point towards the experience of injury within the psychiatric system being, in broad terms, generally similar across countries. Examining this relationship further would be an interesting venue for future research.

Apropos, the theoretical framework of this thesis considered the *social* processes of institutionalization, arguing that reality becomes institutionalized by the practices and meaning making of individuals in society (Berger & Luckmann, 1966). For Berger and Luckmann, the 'leper colony', which represents the *othered* community that constructs its own counter-reality, consists of the stigmatized individuals within a specific society and its cultural context. In this thesis, the 'leper colony' is not local but global; the informants do *not* hail from one society that shares cultural contexts nor institutions. Nonetheless, they have congregated and established their own counter-reality, where their narratives and expressions of this reality largely resonate with one another while rejecting the normative understanding of psychiatry, psychiatric practices and mental illness; not only in their respective social, cultural contexts but also in relation to other online mental health communities. There exists a point of commonality here that allows for the internalization and habitualization of such a structure that enables the informants to shape and grow this community to the point of producing new realities and identities that are meaningful for them, despite the heterogeneity in terms of origin and subsequent enmeshments of systems and institutions.

This connects with the conceptualizations of resistance and the patient's perspective on the knowledge and practices of medicine (e.g., Bradby, 2009; Lupton, 2012). Here, we see a patient group that rejects the hegemonic knowledge of psychiatric medicine, and collectively form a community that challenges the established narrative in different ways. The platform itself becomes important in this process (Lupton, 2012:132), as do the rhetorical strategies the informants employ to express resistance. For instance, how informants like Kyle and Megan utilize the analogy of sexual assault is a political action that attempts to delegitimize the medicalized narrative, and in particular the narrative of medicine as based on altruistic ideals. This adds to the understanding of how resistance against medical power draws on contemporary cultural understandings (Lupton, 2012) by connecting with trending discourse

in the aftermath of the global, survivor-led 'Me Too' movement. Furthermore, this also follows the argument of Ashe (2021:256), in that there exists an experience of there being a difference between non-intentional, systemic violence, and actively destructive, agentic violence that is directed towards the individual but nonetheless rendered 'good'.

In line with Giddens's (1990:90) assertations of trust in institutions and expert knowledge, this further illustrates that personal, unfortunate experiences with professionals can cause an erosion of trust in the insitution. This poses the question of whether something like forced treatment can be executed in a manner that does not cause such a rift; is it possible to uphold trust in a situation where the individual is in emotional crisis and will subsequently be having their agency limited and their bodily integrity violated? Similarly, it begs the question if it is possible to craft a patient-provider relationship where the agency and the subjective needs and experiences of the individual are centered when treatment is forced or when the individual experiences coercion by deception, and likewise how such a feat can be accomplished if the individual does not have the opportunity to understand the full scope of the risks of treatment. As such, the results of this study not only invoke questions about the relationship between forced treatment and trust in institutions, but also the relationship between agency, informed consent and harm in medicine, all of which speak to larger discussions within medical sociology on how healthcare should be structured (e.g., Lupton, 2012).

Furthermore, regarding Giddens's (1990:90-91) argument that lay people need to have access to expert knowledge to themselves handle situations that require such knowledge, this thesis presents a perspective where expert knowledge is not necessarily easily defined. Normatively, the understanding of expert knowledge in this context is the psychiatric and psychological expertise of treatment providers. In this study, the informants illustrate the ability to not only appropriate this knowledge but also question it. Here, informants lay claim to having *more* knowledge than their individual treatment providers, especially pertaining to issues of the efficacy of psychopharmaceutical treatments, but also regarding therapy modalities and the intersections of structural oppression. Importantly, what they argue resonates with what has been posited in the field of critical psychiatry studies (e.g., Healy, 2004), meaning that the informants go beyond having appropriated the expert knowledge of their treatment providers and move on to deconstruct these expert claims, ending up questioning its legitimacy and practices.

As this thesis departed from an ontological and epistemological perspective that was strongly influenced by critical psychiatry studies, which shaped the data collection and the analytical proceedings, the results have largely resonated with the previous research in this field. Importantly, this study illustrates how the informants themselves attempt to shed the psychiatric, biomedicalized narrative that they have been forced to understand themselves through (Illich, 1976). Instead, they discuss their experiences with a certain analytical distance that allows them to produce critical explanations for how they got injured. An interesting thing pertaining to this process is that the informants still often utilize the narrative offered by the psychiatric system and renegotiate it and reframe it, meaning that they do not necessarily fully reject the medicalized discourse but alter it to fit their own experiences. This can be seen in how informants like Laura and Joy attribute their psychological and behavioral issues that resulted in them first receiving psychiatric treatment to previous experiences of trauma. This lets them draw on psychiatric discourse not only to explain their experiences, but also to criticize psychiatric practices. This is especially poignant with the informants who describe having received extensive interventions in the form of therapy, where it becomes apparent that they have learned to use the therapeutic language to examine their own experiences, but also the practices of the treatment providers. Thus, one interesting thing this study illustrates is that the informants in a sense renegotiate and simultaneously deconstruct their own experiences. Compared to critical psychiatry researchers like Rose (2019), who theorizes social adversity disorders as structural issues by utilizing the perspective of the researcher outside the psychiatric system, the informants, on the other hand, are utilizing a meaning making scheme from within psychiatry, but they alter it according to their experiences and utilize it for a purpose which suits them. In a sense, they flip the script on the psychiatric discourse by utilizing it both to understand themselves and their experiences while simultaneously delegitimizing the very system they are drawing upon.

Illich (1976:6-9,54) posits that iatrogenesis occurs as a consequence of medical intervention, because society has become dependent on medicine, which is an overarching power that prevents healing outside of the medical system. The results of this thesis resonates with this argument, in that the informants have been looking for answers within the medical system and often found themselves in a reoccurring cycle of being injured. On a group level, in their reaction to the injuries and lack of accountability they have faced, however, many have eventually constructed an attempt to remove themselves from this setting and find alternative ways of healing that do occur outside the medical system, reminiscent of the self-care that Illich

proposes could dismantle the dominance of medicalized medicine. This is not an argument that the informants are even in the vicinity of accomplishing this, nor is it an argument that they have placed themselves outside psychiatric, medicalized discourse. It does illustrate, however, that the informants of this study have constructed alternative paths to healing that do occur outside of the medical system to a great extent, and that those who still interact with psychiaitry actively shape their practices and environment in a way to avoid further injury. Consequently, while the conceptualization of iatrogenesis as a societal problem (Illich, 1976) aligns with this thesis, this particular patient group is actively producing their own, personal way of dealing with illness and suffering that contradicts the medicalized discourse, even if they cannot exit a medicalized society. This adds to the understanding of the complexity of how de-medicalizing projects may occur. Similarly, it illustrates how peer support and patient resistance can take place without face-to-face interactions, expanding on questions of power and patient resistance to encompass the understandings of what a de-medicalization process might look like for this specific social group. Furthermore, it connects de-medicalization with the act of resistance towards this particular form of being governed (Foucault, 2007), which resonates with the general perspective within critical theories, that sees resistance as a bottom-to-top project developed by grassroots movements (e.g., Costa et al., 2012, see also Collins, 2015).

The theoretical framework of this thesis draws heavily on the psychiatric and psychological framing of mental illness as something which obfuscates reasons for suffering and struggles rather than alleviating the suffering (Rose, 2019:185-186). The lack of accountability and the lack of recognition that the informants experience underlines and illuminates this process of obfuscation, but it also adds to the understanding of how medical trauma can be part of the conditions that create suffering. For many of the informants, the iatrogenic injury they have sustained *is* their primary trauma, rather than the issue which prompted them to seek treatment, which expands on the understanding of 'mental illness' as something that obfuscates societal reasons for suffering to it *being* the cause for suffering. This, in turn resonates with the theories on iatrogenesis that Illich (1976) and Ashe (2021) put forward, where iatrogenesis is the outcome of medicalization, because as informants like Jade and Kyle state, being harmed leads to an impasse. As such, this thesis expands on the understanding of 'social adversity disorders' (Rose, 2019) in that adversity can be brought on *by* the medical system, something which complicates further interactions with this system for those afflicted.

One important limitation of this study is that it lacks the ability to adequately contextualize each informants' experience, which is a consequence of using a qualitative survey that couldn't

capture the complexity of interacting institutions and systems. Similarly, the sample selection poses a limitation on this study in that selecting for individuals with critical views undoubtably skewed the results in a critical direction. However, while the informants cannot be argued to be representatives of a generalized group of people who seek mental health treatment, their experiences might nonetheless invite to consider to what extent these experiences occur amongst other patient groups within psychiatry, who don't subscribe to identities such as 'survivors' or 'critical'. Importantly, most of the informants did not start out with critical views. Thus, in relation to previous research that posits that labeling can have negative consequences (Horley, 2011; O'Connell, 2023, Szasz, 1977), that there is a power imbalance between treatment provider and patient that might cause harm (Gosselin, 2019), that epistemic injustice can be a problem in medicine (Ashe, 2021; Gosselin, 2019) and that there is a lack of openness about the limitations of psychiatry (Dixon & Richter, 2018), and so on, future research might benefit from attempting to outline how common the experience of injury and trauma sustained within psychiatric treatment might be. This could be important, because it poses significant questions about the benefits and drawbacks of utilizing psychiatric treatment as a catch-all option for the many different versions of suffering described in this study. As it is, it seems that the psychiatric system is faced with the task of solving any problem that concerns individual, emotional suffering, and we might ask whether this is possible to accomplish, or even desired. Going back to the conceptualization of 'social adversity disorders' (Rose, 2019) and connecting it with the results of this study, where the informants express that the adversity they have experienced has been overlooked or disregarded in favor of psychopharmaceutical treatment or behavior modification, points to the necessity in questioning the boundaries between psychiatry and other societal institutions. As well, it provokes the question of whether the psychiatric paradigm is gainful for understanding emotional suffering, and what can be done when the suffering is caused by the very institution that is supposed to help.

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## **Appendix**

Page 1

## Master Thesis Research Study about Traumatic Experiences and Injury caused by Psychiatry

Uppsala University, SwedenThe Department of Sociology

You are invited to participate in my master thesis research study about traumatic experiences in relation to psychiatric treatment and its real-life implications for the survivor, based on your (active or 'lurking') participation in a community which critically discusses (aspects of) psychiatric treatment. The aim of the study is to learn more about the experiences among individuals interacting in these communities, and the results could possibly be utilized to raise awareness about the problems of injury and psychiatric treatment. Participation in this master thesis research study will consist of you answering a qualitative survey containing ten questions about your experiences with psychiatry, all of which are open-ended. Your participation in this study is voluntary. You remain anonymous, and since no personal information will be collected, participants will not be able to withdraw from the study once their answers have been submitted. The data will be securely stored on an encrypted, external hard drive, and only the student researcher and the faculty advisor will have access to the data material. The material will be analyzed and the results made public in the form of a master thesis at the Department of Sociology at Uppsala University. Any potentially identifying information will be anonymized before the analysis is conducted, and the subsequent master thesis publication will not contain any identifying information. All original data will be permanently deleted once the results are published.

If you have any questions or would like additional information to assist you in reaching a decision about your participation, please contact me (Amelia) at the e-mail listed below. Best, Amelia Johansson-Everday, master student

Master Student

Amelia Johansson-Everdayamelia.johansson-everday.4712@student.uu.se Faculty SupervisorFredrik Palmfredrik.k.palm@uu.se

Please note that this study contains potentially sensitive questions. Caution is thus advised. If you do not have sufficient support, or consider yourself to be in a vulnerable state of mind, you should not partake in this survey.

By submitting the answers I consent to the following:	○ Yes ○ No
Throughout the duration of the project, the data material will be stored on an external, encrypted hard drive which is securely stored and only accessible to the master student and the faculty advisor. Once the results are published, all data will be permanently deleted. The data material will be thoroughly anonymized and subsequently analyzed as part of this specific project. The results of the analysis will be published in the form of a master thesis at Uppsala University. Since no personal information is collected for this specific project, participants will not be able to withdraw from the study once their answers have been submitted.	O NO
Please state your location (country)	
Please state your age	
Please state your gender	
How did you feel before you first encountered psychiatry? How would you describe your state of mind?	
Describe one or several defining moments in your encounters with the psychiatric system	

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How did the moment(s) you described above relate to your expectations of the kind of care/treatment you were expecting to receive?	
Describe your experience in being able to influence the treatment(s) you received	
Do you have any health issues which you link to psychiatric treatment?	
Describe your experiences with other societal institutions in relation to your experiences within psychiatry Examples of such institutions are law enforcement, the healthcare system beyond psychiatry, the educational system	
There appears to be a discrepancy between the way people posting in this community experience psychiatry, as compared to how people outside of this context understand psychiatry and its treatments. Is this something you have experienced yourself? If so, describe	
Describe how this community has influenced how you understand yourself and how you understand psychiatry	
How is your life today? How do you see yourself in the future?	
Is there anything you would like to add that you feel is important to understanding your experiences of psychiatric maltreatment?	

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