A BODY IN DISSONANCE: YOUNG WOEMN NAVIAGTING MENTAL HEALTH AND LIVING WITH DEPRESSION IN CAPE TOWN

by

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DECLARATION

I, ………*Simone Oosthuizen*………………………., hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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ABSTRACT

This dissertation investigates the experiences of young womxn diagnosed and living with depression in Cape Town. The investigation focuses on the relationship between the young womxn and their bodies as they live with depression and move through depressive episodes. The ethnographic findings expand on the dissociative - depersonalization and derealization- symptoms of depression. Secondly, the investigation focuses on problematizing the theoretical construct of the body. These young womxn experienced their bodies beyond subject/object, internal/external, body/mind dichotomies. The dissertation frames the ethnographic findings with a phenomenological lens. Additionally, the dissertation uses a sensory gaze to understand the young womxn's bodily experiences and experiences with depression.

CHAPTER ONE

An individual walks out the psychiatrist's office in Cape Town with a diagnosis of depression, the hope to attain some form of 'better', and a plan for treatment, but the patient has to live within this pursuit of 'better'. A tick box for a diagnosis never really captures the complexity of the experience it symbolically wants to demarcate in its four joint lines. After being diagnosed with depression, the individual becomes a part of the mental health community and begins to manoeuvre through the various treatments available to attain health. Within this community, the concept of 'better' circulates and indicates a much larger system at work underneath. "I want to get better". "Will I ever get better"? "Hopefully 'x' will make me feel better". "I don't think it is about getting better". These statements of 'better' and betterment became the entry point for inquiry into this dissertation.

The initial research question surfaced of how did 'better' arise and unfold in the experiences of people living with depression. This 'better' translated into seeking certain forms of treatment and it kept surfacing around a particular depiction of health and illness narrative of depression. 'Better' became indicative of a patient's health journey, a reference to a biomedical health narrative, and a method of undergoing treatment. In contradiction, my participants moved away from the notion of 'better' during their experiences. Rather, they moved towards notions of well-being, management, and "*making the best of it"*. It was during this shift towards well-being that I began to notice a method of navigating health and treatment by my participants who were diagnosed with depression. They first encountered a biopsychosocial model of medical understanding of health. Their treatments methods were predominantly made up of psychiatrists, psychiatric medication, psychiatric hospitalization, psychologists and the accompanying psychotherapy. However through letting go of 'better' and shifting towards different health goals, my participants explored complementary treatments to ascertain their well-being. In addition to the aforementioned treatments of the biopsychosocial model, my participants approached homeopaths, massage therapists, acupuncturists, dietitians, and other alternative medical practitioners. This included exploring various complementary treatments both in the biopsychosocial model and in alternative/complementary medical systems.

While researching into 'better' and my participants' treatments for depression, I began to focus on the relationship my participants had with their bodies, their navigation of a depressed body, and the correlation with their choice of treatment. In order to aid my focused inquiry, I began to ask a series of questions:

1. What are their understandings of their body with depression?
2. What are their bodily experiences of depression?
3. How does the relationship with their body change with receiving a diagnosis of depression?
4. How do their bodily experiences change their definitions of health and health goals?
5. How do my participants navigate their body to gain well-being?
6. How do my participants navigate their choice of treatments?
7. Why do my participants choose a particular form of treatment?
8. How does bodily awareness play a role in their healing?

My investigation into 'better' led to the inquiry into my participants' navigation of a depressed body. In addition to this inquiry, I began to ask why this bodily awareness and bodily navigation was significant in the context of Western Cape mental health services. Firstly, my participants state that their experiences highlight the limitations of the mental health services in South Africa. The mental healthcare services were largely unsupportive, expensive, and fragmented. It was their responsibility to navigate this medical system, identify what treatments they needed, and find the appropriate medical professional.

Secondly, my participants advocated for attaining well-being through an interdisciplinary and medically plural manner. My participants found that the biopsychosocial model and its treatments had a limited understanding and approach to mental illness. It was limited to the mind, the cognition, the brain and the neuro-chemicals of the mentally ill patient.

My participants sought out, or were advised by mental health practitioners to seek out, complementary and alternative forms of treatment and healers to address the other aspects of mental illness that fell outside the biomedical purview of mental illness. In practice, both patients and practitioners branch outside out the biomedical and biopsychosocial approach to mental illness. This presented an opportunity to have a more expansive understanding of health and body that is defined by the patients themselves, which helped the patients attain well-being.

1.1. SOUTH AFRICA’S MENTAL HEALTH LANDSCAPE

In a post-apartheid South Africa, there have been two key legislative reforms in regards to mental health policy. In 2004, the Mental Health Care Act (No 17 of 2002) proposed the introduction of mental health care into general health care services, the development of community-based mental health services, and mental health regulation (Department of Health, 2013; Szabo and Kaliski, 2017). In addition, the South African government amended health care legislation to reflect the progressive principles, from the newly adopted constitution, by acknowledging the human rights and patient rights for those with mental illness (Department of Health, 2013).

The Mental Health Care Act (No 17 of 2002), aside from consulting stakeholders, was built upon the World Health Organization’s (WHO) ten principles guiding mental healthcare law (World Health Organization, 1996; Szabo and Kaliski, 2017). WHO sets out ten basic mental health principles for the protection of persons with mental illness and the implementation of improved mental health care : 1.) promotion of mental health and prevention of mental disorders; 2.) access to basic mental health care; 3.) mental health assessments in accordance with internationally accepted principles; 4.) provision of the least restrictive type of mental health care; 5.) self-determination; 6.) right to be assisted in the exercise of self-determination; 7.) availability of review procedure; 8.) automatic periodical review mechanism; 9.) qualified decision-maker; and 10.) respect of the rule of law (World Health Organization, 1996). However, South Africa’s Mental Health Care Act (No 17 of 2002) constructs an ideal that relies on infrastructure, medical systems, medical services, and medical staff to be implemented. The Mental Health Care Act (2002) presumes a functioning primary healthcare clinic, with a trained practitioner, a functional psychiatric unit, with the necessary facilities, staffing, and access to medication (Szabo and Kaliski, 2017). There is a gap between the ideal and the current mental health context for South Africans struggling with mental illness. The National Mental Health Policy Framework and Strategic Plan 2013-2020 was introduced to bridge the gap between the reality of mental health service in South Africa and the Constitutionally enshrined mental health rights (Department of Health, 2013). The South African government aimed to make accessible, provide, and fund essential health care to the country and the affected community (Department of Health, 2013). They consulted the mental health workforce – nurses, psychiatrists, psychologists- amongst other stakeholders such as the patients and policy makers in constructing this strategic plan (Sukeri, 2017).

While the WHO’s ten principles have been enshrined into South African legislation, it does not translate into practical application of the public health system, in particular into the systems of care for mental illness. There is a large disparity between our legislation and our practice. In our legislation, we constitutionally have a coveted stance on human rights, but the reality and the practicalities is that the majority of South African citizens live in conditions that violate their human rights (Tarantola et al, 2009). The lack of practical implementation of mental health rights around mental health is not an exception to this. While South Africa has constructed the National Mental Health Policy Framework and Strategic Plan, the application and approach thereof has been fragmented, under-funded, under-resourced and the practical implementation fails to provide comprehensive mental health care to the majority of South Africans (Daniels, 2018). Mental health services are a low priority in relation to medical care more generally. There is an insufficiency of mental health care services. This detrimentally affects South Africans in lower income groups, or unstable socio-economic positions, who cannot afford private mental health care; rural communities who have to overcome geographical barriers to access healthcare; women and children who are experiencing interpersonal and gender-based violence; and people of colour who are experiencing racial discrimination (Daniels, 2018; Lund et al , 2010, 2011, 2012) .

South African Mental health services are characterized by a low service delivery of mental health care and insufficiency of mental health care professionals (Lund et al, 2011). However, the highest mental health service provision is in the Western Cape. The Western Cape has the largest number of mental health non-profit organizations and three psychiatric hospitals based in the area (Daniels, 2018). The lowest provision of mental health services are in rural areas, which reflect the geographic distribution of mental health services. Daniels’s (2018) research shows that 82.6% of mental health services are located in urban areas, which is followed by 10% in peri-urban areas and 9% in rural areas. Aside from this, there is an overall shortage of mental health practitioners and those that do practice are often integrated into the private sector. South Africa has a shortage of mental health human resources, where there is less than one psychiatrist for every 100 000 people (Docrat et al, 2019). Due to the under-resourced mental health care services, three out of four individuals with a [1]DSM-5 diagnosis, regardless of severity, have not received mental health care in the 12 months following a diagnosis (Williams et al, 2008). There is an overwhelming consensus by mental health professionals and mental health patients that mental health services are under resourced (Daniels, 2018). Daniels (2018) found that more hospital beds were needed for in-patients. The call for more beds has been called for in order to address the availability of mental health services. Furthermore, this call for more bed were for patients to be able to have access to mental health services when needed. Additionally, out-patients found that medication provision was inconsistent from pharmacies (Daniels, 2018). A pharmacy might provide a portion of the necessary medication or be out of stock. Mental health patients would need to go to other pharmacies or hospitals to get their prescription. Or, they would need to get the second portion of their prescription that is if there was medication available. In rural areas or areas with less access to health care facilities, this becomes a barrier for mental health patients to access treatment (Daniels, 2018; Mkhize & Kometsi, 2008).

Despite its high morbidity, mental health care services are a low priority and it is routinely under-funded and under-resourced (Department of Health, 2013; Buchanan, 2019; Jacobs and Coetzee, 2018). In practice, South Africa has a reactive model to address the mental health crisis. Mental health disorders are ranked as the third biggest burden on the public health system after Tuberculosis, HIV/AIDS, and other infectious diseases (Department of Health, 2013). South Africa allocates 5% of its overall public health budget to mental health, which leaves the infrastructure and processes underfunded (Docrat et al,2019). Thereafter, 42% of the mental health budget is spent on psychiatric institutions. It is a hospice-centred approach, where funding goes towards patients admitted into state funded hospitals. This reactive approach is a short-term solution to address the lack of resources, human expertise, and infrastructure needed to address mental health in South Africa. It has been shown that nearly a quarter of patients, or one in every four patients, are readmitted within three months of their previous admission from a state hospital. As a result, in-patient care is the primary focus of care for people suffering with mental disorders or mental illness (Docrat et al, 2019). The outcome is that the medication and treatments necessary for patients are unavailable outside of hospitalization, unless they have the medical aid or financial ability to pay for it.

The fragmented, under-funded, and under-resourced mental health care services are further compounded by poverty, adverse living conditions, and South Africa’s social inequality. Mental illness has multiple biological, psychological and social determinants, but

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[1] The DSM-5 is the psychiatric handbook used by medical professionals, or “trained clinicians” for classifying and diagnosing mental illness (American Psychiatric Association, 2013).

evidence shows that mental illness and mental health is in a cyclical dynamic with a person's socio-economic context. Mental illness has a higher prevalence in middle-lower income groups (Matlala et al, 2018). In particular, mental illness interacts in a negative cycle with poverty (Department of Health, 2013; Lund et al. 2011; Mkhize and Kometsi 2008). This cycle illustrates that individuals with mental illness have a higher likelihood of drifting into poverty, because of factors such as the inability to keep a job, or work-place discrimination (Department of Health, 2013; Lund et al, 2011). In addition, these cyclical patterns show that those who live in poverty are at a higher risk of mental illness, because of socio-economic instability and the exposure to adverse living conditions (Lund et al, 2011). It was found that the socio-economic determinants, or factors, of mental illness include income, housing, stress, childhood experiences, job satisfaction, social exclusion, education level, sanitation, social support, and lack of access to resources (Department of Health, 2013; Matlala et al, 2018). Aside from these factors, South Africa is especially at a higher risk due to the Apartheid legacy of structural, resource, economic, and racial discrimination. During Apartheid, there was a segregation of people and an unequal distribution of resources between these groups. This systematic discrimination on the grounds of race was heavily and violently enforced. The racialized social policies of Apartheid and the political violence created a context and system that fosters a reproduction of inequality and mental illness (Dawes, 1990). As a result in a post-Apartheid South Africa, mental illness disproportionality materializes along these discriminatory categories (Daniels, 2018). It also reflects the distribution and whom has access to mental health care and mental health services (Daniels, 2018; Tarantola et al, 2009).

Mental illness has a higher prevalence with those that are living in adverse living circumstances, those experienced childhood trauma, minority groups, LGBTQ+, and women (Department of Health, 2013; Williams et al, 2008; Lund et al, 2010, 2011, 2012; Das-Munshi et al, 2016). There is a higher prevalence of depression in women than men, in those who identify as LGBTQ+, in middle-lower education levels, in higher unemployment rate (Tomlinson et al, 2009; Williams et al, 2008). In a study with adolescents in Cape Town, it was found that mental health inequalities have been associated with material disadvantage and self-identification with historically disadvantaged groups (Das-Munshi et al, 2016; Lund et al 2010, 2011, 2012). Racial and ethnic inequalities remain interwoven with material inequalities within a post-Apartheid South Africa (Das-Munshi et al, 2016). This situation is further complicated by a high prevalence of violence, predominately inter-personal and gender-based violence and neglect. Lastly, studies have found that childhood adversity has been associated with mood disorders, Post-traumatic Stress Disorder (PTSD), Major Depressive Disorder (Department of Health, 2013). In contrast, mental health is protected by a safe, supportive and stimulating childhood environment. Additionally, mental health is protected by having opportunities for learning, work and fulfilling social roles.

1.2. CHOOSING A SAMPLE GROUP

This research inquiry situated itself within a biomedical and a biopsychosocial model. I engage focus on the bodily fields of patients, who have gone and continue to go through medical systems, the psychiatric field, and various treatments for depression in Cape Town. However, mental health intersects with race, class, medical access, medical insurance, mental health resources, and geographical location. Thus, there was a requirement for further stipulation as to the determinants of my participants and their experiences. This research inquiry focused on five participants whom could be classified as young womxn, ranging from the age of eighteen to thirty, who have been diagnosed with depression and have sought treatment with the aid of medical insurance. In addition, the participants that I chose to include into the study had an active support network. The aim behind these qualifiers was to centralize care within the research approach and framework as an ethical requirement.

1.2.1. DIAGNOSED DEPRESSION

My participants were comprised of individuals who had been diagnosed with depression by the criteria of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). These individuals had sought, or continue to seek, 'treatment' for their depression. The DSM-5 is the psychiatric handbook used by medical professionals for diagnosing mental illness, particularly in diagnosing depression (American Psychiatric Association, 2013). The choice of using the DSM-5's criteria is purposeful as it situates the participants within the biopsychosocial model that is the hegemonic medical model used to understand mental illness.

1.2.2. ACTIVE SUPPORT NETWORK

I insisted on participants having an active support network in place. This active support network was defined by the participant's preferences which included, but was not limited to, an active relationship with a psychologist, a support group, online websites, personal relationships, and/or a psychiatrist. The reasoning behind this choice was to ensure that there was a system of care in place for participants. My secondary aim was to ensure an element of care for the maintenance of well-being during the research process. Alongside this element of care, it would have been unethical for me to play the role of a care-giver, especially as I am not a medical professional nor trained as a care-giver. This qualifier became necessary, during the research phase, as one participant had to withdraw from the research when they became mentally unwell. I felt that it was my ethical duty to act on the principle of care to make sure they received the medical treatment they needed and remove them from the research.

1.2.3. SEEKING TREATMENT WITH MEDICAL AID

The third qualifier was designed to help situate the research focus in order to examine 'better' that occurred with or alongside the seeking of treatment for depression. Therefore, the sample group was comprised of individuals who had been diagnosed with depression and had sought 'treatment' for depression. A diagnosis of depression is often accompanied with a prescription for psychiatric medication, a recommendation to a psychologist, and/or instructions to make 'life changes'. However, the qualifier of seeking treatment was broadened to mean various forms of treatment from a variety of medical models rather than those within the biopsychosocial model. Due to my own privilege, I found that the mental health community, to which I had access, were medically insured and were able to access private mental health facilities. My participants were heavily reliant on medical aid, or their hospital plan, to help them get the health care and treatments that they needed. Thus, this became a criteria for selection for the research proposal.

1.2.4. YOUNG WOMXN

The sample group as it stands has the parameters of including depression, active support networks, and participation in treatments with medical aid. The research design further filtered its sample group by focusing on young adults.

Identities do not exist in a separate realm from illness narratives, social and medical systems, and the pursuit of 'better'. As Scheper-Hughes and Lock (1987) have effectively argued, bodies are not the same everywhere and they do not experience realities similarly. Identities, societal markers of difference, have an impact on biology, sociality, and experiences of the medical, political and economic systems (Scheper-Hughes and Lock, 1987). A child's experience of depression and framework for dealing with depression can be different from a middle-aged person. Similarly, a full time student's depression and experiences of depression can differ from a job-situated person's depression and experiences. Class, economic means, physical location, ideological orientation, gender, and race are a few of the identities and experiential 'realities' that play a role in shaping our understanding and how we subjectively experience the world. Thus, these factors did play a role in the experience of ‘better’ and treatment.

As identities are not mutually exclusive or apolitical, my positionality and identity was a determinate factor in choosing my sample group. I am white, female presenting, with a middle to upper class background and the financial history or privilege that follows. At the same time, I have had access to the mental health community from my personal experiences. I am a postgraduate student who has built a mental health network and has access to ‘depressed’ young adults. These young adults are moving out of the school environment, at university, or have entered the corporate environment. Thus, young adults in the mental health community are those to whom I have access.

Initially, the research did not intend on having a gendered aspect to the sample group. The research design intended on involving participants across the gender spectrum. While there were two cismen briefly interviewed, the in-depth, semi-structured interviews were solely done with womxn. Thereafter, I continued my research into the bodily experiences of these young womxn as they navigated depression within the context of Cape Town. Therefore, my research came to include a gendered aspect.

1.3. METHODOLOGY

The research design was made up of three components. The first component was approaching participants. The second component was comprised of composed of semi-structured interviews that will be needed to obtain the data required for the research focus. The third component facilitated the emergence of data through focus groups.

The approaching of participants had been carefully considered and two approaches were selected for this research design. Firstly, I approached my social networks that I have established within my own navigation of mental health community, depression and treatment. Thereafter, I used a snowballing effect where my contacts reached out to contacts they knew, whom had been diagnosed with depression.

Initially, I was hesitant to use, or mechanize, my familiar social networks dealing with mental illness. However, the research focus was mainly inspired by conversations occurring within my social network. Also, my personal social network had expressed interested in continuing these conversations for further investigation. Secondly, I reached out along my familiar social networks to their mutual acquaintances for participants willing to participate in my research. Thereafter, I held consultations with potential participants. The consultations were the initiation of contact between the researcher and participant, where the research project and consent were discussed. This step was vital in establishing a prior ethical conduct and constructing a safe space.

I incorporated two data gathering tools for this ethnography. The first aspect to the research design were the semi-structured interviews. The interviews were conducted in a qualitative and semi-structured manner. The interviews were designed to be conversational, or with semi-structured questions and the usage of prompts. My participants were recorded during interviews as I took field notes. However, the majority of my data and understanding came from ‘off the record’ conversations.

The second data gathering tool used in this research design were a series of focus groups. These focus groups were held with my participants, or with those that they brought into the space for an interview. At one interview, Ginny brought a Maria to an interview. This became a regular focus group, where I held a group discussion amongst the three of us. Initially, I aimed to make my focus group number between three to six people, but I found it more conducive to hold a focus group with two to three individuals. This allowed each member to contribute and the contributions to stimulate new thoughts or ideas with the space to express themselves. The focus groups were held after a series of interviews had been conducted, or roughly halfway through the research process in the case with Maria and Ginny.

1.4. ETHICAL CONSIDERATIONS

The ethical considerations within this research were drawn from the ethical guidelines stipulated by the Association of Social Anthropology (ASA), American Association of Anthropologists (AAA); Anthropology of Southern Africa (ASnA); the Faculty of Humanities at the University of Cape Town (UCT), the Health Professions Council of South Africa, and the Health Professions Act 56 of 1974 (as amended in 2009). These guidelines have performed as tools in directing my movement in the field and within relationships with participants. The various ethical guidelines stipulated that there are three factors defining the researcher’s conduct, responsibilities, engagement and integrity. The first factor was the establishment of consent and the handling of the consent. Secondly, confidentiality was a factor for ethical consideration, especially as I had engaged with personal experiences and medical information. Lastly, care was the third factor. Care was the foundational principle underpinning the formation of my research design and practice.

1.4.1. INFORMED CONSENT

My participants were asked to sign a consent form to participate in this research project. Prior to signing the consent form, I fully explained the research design, research topic, and the possible consequences of the research process. The purpose behind informed consent was to ensure the willingness of participants. Additionally, the consent form was imagined as a protection device for my participants. It stipulated to my participants what was involved in the research process. The aim was to ensure complete transparency of the research process and fully informed consent before my participants gave their agreement.

My participants signed a consent form and began the interview on mental illness during the consultation. I reiterated consent before each interview during the research process, because the lived experiences of the research process could have differed from the imagined research process for the participants.

My participants were informed that they could leave the study at any time. they could refuse to answer my question, or say that they do not want certain information published. This stipulation became necessary to implement care into my research design. One participant withdrew from the research process due to her mental illness. She needed to scale back on her commitments to focus on her health.

1.5.2. CONFIDENTIALITY

Confidentiality was a key ethical issue as I have discussed my participants' medical information. During the first interview, I discussed the use of protection devices for the participants. The participants felt protection devices, like pseudonyms, would be necessary for their right to privacy. My participants were sent my final dissertation to check whether their information does not compromise confidentiality and their medical information has been presented accurately.

Accuracy did become a dilemma during my research process, because they preferred to discuss their mental health "off the record". I previously included into my research design a strict policy of only using "on the record" transcripts. However, this was no longer possible due to my participants preference. I had to retrospectively ask permission to use the "off the record" information. At the same time, I had to check the accuracy of my fieldnotes and the data I had noted.

Within my research methodology, I encouraged my participants to bring in materials that expressed their experiences. These materials included medical scans, medications, and alternative treatments. I have not incorporated these visual medical materials into the dissertation, but I have used them to aid in a deeper understanding and in my analysis.

1.5.3. CARE

The ethical principle of care has been the shaping principle for my research design and the guiding principle for my fieldwork. I first introduced the ethical principle of care with the consent forms, where I asked about personal boundaries and triggers that should be noted. However, the principle of care was mostly implemented in practice. In order to practice care in the field, I had to practice understanding, empathy and tolerance. During my research, it was not uncommon for participants to cancel or not show up for interviews or focus groups. As previously mentioned, there was an instance where my participant had to withdraw from the research to focus on her mental health.

The research process used the consent forms and consultations or first interview as an opportunity to establish a code of conduct, code of engagement, and a code of care. It was crucial for a repertoire of respect, transparency, and fairness to be set up between participant and me. The consent form and consultations sessions were initially used to construct a template on my participant's boundaries and what I should note for interactions. It was during a consultation session with Ulima that she set the boundary of no touching, even friendly greeting gestures, and she preferred distance between herself and others. With the first discussion, I established how the participants wanted to be treated on an interpersonal level. This included the participant's understanding of personhood, how they would like to engage with the researcher or the research, gender pronouns and understandings about physical contact. The underlying aim was to open a channel of mutual trust and care, while creating a safe space for the participants.

1.6. REFLECTION

Ethics in practice is murkier than one can imagine in the research design period. Ethical theory teaches you to 'do no harm', but navigating ethics in practice requires more mindfulness and cognisance than theory can give you. One ethical dilemma that began to emerge in my research was where do I draw the line? How do I draw boundaries in my research? I knew the participants from my own navigations in the mental health network in Cape Town. This is a community with whom I am familiar. I was not an outsider coming in, but rather I was a local researching into my own observations. I struggled with establishing myself as a researcher and differentiating the researcher and the friend. This translated over into 'on the record' and 'off the record' information disclosure. My participants would share freely and openly 'off the record', but they would clamp up 'on the record' or they would get 'weirded out' by my shift into a researcher. Secondly, how does one ethically care when one is in the field?

Interactions in friendship are different from those between a researcher and participant. Friendships are about support rather than being instrumental. However, there is an underlying purpose and motive within the researcher-participant relationships. These relationships are highly instrumental in undertaking research and acquiring data (Sapsford, 2007; Furman et al, 2004). The researcher adopts a demeanour of valuing the participant during the research process and maintains this throughout collecting data. These researcher-participant relationships take on the appearance of friendship (Duncombe and Jessop, 2002 ; Owton and Allen-Collinson, 2014). There is thick theory on this relationship and power dynamic, but what about the ethics and the power dynamics in the reverse? In my research, the role of being a researcher was intrusive on my connections to this community. It did become more one-sided with them sharing rather than our conversation being a casual back and forth. Reinharz (1979:95) critiques the research process by stating that it is intrusive "...into their subject's privacy, disrupt their perceptions, utilise false pretences, manipulate the relationship and give little or nothing in return. When the needs of the researchers are satisfied they break off contact with the subject". While I was not intruding into my friends' privacy, I was intruding into my participants' privacy, because they had given to me as a person, rather than the me-researcher, their trust and confidence. This break and disruption in their perception of me became pronounced within interviews. They would speak freely and openly about depression 'off the record', but would simplify their answers and became withholding in their responses as I began to record the interview. Retrospectively, it can be asked why did I not stop recording and have a conversation? I was dedicated to following the ethical guidelines and sticking to my assumed script of what a researcher is 'supposed' to do. I wanted to record the interviews to ensure that I had exact record of what my participants said. I had assumed that the accuracy of their words would be more ethical than retrospective musings, where I could interpret or misinterpret their words.

Researcher-participant relationships have been critiqued as intrusive and there can be a distinct 'taking advantage of' or power dynamic present in research practices. There are methods to 'level the playing field'. One of these methods is through self-disclosure, where you let the participant get to know you and there is mutual sharing (Eide and Kahn, 2008). During interviews, the researcher and the participant engage in a dialogic process to evoke stories, memories, and contributions that wouldn't have occurred otherwise (Eide and Kahn, 2008). This is done as both an ethical act and an act of care. Care is described as a fundamentally moral experience (Klienman, 2012). It is also understood as the devotion to others. There is a clear distinction between the care-giver, who provides for the ‘other’, and the care-receiver, who benefits from the care (Kleinman and Van der Geest, 2009). However, my experiences of trying to extend care were not as clear cut as the theoretical dynamic of care would suggest.

> *“S: What can I do to make you feel better?*
>
> *C: There is nothing to make me feel different*
>
> *S: Why different and not better?*
>
> *C: Because you said better or worse”*
>
> *[Extract from Chloe*[2] *interview]*

In the interaction with Chloe, I tried to extend care, but what was actually caring in that moment? It’s not just about right or wrong, ethical or unethical. I could hold space for Chloe. Or, I could make things *“better”,* but what type of caring was applicable in this situation? This led me to ask how is caring different from rescuing? I tried to care with an offer to make things better. In retrospect, I was acting out of a place of rescuing and it disempowered the interview space. Thus, I had the ethical intentions, but I did not have the practical application of those ethics.

It is could be important to consider interpersonal boundaries between the researcher and participant. This could be necessary for the interview space to be ethical and allow for the space to be empowering. My personal issue with and practice of co-dependency was conflated with care. The act of oversharing was supposed to ‘level the playing field’ in the power dynamics in-between the researcher-participant relationship. However, my participants had to carry what I had shared. In turn, I also carried what my participants shared. The sharing space felt burdened and heavy. There are dangers and personal consequences to researchers that take this approach, especially if they disclose too much of themselves (Duncombe and Jessop 2002: 118-9). At other times, I found that I got caught up in Ginny’s cognitive distortions. She would begin to dissociate from her feelings and intellectualize, which led her into a loop of how life means nothing. What would be the act of caring in that moment? As a friend, I would call her out on this cognitive distortion and tell her that she is entering a rabbit hole of despair. As a researcher, I engaged in the cognitive distortion by allowing her the space to continue. Was the caring act putting a stop to the destructive spiral? Or is the caring act being respectful by making space? Also, how do I care for myself in that moment, because I was vulnerable to

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[2] Chloe is a pseudonym. It should be noted that all names of participants have been changed and pseudonyms will be used.

those cognitive distortion? This resulted in harm to my participants and myself during the research process. I did not act in care for both my participants and for myself by having a lack of boundaries.

There is the common adage that one has 20/20 vision in hindsight. I encountered a couple ethical dilemmas in my research process, but there is the overarching theme that I was the biggest obstacle, my lack of insight into care, and my inexperience were the biggest hinderances in my ethical conduct. What I has imagined the field to be in my research design was different from the actuality of the field. I had naively thought that ethics was about consent forms and upholding certain standards of research practices. While it was that too, it also was about establishing trust, care, and boundaries with both my participants and myself. It came as a surprise to me that there was an 'I' who was in the field as well. I came with all my preconceived ideas, baggage, and perspective. This does not fall away when one assumes the role of researcher, but rather it shapes who you are as a researcher. One enters the field with the full complexity of a person, which impacts who you are as a researcher and how you do research. I did not suddenly become a blank slate. In retrospect, I would consult the ethical guidelines, but personally I would go to the heart of what does it mean to respect someone and what does it mean to care for someone in future ethical considerations. I would be more cognisant of who I was as an ethical person and how that extended into an ethical researcher.

1.5. CHAPTER OUTLINE

In the following chapter (Chapter Two), I will lay out the theoretical frameworks within my research and my dissertation. My introductory frameworks on mental illness have been pre-established as they are the hegemonic frameworks giving shape and understanding to depression. Depression is framed as a psychiatric illness within a biopsychosocial model and within biomedical frameworks. Biomedicine is not the monopoly health care system, nor the central medical structure, in some of my participants' preferences of medical systems or medical treatment. However, this paper will enter into the discussion of depression through the framework of biomedicine and the biopsychosocial model, because it is the predominant medical system in Cape Town for treating depression.

It is from this starting point, in Chapter Two, that I will introduce my participants and their journeys to being diagnosed with Major Depressive Disorder. I address the question of what is a diagnosis of depression and what experience does this diagnosis demarcate. I discussed my participants' diagnoses and the diagnostic criteria. Thereafter, I briefly explain the hegemonic frameworks of the biopsychosocial model. Further into this chapter, I address the notion of the ‘medical gaze’ and how the body is perceived in the biomedical model, the biopsychosocial model, and by my participants. I address the body gaze through the narrative of “better” and ‘betterment’. Lastly, I theoretically grounded my dissertation with my theoretical frameworks in my final section of Chapter Two.

In Chapter Three, I re-examined a methodological moment that I had experienced. This methodological moment became vital in understanding my research experience. It led me to examine my participants relationship with their bodies and medical structures more closely. My participants were not passive receiver of medical care. In Chapter Three, I expand on how my participants practiced their agency. How did their agency interact with their bodily awareness? Thereafter, this methodological moment helped me chart the ways my participants used their bodies, bodily understanding, and bodily experience as navigational tools to navigate medical treatments.

I began to engage with my main ethnographic data within Chapter Four, *Body with and in Depression*. I present the case study of Ginny’s experience with “*dead man’s finger”.* This case study aims to explore the dissonance my participants experience around their bodies and how they dissociated from their bodies. This chapter closely examined my participants’ relationship with their bodies in these dissociative experiences of depression. Furthermore, this chapter asked how were my participants’ bodies experienced. Thereafter, I charted how their bodily dissonance translated into varying ways my participants experienced their bodies, particularly in regards to depersonalization and disembodiment. I continued to present my ethnographic data in the second section of Chapter Four, *Unreality from a Sensory Gaze.* I approached the body from a phenomenological gaze to examine how my participants came to experience depression as a “*tangible phenomenon”.* In addition, I illustrated my participants’ sensory experiences and experiences from an ‘unreality’ they used to navigate depression.

CHAPTER TWO: DEPRESSION AND BEING DIAGNOSED

Researcher: How were you diagnosed with depression?

Chloe: I have actually been in two [psychiatric] clinics… The first one was for ten days in Pretoria. After that, I came down to Cape Town for my second year of Varsity and the [psychiatric clinic] doctor in Pretoria recommended a psychiatrist for me here [Cape Town]. I think that was when I was officially diagnosed with ... I think the words were 'Major Depressive Disorder and Generalized Anxiety'. So I was probably officially diagnosed in February 2017.

Researcher: What led up to you being placed into a psychiatric clinic and being diagnosed with depression?

Chloe: So my first year of varsity was a very, very hard year for me. I was really struggling to just 'be' and I didn't really want to live anymore. My mom told me that she thought I was depressed, but I just brushed it off. Then in the December to 2016, I just couldn't do it anymore. I started to plan... to commit suicide. I was on sleeping tablets at the time, because I had had insomnia for about four months. So I was on sleeping tablets and I starting collecting them and I stopped taking them, while I was on holiday. Then on the fourth or the fifth of January, because I waited for after my sister's birthday, I took them all. I didn't take enough, because I woke up the next day and I was very groggy. My mom took me to a psychiatrist and then I ended up going to the clinic, because they realized I tried to commit suicide. They found my letter.

Researcher: What was your experience around that?

Chloe: It was very intense... So I was in the middle of taking the tablets when my mom came into my room. She didn't realize what I was doing, which is why I didn't end up taking all of them and I just fell asleep. So it was an intense thought that my mom accidentally saved my life. I was upset that I didn't die- I guess. I was upset, because I had a mini semester that had started on the 9th January and I was in clinic at the time. So I couldn't come through to Cape

Town. So I was very upset about that and felt that I was missing out. I didn't want to be in the clinic where I was. I wanted to be somewhere else, but I also didn't want to be in Cape Town, because I hated my degree at the time. I hated everything about it [degree]. Now in retrospect, I realize it [depression] started when I was seventeen. I found out some very intense stuff about my father and stuff he had done to my mom and I had to keep it a secret. It took a really big toll on me and I started getting a lot of anxiety in matric, because I worked really hard and I really wanted to get into medicine. I think I wasn't looking after myself and I started having these bouts of sadness. That is how it started when I was in matric. I remember coming to Cape Town for first year and feeling like I wasn't ready. I felt like I couldn't do it and I was waiting for the feeling to stop and it just carried on and it just got worse. It got to the point where I just didn't care about anything anymore and I am very much a person that cares very much. I care too much a lot of the time. I just stopped caring about class and I didn't want to make friends. I couldn't get out of bed some days, especially in my second semester of first year. I just stopped going to class or doing anything. I didn't enjoy anything anymore. I just felt this crushing sadness all the time or alternating with this numbness. I think I had never felt anything so intense in my life and I just didn't enjoy anything anymore. I remember feeling this... It was very strange, because it felt like my mind was so full that I couldn't focus on anything else, but I also felt like I was empty and I didn't understand it... I just constantly felt overwhelmed and I didn't know why. I felt inadequate. I felt that I couldn't handle my degree and that I was weak. I just kept thinking that there was no point in being alive and that I wasn't valuable to society and I was contributing to anything. I just remember wanting to die... Just wanting everything to be gone, wanting everything to stop...

(Extract from interview with Chloe)

Chloe was officially diagnosed with Major Depressive Disorder and Generalized Anxiety. She took a moment to recall her official diagnosis, but her experiences of depression stayed with her. These experiences of depression rather than her diagnosis was the focus of her attention. However, how were Chloe’s experiences of depression understood by medical practitioners? What does it mean to be diagnosed with Major Depressive Disorder? In Chapter Two, this chapter will establish the necessary theoretical foundations for understanding the diagnosis of depression. The first section will establish a reference point for what is meant by depression. Furthermore, it is necessary to illustrate the criteria of depression as it has come to represent the hegemonic experience of depression. In addition, this section will introduce my participants and address how they were diagnosed with Major Depressive Disorder.

Depression is a lived and phenomenological experience, but the experience becomes a culturally and medically shaped phenomenon (Kleinman, 1988:3). Kleinman's (1988) argument made me pause and influenced me to examine how depression has become medically and culturally shaped. This led me to examine the epistemological frameworks underlying the diagnosis of depression, which I explore further in section two and section three. In section two, I have examined the biopsychosocial model, which is the main model and the classification model for depression. Depression is not a static fact, but rather is a relationship and that relationship is the product of a classification system (Turner, 1984). Therefore, the biopsychosocial model shapes the practice of practitioners and hegemonic understanding of depression. I expand on these point to argue that the forms and functions of depression are not "givens" in a natural world.

A psychiatric diagnosis is an interpretation of a person's experience and a tool to understand a person's experience. A diagnosis does not create the experience, but it is a mean to understand it, organize it, and interpret it. (Kleinman, 1988). The DSM-5 has been the means, or the tool, to perceive, organize, and express experiences of distress and personal experiences in regards to depression. However, the diagnostic classification model and criteria of the DSM-5 is constrained by politically, socially, culturally, and historically as much as it is biologically (Kleinman, 1988:4). In the third section of this chapter, I will address the ways the ideological constraints and the theoretical frameworks around depression and the experiences of depression. Thereafter, I will close this chapter with a fourth section on my dissertations' theoretical frameworks. I present my theoretical frameworks for how I shape, approach and understand my participants' experiences of depression.

2.1. DIAGNOSIS OF DEPRESSION

My participants were comprised of individuals who have been diagnosed with depression, in particular with Major Depressive Disorder or Clinical Depression, by the criteria of the Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-5). My participants have sought, or continue to seek, treatment for their depression through psychiatry, psychology and/or other forms of treatment. The DSM-5 is the psychiatric handbook used by medical professionals, or "trained clinicians" for classifying and diagnosing mental illness (American Psychiatric Association, 2013). The DSM-5 and the previous editions were used by psychiatrists to diagnose my participants with Major Depressive Disorder or with a Major Depressive Episode. The DSM-5 conceptualizes depression as a cognitive and neurobiological illness that effects psychological, physiological, behavioural, emotional, and social processes. The DSM-5 and its usage by medical professionals situated my participants within a biomedical framework of illness and a biopsychosocial medical treatment model, which relies on psychiatry and psychology as the main treatment methods (Pilgrim, Kinderman, and Tai, 2008).

In the preface of the DSM-5, DSM-5 is defined “a classification of mental disorders with associated criteria designed to facilitate a more reliable diagnoses of these disorders” (American Psychiatric Association, 2013:14). It has become the central tool for mental health practitioners in their daily practice and diagnoses of patients. It is their “standard reference” point and acts as a “practical, functional, and flexible guide for organizing information that can aid in an accurate diagnosis” (American Psychiatric Association, 2013:14). It was the principle tool for diagnosing my participants and cataloguing their experiences of illness. A diagnosis of depression falls under the category of depressive disorder in the DSM-5 classification model, but there are nuanced experiences and presentations of depression according to this classification model. The DSM-5 distinguishes a diagnosis of depression into Disruptive Mood Dysregulation, Major Depressive Disorder (MDD), Major Depressive Episode (MDE), Persistent Depressive Disorder (dysthymia), depressive disorder due to medical condition, medication-induced depression, and other depressive disorders (American Psychiatric Association, 2013).

The DSM-5 presents diagnostic criteria for Major Depressive Disorder for trained clinicians to use in assessing patients. Both the DSM-5’s theoretical patients and my participants had to present with five (or more) of these criteria, or symptoms, in their experiences to be diagnosed with Major Depressive Disorder (American Psychiatric Association, 2013:161). These symptoms are constructed from the generalized experiences of individuals suffering from depression. In pursuit of creating a “standard reference”, the universal criteria of symptoms has been constructed by using the commonality, or shared experiences, amongst patient cases or experiences of depression (Kleinman, 1988). The diagnostic criteria has classified nine experiences for the diagnosis of Major Depressive Disorder: depressed mood most of the day; markedly diminished interest or pleasure in all, or almost all, activities; significant weight loss or weight gain; insomnia or hypersomnia; psychomotor agitation or retardation; fatigue; feelings of worthlessness or excessive guilt; diminished ability to think or concentrate, or indecisiveness; recurrent thoughts of death, or recurrent thoughts of suicidal ideation (American Psychiatric Association, 2013:161).

In 2017, Chloe, who is currently a medical student at the University of Cape Town, was diagnosed with both Major Depressive Disorder and Generalized Anxiety. Chloe was motivated to become a doctor herself, because she has a passion for helping people. During an interview, she mentioned that depression had given her the experience of being the patient, which has pushed her to focus on her bed-side manner for her future patients. Chloe hypothesizes that her experiences with depression began in high school, after distressing information was revealed to her. This distress was further compounded by her academic stress. She was a high achieving student and she put herself under pressure to achieve her dream of being a doctor. However, Chloe became overwhelmed and began to struggle with depression at the end of her first year at university. She struggled to *"just be"*. Her experiences of distress fit the patterns of experiential symptoms laid out by the criteria of the DSM-5. She had insomnia for four months leading up to her first suicide attempt. She had a "markedly diminished interest" in activities, where she *"didn't care about anything anymore"* and she *"didn't enjoy anything anymore"*. She experienced a fatigue where she couldn't get out of bed some days. However, Chloe had Major Depressive Disorder simultaneously with Generalized Anxiety. Chloe and my other participants found that their experiences of their illness didn't fit neatly into a single diagnostic category and the generalization of experiences misrepresented their experience.

As Ginny, a womxn I had met at a psychiatric clinic in Kenilworth, told me *"I think the DSM doesn't take that into consideration. It looks at a set of features and quantifies them. It attempts to amalgamate a whole bunch of different things, but its model is not broad minded enough*". When I met Ginny, she was working as a waitress and situated in the Northern Suburbs. During the time of these interviews, she stayed in a communal house with people she had met at a psychiatric clinic. In their communal kitchen, there were boxes for each person's medication with a weekly pill dispenser on top of each box. Ginny had moved to Cape Town from Durban a few years prior to pursue a university degree in psychology. In an interview, Ginny discussed the symptoms cited in the DSM-5. She described how the DSM-5 has taken the experience of depression to make *"a set of features"* and quantifies her experiences of depression. She wondered about the symptoms presented in the DSM-5, because the symptoms listed, while they are present in depressed patients, do not speak to the root from where these experiences arise or lived experience of these symptoms. Ginny found that the DSM-5 attempted to *"amalgamate"* the varying nature and differing experiences of depression into symptomatic categories. These symptoms then come to represent the 'nature' of depression as an illness. "Illness refers to a person's perceptions and experiences of a certain socially disvalued states including, but not limited to, disease" (Young, 1982:265). In this case, the DSM-5 is the evaluation and amalgamation of people's experience by medical practitioners using a biopsychosocial model to construct an understanding of depression, the socially devalued state. While the diagnostic criteria assist in diagnosis for medical practitioners, Ginny found that the diagnostic criteria was not *"broad minded enough"*. It misrepresented or underrepresented the experience of the illness itself and the lived experiences of depression.

In addition to their diagnoses not fitting a single category, my participants found that their diagnoses were not static facts but shifted alongside their phenomenological experience of depression and that their diagnoses were prefaced on their behavioural, cognitive, and emotional patterns. Ulima personally experienced a shifting diagnosis. Ulima came from a lineage of medical practitioners. Her mother is a doctor and her grandmother was a nurse. She has been exposed to biomedical diagnoses and she was familiar with biomedical practices. When she was first diagnosed with depression, she and her family were quick to adjust to the diagnosis, since they had a family history with mental illness. Ulima had a traumatic event with sexual assault, which she thinks triggered her family genetics with depression. In Ulima's case, she was first diagnosed with Major Depressive Disorder, but her psychiatrist changed her diagnosis to bi-polar. Ulima was mistakenly diagnosed with bi-polar when her anti-depressants pushed her mood too high and she had manic episodes, where she was *"extremely talkative"*. "*I was extremely talkative. I would say things that don't even make sense. Just for the sake of filling space with chatter. I was just talking.*, After changing her medication, Ulima's diagnosis was returned to Major Depressive Disorder. As she continued seeing her psychiatrist and shared her experiences, her diagnosis changed to Major Depressive Disorder with mood congruent psychotic features and Post-traumatic Stress Disorder.

Both my participants' experiences with their diagnoses and the usage of the DSM-5 by practitioners break from the notion of illness as a fixed thing. Diagnostic categories are amended with the practical application of the diagnostic manual. Additionally, the boundaries between disorder categories are considered more fluid than static (American Psychiatric Association, 2013). The DSM-5 admits that depression, or a diagnosis, can present with or overlap with other diagnoses, and cannot necessarily be categorically separated in practice as in theory (American Psychiatric Association, 2013). What this has meant for my participants is that they have been diagnosed with Major Depressive Disorder, but their experiences of diagnosis and diagnosis temporally has changed, been co-morbid, or presented "with features" of another diagnosis.

2.2. BIOPSYCHOSOCIAL MODEL

The practice of treating Major Depressive Disorder (MDD) challenged the ideological frameworks of biomedicine that has historically underpinned psychiatry. It was previously found that the biomedical approach and biological reductionism in psychiatry resulted in inadequate treatment. Thus, Engel (1977) proposed a biopsychosocial model to incorporate the social dynamics and the human aspect of the patient into the medical model through the addition of Systems Theory. It included the social, economic, and environmental impact on the body and health. Rather than gazing onto the body as an object from a blank background, the biopsychosocial model proposed viewing the body as both an object and subject within a context. This allowed for the adoption of psychology into the treatment of mental disorders (Engel, 1977). This biopsychosocial model became the dominant approach to treating mental illness, where either psychiatric medication, therapy, or a joint treatment is recommended (Pilgrim, Kinderman, and Tai, 2008). This model has served as the guide for physicians, psychiatrists, and psychologists to administer a diagnosis, care, and treatment.

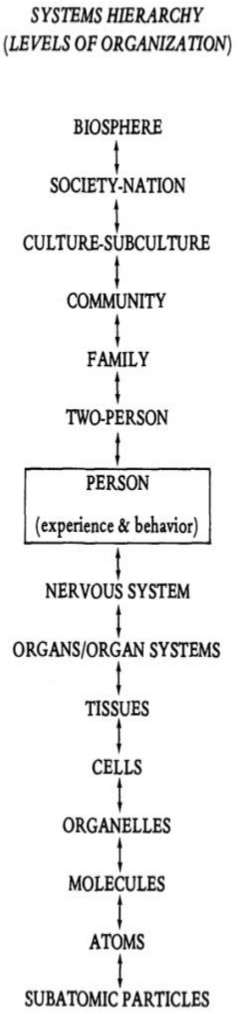

Figure one: Systems Hierarchy

(Engel, 1981:537)

The biopsychosocial model is Engel's proposed amendment to the biomedical model and the separation of science from subjectivity, society, morality, and a particular time and space. Engel (1977:130) said "[the biomedical framework] leaves no room within its frameworks for the social, psychological, and behavioural dimensions of illness". The biopsychosocial model constituted a challenge to biomedicine by addressing the reductionistic principles of the biomedical model. It did this by including dimensions of the biological, psychological and the social dimensions of a person's life (Engel, 1977). It aimed to contextualize the patient rather than removing them from their context and working with a laboratory-like body. Engel (1977) took the biomedical model that conceptually organized the 'natural' world (tissues, organs, cells) and continued the theory of natural systems with Systems Theory. The biopsychosocial model is a dual system that incorporates the natural systems approach of reductionism, but it also incorporates the Systems Theory where a component is viewed as a whole and a part of a greater system- holism (Engel, 1981). "Each system is at the same time a component of higher systems", Engel (1981:537) wrote, explaining Systems Theory. While reductionism has been useful for the medical achievements for biomedicine, the biopsychosocial framework allows for contextualization and the dynamics of the components. Engel argues that it is important for the physician to not only examine the material internal components, but also the external dynamics of information and relations of a patient.

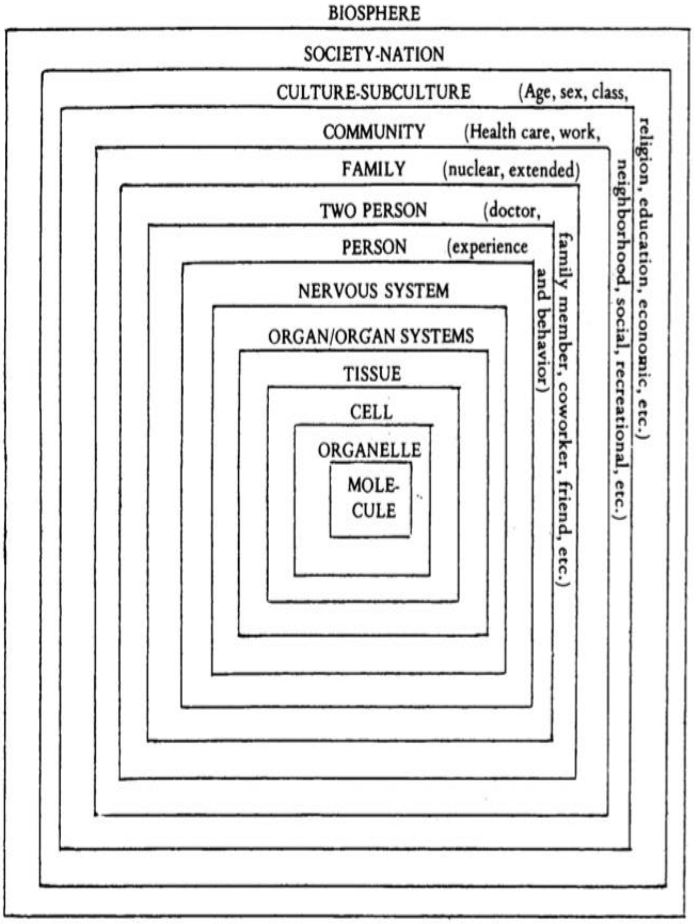

Figure two: Systems Theory

(Engel, 1981:537)

“A crippling flaw that the biomedical model does not consider the patient and his attributes as a human being” (Engel, 1981:536). Engel argued that the biomedical model was reductionistic, which broke down the body from a whole into parts. The physician’s approach was defined by this “laboratory model” and resulted in a preoccupation in the material body and the disease (Engel, 1981:538). As such, Engel (1981) argued that we should also do the reverse by examining how the patient is a part of a greater whole through a holistic approach. “Systems Theory, by providing a conceptual framework within which both organized wholes and component parts can be studied, overcomes this centuries old limitation and broadens the range of the scientific method to the study of life and living systems, including health and illness”, Engel (1981:536). Engel (1981) argued that we should take note of how the patient is characterized as a patient and as an individual in terms of a larger social system. An example of this is to consider a patient’s identification as an important factor in diagnosis- age, gender, occupation, and so forth (Engel, 1981).

The aims behind the biopsychosocial model and its various approaches were to establish a more empathetic and compassionate approach to the patient and medical care. Additionally, Engel’s model aims to consider the dimensions of life and be more contextually applicable in the physician’s process (Engel, 1977).

2.3. EXPERIENCE OF ‘BETTER’

The usage of ‘better’ in mental health communities is what initially began this investigation into young adults, later young womxn, diagnosed with Major Depressive Disorder. The idea of ‘better’ was an indicator of health standards and perceived health norms. My participants encountered ‘better’ and its surrounding frameworks, which illustrated how participants’ bodies were medicalized. Gordon (1988) argues that terminology illustrates and describes the experience of the cultural scaffolding and social processes of biomedicine. I suggest that the diction “better” was verbally symbolic of a biomedical ideology and conceptualizations of health. In addition, better was indicative of a particular set of health goals and approach to health.

2.3.1. BETTER AND NORMAL

“I started taking Prozac before I hit puberty and I hit puberty early. I hit it about two years before any of my peers. I never heard the diagnosis of depression. It was like “ maybe she needs a little help for now” kind of thing. I never went to a psychiatrist. My meds were prescribed to me by my GP. So I didn’t hear a lot of diagnosis talk or anything. Then, when I start menstruating, my menstruation was really uneven. I would bleed for three months and then not have anything for three months. So I went on birth control to help sort that out. At the time, I was getting a lot of acne and it felt that maybe a lot of my mood instability might be linked to some hormonal fluctuations. I stopped taking Prozac while I started on the birth control. I can’t remember the circumstances, but then, I went back on Prozac and then I was on both of them. I was on and off of medication. I would take it for a few months and then not take it for a few months. I wasn’t very disciplined about it. I didn’t really get it that I needed to take it every day to feel better, um… well, for it to work... *I got puberty earlier than my peers. It [depression] was like another weird thing that was happening to me that no one else was experiencing. During my teen years, I never really had a diagnosis. I was self-diagnosed with depression. I didn’t have a psychiatrist. I was just getting prescriptions from my GP. Diagnosis talk wasn’t something that happened… I went with the diagnosis of depression for myself, because it made easier to explain what was going on. During those teen years… Everything is awkward for everyone. Everyone is going through changes and everyone has no idea what they are doing, but I still had the feeling that what I was experiencing was different from my peers. I didn’t really know how to explain it or justify it. I could tell that whatever was happening with me wasn’t happening with people around me.”*

[Extract from Ginny interview]

Ginny was introduced to psychiatric medication at the age of eleven by her General Practitioner (GP). However, her symptoms of mental illness, such as mood swings, were confused with "*normal pubescent development"* and rather a sign that she *"needed a little help"* at the time. She did not get a full diagnosis of depression, or MDD, by a psychiatrist until she was *"of age",* which was in her final year of high school at the age of eighteen. During the time between her introduction to psychiatric medication by a General Practitioner and being diagnosed by a psychiatrist, Ginny had to grapple with *"normal pubescent development"*, a model of health, and her experiences of her body, 'her normal'. Ginny had to deal with the notion that her depression was a 'normal' process and that her body was the 'normal' adolescent needing 'help'. When Ginny's body and its functions did not comply with 'normal' or the bodily 'norm' in her final year of high school, she sought out a psychiatrist, where she was introduced to the biomedical and biopsychosocial gaze on her body through the psychiatric discipline.

Biomedicine approached the body with a scientific objectivity and naturalism. It focused on the body as multiple objects, such as a brain, nerves, and so forth (Foucault, 1975). This clinical gaze viewed the patient as an object or a site. The focus was on the disease (Armstrong, 1983). Foucault (2012) stated that the biomedical gaze compares the 'model of a man' against the sick man. This medical gaze centred the "knowledge of a healthy man, that is a study of the non-sick man and a definition of a model man*"* (Foucault, 1975:34). In this medical approach, medical students are taught how they should treat *all* patients and bodies rather than how to treat a specific person (Engel and Schutt, 2009). Within this model, the quantitative data, bodily functions, and material structures of the body are the source of information rather than the patient, their experiences, or their context. Bodies and patients are standardized amongst each other in order to generate the "normal" or "average" person within the "model man" (Engel, 1977). The collective or the objective holds more weight than the patient's experience in their singularity (Foucault, 1975:29). Engel (1981) pointed out that the biomedical approach or gaze has made it easier to organize people, but also made it "more difficult to create a personalized and individual approach of medical interaction" (Engel, 1981:536).

Both the phenomena of the disease and the body were standardized to create 'norms' for reference points in the biomedical model (Armstrong, 1983). However, the biopsychosocial model established a contextual or subjective 'norm' amongst bodies in a collective for health reference points. The biopsychosocial model used contextualization to avoid the establishment of a universal or objective 'norm'. Instead, it used the body of the patient in the context of 'other subjects' to measure differences and similarities (Armstrong, 1983). This model, rather, aimed to create relational norms. Engel (1981) shifted the biopsychosocial gaze to view and compare patients against each other in this conceptual health model, which has been normalized and/or made invisible, but is present in treatments and approaches to the body. "How physicians approach patients and the problems they present is very much influenced by the conceptual models around which their knowledge and experience are organized" (Engel, 1981:103). Armstrong (1983:20) talked about this further by saying the approach, or 'medical gaze', is reflective of the hidden cultural frameworks and social processes that shape knowledge and practice. The body is not a natural given, a universal truth, or objective norm. It appeared this way, because it is the way the body is taught and displayed in medical education, which is the cultural background against which practitioners learn to become physicians (Engel, 1977, 2009). The biopsychosocial model challenged the notion that the body is a natural given or exists as an objective truth. It has done this by addressing the flaw of the biomedical model that focus on disease and medicine without including the patient.

EThere is a standard and method of standardization that is created for subjective experiences. "The data appear in behavioural and psychological forms, namely, how the patient behaves and what he reports about himself and his life" Engel (1981:536). Engel's biopsychosocial model addressed the lack of humanity in the biomedical model by including the subjective – patient-centred care and the patient's context- into diagnostic consideration, which allowed bodies to be both subjective and objective. However, the model also introduced a quantitative, comparative, and objectifying approach to subjective experiences. This can be seen in the DSM-5, where the symptoms of depression are standardized into criteria. It constructs a normative or average subjective experience of depression, such as the markedly diminished interest or loss of pleasure in activities (American Psychiatric Association, 2013).

> "The main goals of the DSM were to increase reliability and consistency in psychiatric diagnosis. The reliability levels of agreement between two clinicians who are evaluating the same information have increased considerably since the first publication of DSM-1. Patients have also benefited from the increased objectivity provided by the diagnostic criteria." (Andreasen, 2004)

The biopsychosocial model uses a comparative measurement and standardization of a contextual collective rather than looking at the individual and comparing the body's functioning against the individual's body/ itself. As Ginny stated, "*whether you have mental illness or not, you deviate from the norm*". My participants were exposed to both the biomedical gaze of their body and the biopsychosocial gaze of their body with being diagnosed with MDD and seeking treatment for depression. These two gazes were predominantly used to understand what was happening with and in their bodies and experiences with depression. My participants became aware of their bodies and aware of how they related to their bodies via their own ideology or through medical constructs. It became evident through my interviews that my participants shifted away from comparative approach to their bodies and rather used themselves (their various bodily experiences and bodily states) as a reference point for health.

> *"It has been a long time that I have been on these meds. So it is difficult to pin point them now. This is my new normal I guess. I remember when I first started them, it was very strange for me, because - Someone explained it to me - it is like having the outer layer of your skin numbed and that is how it kind of felt. It felt that things would happen to me and I wouldn't be quite able to interpret/feel them as I thought I should. So I think it does sort of numb you. Some of the meds I was on, like I said, destabilized me and it made me more suicidal... The meds I am on now, I feel quite stable. I just don't feel things the way I think I should. Sometimes I find I should feel sad about something and I just feel nothing, which is a bit scary. But, I suppose it is better than the debilitating sadness that I had at a stage."*
>
> *[Extract from interview with Chloe]*

My participants redefine normal or what was their experience of normal. It was no longer a static universal from a biomedical model nor necessarily a socially comparative normal from a biopsychosocial model. My participants used their own bodies and bodily experiences as reference points. This is demonstrated in Chloe comparing her numb 'normal' to her debilitating sadness of depression 'normal'. 'Better' was in comparison to their experiences and in reference to their health needs rather than the achievement of health or the average body/norm.

2.3.2. BETTER AND REDUCTIONISM

In the previous section, I examined *how* biomedicine, the biopsychosocial model, and my participants gaze at their bodies. However, the substance of the gaze is a factor in understanding the body and navigation of treatment. This gaze is an integral factor for how the body gets ordered and how disease is ordered (Foucault, 2012). Firstly, biomedicine relies of Naturalism, or 'science, and its values to interpret and order the body. The body becomes a neutral object with an emphasis on its functionality, mechanics, and materiality. Secondly, the biopsychosocial model interprets the body as both an object and subject within place. While the biopsychosocial model allows for subjectivity and contextuality, the substance of its gaze is an extension of the biomedical gaze. It continues the atomism and reductionism of the biomedical gaze, but it additionally orders and places the social into a hierarchical structure.

In regard to the substance of my participants' gazes, this will be examined in a following ethnographic chapters.

The biomedical gaze is distinguished by how it has been characterized by its relationship with Naturalism, or commonly referred to as 'science' (Gordon, 1988). This gaze in particular is characterized by biological reductionism and atomism. "Biomedical practitioners approach sickness as a natural phenomenon, legitimize and develop their knowledge using naturalistic method (scientific rationality) and themselves as practicing nature's human representative - the human body" (Gordon, 1988:24). Naturalism asserts a separation between nature from the supernatural, from culture, from society, from morality, and from a particular time and space (Gordon, 1988). Within this gaze, it also asserts the difference between objectivity and subjectivity. There is an assumed difference between the objective nature and the subjective experience of sickness. In order for nature to have meaning, it needs to have meaning distinct from an observer and in of itself (Gordon, 1988). In other words, it needs to have meaning in essence and in being rather than in a process or in a relationship (Taussig, 1977). Diseases are considered separate entities from a host and are located and treated in the 'atom' (Gordon, 1988). This further extends to the human body. The human body is divided into parts and parts are approached as autonomous units (Gordon, 1988). These autonomous units, of organs and of other body parts, are seen to function separately from the subjectivity and actions of the person (Gordon, 1988).

> *"It is because your brain is the centre of processing and control. A lot of the time it is the hormones that are supposed to be released from your brain that are out of whack- your hypothalamus and pituitary. I think it is medically it is the systems in your brain that aren't doing what they are supposed to. But your thyroid can also cause it, so... In general, the first thing they test is your thyroid. They did with me. I have had multiple tests, because they always think it is something else."*
>
> *[Extract from interview with Chloe]*

In regards to my participants' experiences with the biomedical gaze, depression was isolated to the brain and its functioning. Chloe stated that "*your brain is literally sick".* Their bodies were biologically reduced to a *"brain", "pituitary", "thyroid", "mis-firing neurons", "serotonin", "dopamine"*, and "*out-of-whack" "hormones"*. Their health and illness was defined in terms of materialistic indicators. In particular, their bodies were derived into physio-chemical terms to explain the presence of depression in their bodies.

Within the framework of biomedicine and the values of Naturalism, nature is separated from subjectivity, but it is also separated from consciousness and society. It predicates that the 'natural man' is different from the 'cultural man' and body is distinguishable from mind (Gordon, 1988). This approach assumes that all humans are basically the same , particularly at the level of physiology and biochemistry, underneath the exterior cultural coating (Geertz, 1973). Within this biomedical gaze and approach, it is the physician's role to "decode" symptoms (Gordon, 1988:28). The cultural and the subjective are superficial and external to biology and disease, while biology is considered universal (Gordon, 1988). The disease and the objective body rather than the patient is core of this medical approach (Mead and Bower, 2000). The fundamental values and hidden assumptions of Naturalism state that reality is directly proportional to materiality (Gordon, 1988). The more something can be explained in the physical and the mechanical, the more 'real' it becomes within this framework. Thus, in this framework "'Real' illness corresponds to the degree in which physical traces show up in the body" (Gordon, 1988:24). Nature is a given and distinct from its observer, which means that it needs to be understood on its own terms in essence. This view has "subjects" encountering "objects". Its essence is separate from its meaning for someone (Lakoff and Johnson, 1980:199). "Medicine distinguishes between "signs", objective indicators in the patient's body, and "symptoms", the patient's complaints" (Gordon, 1988:25). However, mental illness, depression in particular, does not allow for this categorization and separation of nature from society, from the individual, or from the subjective.

Addressing the objectification and reductionism of the patient, Engel (1977) proposes Systems Theory within the biopsychosocial model. Engel (1977) argues to amend the biomedical model with a dual process of reductionism and holism, where an object/patient is viewed in relation rather than in isolation or in essence. This dual approach allows the patient and their body to be both reduced into parts (physio-chemicals, organs, etc.) and made into wholes or components within a greater social system. However, this theory and the biopsychosocial model, similarly to biomedicine, have hierarchically ordered the social, the patient and the body through unitary ontology. Engel (1981) creates an atomistic hierarchy of the subjective with his proposed amendments. The social components are essentialized and then examined in external relation. The patient is the transitional object between the internal objective and the external subjective in this model, but the molecule is still the central component of the hierarchy, which reveals that materiality and essentialism are core theories within the biopsychosocial model. However, the biopsychosocial model has centred the patient rather than the disease in its gaze.

So whether you gaze at the body in a universal objective sense with biomedicine, or as a patient in comparison with biopsychosocial, both gazes use a reductionistic framework and categories to impose order onto the body. *"It gives a list of symptoms and invites you to* *look at yourself in light of a set of things"* says Ginny. My participants found that they began to disengage from themselves and look at their bodies as self-objects. They were "invited" to look at themselves from various medical gazes during their manoeuvring for health. The substance of medical gaze onto the body influences how depression and illness is shaped, understood, diagnosed and located within the body. The biomedical model and the biopsychosocial model guide the medical knowledge and practices of psychiatrists and psychologists. This in turn influenced how my participants' bodies and experiences were approached. While Engel's (1977, 1981) Systems Theory considered community and relationships, it overlooked the subjective and sensory experiences of mental illness.

2.3.3. SUBJECTIVE BODIES AND IDIOSYNCRATIC TREATMENTS

Chloe: " ...I knew there were things I could be doing that could maybe make me feel better, but I just didn't feel capable of doing any of them. I knew I should be exercising, eating right, and making friends, but I just didn't care about anything."

Researcher: "Why did you think those were the things that would make you feel better?"

Chloe: "I suppose, because they tell you these are the things you should be doing…As a medical student, I obviously know I am supposed to exercise regularly and eat healthy. I also have some issue with food. So I was struggling with that as well- with eating...right. So when I was about sixteen, I started exercising a lot. I am not very sporty, but I am quite good at swimming. So I started going to swimming lessons and we had a trainer at the gym, who would work us really hard. I never worked so hard in my life that I lost a lot of weight and I got a lot of compliments... for the first time in my life I got a lot of compliments on my body, because I was never skinny or.... I was average and I grew up with this very skinny, beautiful sister. So I had a bit of a complex about that. For the first time in my life, someone told me I was skinny and I wanted to stay that way. I started obsessing about what I ate and when I was seventeen, I became bulimic. So I would have these cycles of binging and purging. It was something that got very out of control in my matric year when I was very stressed about other things. Then coming to varsity, I thought it would be better, because I was in residence. So I thought giving me meals would help, but it didn't, because there was a vending machine and I was just eating too much and then... purging... So I have to be quite careful about how I eat now, because of that."

[Extract from interview with Chloe]

Chloe's experience shows that there is an oversimplification of health and illness that accompanies 'better'. Within this notion of better and her previous held notion of health, she had a prescribed idea of how to achieve and maintain health. The theoretical prescription dictated that you needed to eat well and exercise. However within Chloe's context, these healthy activities were toxic and exacerbating her mental illness. Chloe developed an eating disorder. She was eating healthy, but she was obsessing over her food, which escalated into binging and purging. Chloe was exercising and losing weight, but she was pushing her body beyond its limits and she was triggered by previously held body shame. Exercise and eating healthy are among the few examples of prescribed notions of how to attain health, or 'better' that Chloe had been taught in high school. This theoretical notion of health and the achievement of health, or better, does not take into consideration the nuanced and idiosyncratic formation of the human body. Nor does it take into consideration how people relate to their bodies, in Chloe's case through food or exercise. While practitioners do not necessarily align with this oversimplification of treatment for mental health, my participants found that their treatments had to be designed around their context, their psychology, and their bodily functions.

Theoretically, the diagnostic manual is used to diagnose and aid in designing the treatment for the patient. Alongside the diagnosis, there is a suggested path of treatment to attain health. The issue was that this focus of treatment can be narrow, limited to the mind/cognition, or it could be generalized at first. Ginny spoke about how psychiatry is a *"guessing game",* because these medicines do not work the same with everyone and you had to *"play around"* with the medication until it worked for the patient, which *"only comes with a lot of experience"*. Ginny said, *"taking medication is a risk, because you don't know what it is going to do. Everyone's physiology is different and medication is made standard".* Ginny presented with a medication resistant form of depression, which meant that medication did not work properly or for long periods of time. It also meant that often she received higher dosages of medication than psychiatrists prescribed to other patients. Medication turned into a tool to alter her biological or psychological state temporarily according to her needs at the time. Ginny explained, "*there is no such thing as a happy pill. There is a productive pill or there is a stabilizing pill, but there is no such thing as a magic pill. That is what a lot of people search for, when they are first diagnosed with something. They think the way they are feeling is wrong and something is going to change that. When people speak about medication not working or medication working, people have very different terms about how this is defined".*

These experiences with medication introduced Ginny to a new bodily notion. Ginny discarded the idea of an *"ideal"* body, because her medication revealed the idiosyncratic layout of people's bodily worlds as it produced different effects with its consumers. In addition, Ginny and other my participants would switch, modify and swap between treatments, according to their subjective needs. Additionally, they would seek out treatments from various medical models for their subjective needs, which resulted in resulted in the overlap, co-existence, and collaboration of various medical models.

2.3.4. GOING FROM BETTER TO MAKING THE BEST OF IT

“I suppose something that surprised me was the coming out of the clinic and being on meds and being in a better place. I thought the depression would just go away, something I have realized it is not something that will ever fully go away. It feels like once you have seen the world in a certain way, you can't really go back from that. So even though I am in a much better place in that I am not wanting to die all the time, I still get these bouts of deep sadness and this anxiety that I don't even know how to deal with it. I have realized that my depression might be something that I will carry for the rest of my life or at least in some form, but I just need to find ways to deal with it and cope with it. If this is who I am going to be, I guess I have to make the best of it.”

[Extract from interview with Chloe]

My participants shifted away from the ‘better’ approach to treating depression, where it was assumed that their bodies and minds needed to be fixed . Depression would not *“just go away”* as Chloe stated. They were introduced to the biopsychosocial model and different conceptual frameworks of viewing and relating to their body. As they shifted through these frameworks, my participants became aware of their body and its idiosyncratic make-up. They began to take note of their bodies as material, social, medical and subjective. This led them to become witnesses to and regulators of their bodily functioning.

In order to *“make the best of it”* my participants employed what Foucault (1975, 1977, 2008) describes as the objectification of subjectivity, the medical gaze and the panopticon. Foucault’s theorization in *The Birth of the Clinic* and *Discipline and Punishment* were used as theoretical frameworks to understand my participants’ experiences and shape this dissertation. Foucault (2008) uses the example of the plague and how it was met and managed with order. In health, there is a distinction that is made between the healthy/unhealthy, and normal/abnormal (Foucault, 1975, 1977, 2008). Techniques, systems, and institutions have been created and exist for the measuring and supervising the abnormal or the unhealthy (Foucault, 2008). He also argued that biomedicine derives itself from these mechanisms for controlling the abnormal (Foucault, 2012). Foucault (2008, 2012) introduced the notion of the medical gaze through the biomedical framing of the body, particularly in regards to the objectification and anatomizing of the body. The human body is presented as a natural given.

It is less about the subject than it is about the space, origin, and distribution of disease (Foucault, 2008).

The patient is the site or location of a disease or illness in the biomedical gaze. The doctors peer into their bodies to look at the disease or body part. Their humanity and being is missing in this gaze. The doctors is the authority and the patient’s subjectivity is external to the process of regulating health. However, my participants employed this technique of self-regulation and surveillance internally to navigate their experiences and their medically plural choices in treatment. Foucault furthers his analysis on the medical system in his theorization of the panopticon. Foucault (2008) draws on the example of the plague that has infected a town. The citizens of the town are regulated to their respective homes and the town goes under the absolute authority of the magistrate. The magistrate charges soldiers to go to past each house to check if the occupants are sick or dead. The sick were then attended by the doctor and only the doctor. This allowed the magistrate to have complete control over the process and access to all the information (Foucault, 2008). While my participants sought out medically pluralistic treatments, they became the magistrates of their bodies deploying the metaphorical soldiers out to each house to check on the sick, what Foucault calls biopower. My participants do not fully ascribe to this anatomical view of the body, biomedicine, or the biopsychosocial model. My participants have found themselves in a pluralistic knowledge site where there is a multitude of gazes on the body. They blend and select a gaze that suits them at the time. Rather they use this tool of gazing at the body and self-regulation to navigate the medically plural experience of living with depression and maintaining well-being.

My participants can become both object and subject to themselves. The self can be autonomous and self-determining. They could also distance themselves from themselves without becoming entirely detached. This technique was used by my patients to navigate their subjectivities and idiosyncratic bodies. This awareness can be attributed to my participants’ experiences with various medical systems, especially considering the various perspectives they encounter that makes them think about their bodies. However, it goes further than this. Depression and the treatments have made them aware. Intrinsic to their treatments and management of depression, my participants became aware and implemented self-regulation. This self-regulation arose as a response to their bodies’ on-going demands or needs, which in turn made my participants flexible with their medical treatments. My participants became the patient, the site, the body, the doctor, and the regulator in this process. They lived with these diagnoses and the experiences of depression, which required them to become the authorities on and managers of their experiences. They had to be aware of what to eat, how much sleep, what medication, what treatment that they need. In these attempts of self-regulation and management, my participants moved between treatments and medical structures to gain this. They became flexible with how they responded to their bodies.

Self-regulation was not necessarily about achieving the ideal or enforcing particular notions of health made by outside structures. Additionally, this self-regulation spoke about how my participants managed themselves and their bodies to achieve their own personal goals and health goals. It helped them to *"make the best of it".*

2.3.5. FRAMING THE BODY

Depression in practice is framed by the biopsychosocial model and biomedical frameworks. This dissertation uses these hegemonic frameworks alongside Foucault's concept of the medical gaze. Additionally, this dissertation will use three conceptual frameworks to frame and understand the ethnographic data and my participants' experiences with their bodies. These last theoretical frameworks include the mindful body, embodiment and phenomenology.

These epistemological frameworks are first grounded by Scheper-Hughes and Lock' (1987) theorization of the body. They begin by presenting the body as both a physical and symbolic artifact that is both naturally and culturally produced and is anchored in a historical moment (Scheper-Hughes and Lock, 1987). They present and critique the phenomenological body. The phenomenological body is the lived experience of the body-self. This body-self is on some level has an intuitive sense of an embodied self and exists as separate from other individual bodies (Scheper-Hughes and Lock, 1987). The relationship of the bodily parts – self, matter, mind, etc.- is highly variable in how they are received and experienced in health and sickness (Scheper-Hughes and Lock, 1987). This phenomenological gaze has been critiqued as biologically reductionistic and individualistic. Additionally, it views the body from a white, male gaze and does not consider race or gender influencing the body. Scheper-Hughes and Lock (1987) as an amendment propose the 'mindful body', which bind the three bodies (the phenomenological, the social, and the body politic) through the 'affect' of emotions and feelings. In prior conceptualization of the body, the body had been segmented along the lines of mind/body, internal/external, and biological/cultural. The mindful body brought these various segments of the body into conversation and interconnectedness with one another (Scheper-Hughes and Lock, 1987). Additionally, this allowed for the emotional and felt experience to be incorporated into the consideration of body. The mindful body was the most useful framework, alongside the initial understanding of the phenomenological body, to understand my participants' experiences of body.

This dissertation utilized a phenomenological approach to understand the experiences of ‘living with depression’, and present thick ethnographic data on the depressive symptom of dissociation. However, I first need to establish the framework of embodiment upon which these phenomenological authors (Merleau-Ponty and Husserl) expand. Embodiment and disembodiment are central concepts used to investigate and build my participant’s relationship with their bodies. Essentially, embodiment refers to the lived experiences of the body as well as of life mediated through the body (Barbour, 2004; Nichter, 2008). This mediation is simultaneously influenced by physical, psychological, social, political, economic and cultural environments wherein the body is located (Barbour, 2004; Nichter, 2008). Kirmayer (2003:285) referred to embodiment as the insight that the body has a life of its own and social worlds become inscribed on, or sedimented in, the bodily physiology, habitus, and experiences. Csordas (1990:12) expands on embodiment in that it also involves one’s perceptual experience and mode of presence and engagement in the world. The self and the body are culturally constituted and the existential ground for culture (Csordas, 1990).

Phenomenologist Maurice Merleau-Ponty (1964) aimed to locate the lived body at the centre of individual experience. He argued that it was the body, not simply the mind, that understood and experienced the world. Mind and body were entwined and embodied. Therefore, embodiment was the existential condition of being in the world (Merleau-Ponty, 1964). According to Merleau-Ponty (1964), the mind/body dualism of Descartes could be replaced with an understanding of the ‘body-subject’ which did not privilege mental activity and mind but expressed the relation of a person to their world through their sensory engagement. Husserl (1989) expands on embodiment within a phenomenological lens as a means of connectivity and the experience of connectivity. According to Husserl (1989), embodiment is a twofold structure, where it is both what allows us to perceive and it is the subject of the perception. In addition, the body is simultaneously a perceived object (Husserl, 1989), bearing in mind the critique from the Scheper-Hughes and Lock (1987), and is a perceived subject. The body is lived as well as material, extended as well as internal, subject as well as object (Husserl, 1989; Wehrle, 2019). “A human being always and conjointly is a living body and has this living body as his physical thing” (Plessner, 1970:34). Bodies aren’t merely objects, but simultaneously living subjects – sensing, moving and experiencing – our materiality makes us open and vulnerable to the world and a sensed ‘reality’ (Wehrle, 2019). Wehrle (2019:500) makes the crucial point that “we are not passively located, affected, moved or moulded from the outside as if we were an indifferent object; but, we subjectively feel any external affect from the inside and thus have to somehow relate to it”. Human embodiment is both living and felt, but it is also our awareness of ourselves (Wehrle, 2019).

In addition to Merleau-Ponty and Husserl’s theorization around phenomenology, I also refer to feminist literature in regards to phenomenology, because there is a decontextualization and removal of how culture factors into the body. There is also an erasure of how difference and the "manner in which culture marks bodies and creates specific conditions in which they live and recreate themselves" (Gatens, 1995:71). This is particularly relevant since I worked with a group of womxn. The gender relationship my participants have with their bodies could have influenced their bodily regulation and propensity for self-regulation, which was a vital tool in navigating their health. Gender markers are a taught cultural way of relating to the body, which is why it could have been a factor in the self-regulation and self-monitoring. There are a number of factors that could have influenced my participant’s relationships with their bodies: silence, received knowledge, subjective knowledge, procedural knowledge, and constructed knowledge (Barbour, 2004). A womxn can experience herself as dependent on external authority. She could conceive herself as capable of receiving knowledge rather than creating her own. She learns and applies outside procedures and knowledge (Barbour, 2004). Or, a womxn can view all knowledge as contextual and experiences herself as creator of her own knowledge , where she is on a quest for self and voice (Goldberger et al, 1996). These factors can play a role in my participants developing their ways of ‘knowing’ and how it translated into living with depression and *“making the best of it”.*

CHAPTER THREE: POLITICS OF KNOWLEDGE AND PATIENT AGENCY

During the research phase of this dissertation, I experienced a methodological moment that made me confront my own internally held assumptions. My participants would go into medical details, medical operations, and the chemistry of medication. I have my own experience with mental illness and I could relate to this personal index of medical knowledge. However, I had to go research a particular type of medication and its operations. As a result, I began to question my own assumptions. Who was the knowledge holder? Who was deemed the knowledge holder in the researcher-participant relationship? Who was considered the knowledge holder in the doctor-patient relationship?

I had assumed that the medical structure was hierarchical. In this doctor-patient relationship, the doctor is the healthy, wise, and authoritative person, whereas the patient is perceived as the sick or powerless person (Foucault, 2012). The patient tells the doctor their symptoms, or experiences that are abnormal, in the process and structure of giving a diagnosis (Armstrong, 1983). The doctor is seen as the expert giving the patient information and decoding the patient's symptoms for a diagnosis (Engel and Schutt, 2009). It is the duty of the medical practitioner, in broad terms, to "relieve the patient of their "distress" either rightly or wrongly attributed to illness however conceptualized" (Engel, 1981:536).

Engel's (1981) biopsychosocial model rectified the unilateral and hierarchical doctor-patient dynamic in the biomedical framework. Engel centred the patient and made the relationship dynamic a two-person approach. This placed the patient on equal footing as the doctor (Engel, 1981). In addition, it made space for patients to practice agency in the medical context. Agency, in this text, is the reference to self-hood, choice, intentionality, will, and creativity within a temporally embedded process of social engagement and within a medical field (Mustafa and Mische, 1998). Previously, I had made the ideological assumption that the researcher and doctors are considered the knowledge holder. In the case of mental health, psychiatrists and psychologists were the knowledge holders. I had assumed that they solely played an authoritative role in diagnosis and treatment of depression.

In my methodological confusion, I firstly had to confront my own ignorance of knowledge creation and secondly, to recognize my participants' agency. This moment led to a greater consideration of my participants as knowledge holders and the impact their agency had in the management and experiences of their depression. In this chapter, I investigate this notion of medical authority and the power dynamics within the medical system and doctor-patient relationship. I chart the way that my participants dismantled and reshaped these medical structures and the power structures around ‘authority’.

3.1.EXPERT AND AUTHORITY ON ME: I KNOW

“I had to become an authority on my own body, because no one was going to know me better than me”, Maria stated. My participants used their agency to become an expert and an authority on their bodies and medical knowledge related to their bodies. My participants were not idle recipients of medical systems. I will not generalize and say that this is found with all individuals that have been diagnosed with depression. However, my participants seemed to have a very thorough understanding of medical knowledge and have pursued medical understanding either as a profession or in their spare time. Ulima stated that she had taken online courses to inform herself. Ginny had studied neuropsychiatry, psychology and could recite the DSM-5. Chloe had pursued a degree in medicine and she was in the process of becoming a General Practitioner.

“If you look into neuropsychology, you can see that the optical nerve runs all the way from the front of your brain to the back” or *“…the visual cortex is straight down the middle of your brain”,* Ginny spoke on her medical understanding. Ginny pursued a deeper medical understanding outside her interaction with her medical system. She took psychology and neuropsychology courses in university. During our interviews, she could take me into the bodily operations to explain what was biologically happening with her neurons, her medication, and her nervous system. Ginny would often return to explain or back-up her statements with medical understandings. She tied together her experiences of her body with the biology of her body. After Ginny asked if she could *“go into neuropsychology for a second”,* she proceeded to give me a lesson in neuropsychology. She pulled up an anatomical chart on her phone and explained her neurobiology. The anatomical chart is the biomedical illustration of the human body, which focuses on the placement, location, and functioning of the material body (muscles, organs, veins, etc). She elaborated on the functioning of the brain, neurons, and the biochemical operations of SSRIs. SSRIs, or Selective Serotonin Reuptake Inhibitors, are a class of antidepressant drug that are thought to act by inhibiting the reabsorption of serotonin by serotonin-containing presynaptic neurons, which increases the availability of serotonin as a neurotransmitter (American Psychological Association, 2020).

My participant’s intimate knowledge and deeper understanding of her body and bodily experiences also reflected in her choice of treatment or whether she agreed to a treatment. Ginny explained, “*I could have looked at the fact that my motivation is lower and it is probably a dopamine issue. I could have upped my dosage of Wellbutrin, but then my anxiety would* *have floored me”.* Ginny tracked her emotions and used them as indicators for the performance of her neurons. She charted her body similarly to that of an anatomical chart seen in biomedical systems, but she rejected the ‘ideal’ body and rather used the biomedical lens as a means of understanding her body. In addition, she no longer simply accepted a doctor’s diagnosis or treatment. She objectifies her bodily experiences and uses it as a compass, when she needs to shift doctors and treatments. Her example illustrated the agency my participants practiced in their pursuit for well-being. It also illustrated the deep understanding they developed on their own bodily functions and operations.

In Ulima’s experiences, she became her own psychologist and performed psycho-therapy upon herself. Ulima moved away from the monopolizing notion that doctors or medical practitioners were the only individuals with insight into treatment for mental illness. She also looked to the mental illness community for insight and treatment suggestions. Despite being immersed in the medical system by her diagnosis and her family history, Ulima sought out connections, support, and understanding from the mental health community and those who have also been diagnosed with mental illness. Ulima attends support groups, but she also reached out to spokespersons for mental health.

She built and maintained contact with a YouTuber, who advised on self-care for those with mental illness. Ulima said, *“She gave advice in her YouTube video stating that this is what she did and I implemented that and that worked. I reached out to her about school work. Studying at University is really hard, when you have mental health issues, and she was like "I completely understand"”.* It was this contact that introduced Ulima to the notion of management of the body and her mental illness. Her depression changed in that it was no longer a deviant body, but rather a signpost for care. Her body and her mind became something that she had to work with and live with, which drew her further away from the paradigm of a broken body and bodily attack that she had previously assumed and upheld. These contacts were immensely helpful in the day-to-day care of her ‘mental’ illness.

> *“I used to hear... So this is what happened. When people used to bully me, their words turned into an inner critique. Whenever I read something that inner critique would pop up and say " you are not good enough". What I did to manage that was: if I studied I would have a note pad next to whatever I was doing. Whenever that inner critique came up, I would write down what it is saying and then I would have to write something positive about that to try and conquer or lessen negative affect of what that inner critique was saying. That actually helped me recall a lot of information. I know that took a lot of time. That takes someone a lot of time to actually study sometime than someone who doesn't actually have those issues.”*

[Extract from Ulima interview]

While she was still on psychiatric medication, depression still impacted Ulima's ability to go about her daily life. It was one of these instances that made her reach out to a fellow mental illness spokesperson and it changed the way she navigated her body. Ulima had auditory hallucinations that would arise while she worked or read for her degree. These auditory hallucinations were voices from people that had contributed to her Post-traumatic Stress Disorder (PTSD). She heard that she was not good enough and a narrative of negative self-commentary. Ulima used the advice she was given by this prominent YouTuber on mental illness. Ulima was advised to keep a journal and she should write out the self-depreciating commentary, where she could acknowledge it and healthily engage with it. She wrote out the self-depreciating statements on a separate paper next to her work, where she challenged these thought patterns with counter commentary. She used a dual process of working: she worked both on her degree and simultaneously challenging this narrative. She found she could emotionally deal with those statements after she had written them out by running a counter narrative of self-belief, self-love, or why these comments were not true. This meant that Ulima became both the observer and the participant in her body. She began to develop her own bodily awareness and bodily agency.

3.2.PATIENT AGENCY AND PARTICIPATING IN TREATMENT

My participants became their own monitors, regulators, doctors, and therapists. They dismantled dichotomies arising from the biomedical frameworks and the politics of knowledge. Alongside this dismantling, my participants presented themselves as a knowledgeable equals to doctors and thus took part in the decision making around treatment. They did not allow for unquestioned interference with their bodily experiences and their embodiment or disembodiment.

My participants were not passive receivers of the health care system and medical treatment. Firstly, they gain knowledge through personal research about the medications, treatments, and on doctor's visits. Secondly, my participants use their personal research and their bodily awareness to choose a medical treatment. In some cases, they used their own bodily knowledge to adjust a choice of treatment to suit their idiosyncratic body and their needs. Maria told her therapist how she would prefer the therapist to perform a particular treatment. At the time, she was doing Eye Movement Desensitization Reprocessing (EMDR) treatments with her therapist at their weekly appointments, which is a therapy treatment that induces brainwave lengths to process past trauma. EMDR was originally developed to treat victims of trauma or those with PTSD, but it has been found effective in treating individuals with depression (Shapiro, 1996; and Wood and Ricketts, 2013). Maria had to hold these vibrating buttons in each hand during her session. The vibrations in her hands were picked up by her nerves and thereafter her sensory receptors in her brain. She called this process "*physiological hypnosis".* It uses bilateral stimulation, such as taps, buzzers, tones, or eye movements, to stimulate the information processing system in the brain (Shapiro, 1996). This treatment stimulated the wave lengths used in subconscious thought processes, sleep, memory and thought processing. As a result, these frequencies then stimulated forgotten memories and helped reprocess past trauma, emotions, or "vivid states" (Shapiro, 1996; Wood and Ricketts, 2013). It has been hypothesized that cellular memory contributes to the onset and maintenance of recurrent depressive episodes. EMDR promotes the reprocessing of memories and had been seen as a means to broaden the range of effective treatments for depression (Ostacoli et al, 2018).

"They are trying to mesh technology with natural ways of thinking. What is interesting with this EMDR is that they are using electronic frequencies to stimulate brain wave lengths to produce Delta and Beta brainwave lengths", Maria explained the EMDR view of body. Maria found she had to reformulate her own view of her body. Her memory became a physiological phenomenon and biologically material, which could be stimulated by technological frequencies. In addition, her body held onto past embodied and 'vivid states' of trauma. Her emotions were not entirely psychological, but could be stored, or become "stuck", within the body and be stimulated by physiological frequencies. Her body was not singular nor was it necessarily divided. Rather, Maria's body was layered and it existed as a multiplicity. However during Maria's EMDR sessions, she found that it made her mentally unstable and increased her suicidal tendencies or ideation. It was during this time that she told the therapist what was happening. Maria did not want to stop the treatment as it was helpful. Instead, she told her therapist how she would rather perform the treatment. *"It was too much for me. So I told my therapist that I needed a debriefing session in-between the EMDR sessions. So I rather did EMDR every second week or when I felt that I was able to do it", Maria explained.*

My participants constantly monitored their own bodily experiences in that they are both the participant and the observer of their own embodiment. Ginny told me*, "Sometimes I feel like I know myself better than the doctors and I can tell when a depressive episode will hit. I can monitor my body and my brain. I turn to doctors as a tool for treatment and access to medication rather than a diagnosis on what is happening to me".* She knew that her she was becoming disembodied from her body and entering into a depressive episode. She went to her doctor and asked for her medication dosage to be increased. This shifted the notion of who is the knowledge holder of the body in the interactions between the doctor and patient.

My participants' diagnoses and their bodily experiences made them pursue a medical understanding and interrogate the medical practices they encounter or undergo. Doctors within this dynamic take on the role of consultants and gate-keepers rather than ultimate bodily authorities.

My participants centred themselves, their experiences and their bodies in their considerations of medical treatment. In addition, patient-centred care by practitioners has been associated with better outcomes in terms of patients' experiences of physical symptoms and adherence to care regimens or treatments (Hensley, 2012, p 135). While there is a difference between theory and practice, it has been suggested to medical practitioners to provide the necessary support and explanations on relevant treatments and health issues in order to foster this patient-centred intervention (Drew et al, 2011). Patient-centred approaches support or help develop the skills, knowledge, and confidence for patients to advocate for their needs and make informed decisions for their health (Daniels, 2018). It has been found that patient-centred care fosters empowerment, respect, joint decision-making, and dignity for the patients (Engel, 1977:171), which reflected in the practices of my participants. They did not consider medical practitioners as the sole authority on what treatment they needed nor the only source of knowledge about treatments for depression. This changed the dynamic of how they engaged with medical practitioners in the biopsychosocial model and their engagement with the biopsychosocial model. Through practicing their agency and bodily awareness, my participants began to question the methods of the biopsychosocial model and its practitioners.

Ginny referred to this as a loss of *"naivety"* in regards that she was no longer *"naïve"* about the medical system, the treatments, or the practitioners' methods. Ginny spoke about one place where she lost naivety: *"I don't trust psychiatrists as authoritative figures anymore… like I used to. I used to feel that they held a lot of knowledge and that, because they have studied a long time, they know what they're talking about. At the end of the day, it feels like a lot of guesswork. The people, who diagnose you, don't see you for very long".* Ginny sees her psychiatrist every few months for 45 minutes, but she does not understand how her psychiatrist was able to diagnose her without understanding how her individual mind works. As a result, Ginny tracks her moods, her behaviour, and her cognitive patterns in the interim periods between psychiatric appointments. Thereafter, she makes a list of information that the psychiatrist needs to know about her medication, her moods, her mental stability, and her overall health. When she enters into the appointment, Ginny already has an understanding of what treatment she needs and the state of her own being. Ginny's actions support previous findings, where the participation of patients, in making treatment recommendations and treatment observations, have a direct impact on their rate of recovery (Daniels, 2018:165).

It is not uncommon for my participants to enter into a doctor's room already knowing what treatment they want, what their mind or body needs, what role the doctor is to perform. Essentially, my participants in living with their illness or depression have changed the notion of who is the knowledge holder in that space. They developed their bodily awareness and developed their own understanding of health, well-being, and healing. They navigate health care structures and treatments to reach, produce, or maintain a particular lived body and embodiment. They and their bodies are not just on the receiving end of medical structures. At times, they switch, change, or combine medical treatments from different medical systems to achieve their notion of bodily well-being.

3.3.CONCLUDING THOUGHTS

My participants' diagnoses and their engagements with medical systems made them develop a deeper sense of awareness of their own bodies. It became apparent that bodily awareness was the key aspect to how my participants understand and engage with their bodies. My participants have a heightened sense of their nerves, their limbs, their organs, their nutrients, their senses, and their pain. They are aware of their bodies as a body, a bodily self, and themselves. This awareness allowed them to approach their bodies from different perspectives, positionalities, and frameworks. They do not simply live in a body, but rather their bodies become an internal field site.

My participants intellectually dived into their bodies to examine its functions with a microscope. They familiarized themselves with various medical understandings of their bodily mechanism. Armed with this knowledge, they monitored their bodies. Their medical understandings became a map that orientated them as they closely examined, monitored, and navigated their bodies. Within this awareness, my participants took on various gazes of their bodies that fit their understanding or intention. Figuratively, they can peel back their skins and look within, they can look deeply at one organ, or they could look at a hormone as it moves throughout. However, their examinations did not remain with the biological. My participants take on the gazes of a psychological, emotional, phenomenological, spiritual, and social body.

CHAPTER FOUR: BODY WITH AND IN DEPRESSION

My participants did not only consult the biopsychosocial model and its practitioners for treatment. They approached various medical systems and forms of medical knowledge in their bodily navigation. Mental illness is seen as a brain disease, faulty cognitive functioning, and situated in the internal mind. However, my participants found that depression is a full body experience and sought treatment for depression as a full body experience. My participants found that depression manifested through the gut-brain axis, bodily held traumas, genetics altered by trauma, organs holding emotions, and through neuroplasticity and the nervous system in a body. In this chapter, my aim is to address the relationship between depression and the body outside of a cognitive lens. I chart the way my participants through their depression and their treatments had changing experiences of how they lived in their body and how their body was experienced. I argue that they experienced a *dissonance* between their material body, what they felt was their real body, and the situatedness of themselves in their body. This dissonance translated into varying ways my participants experienced their body/bodies. Lastly, I argue that the body is layered and exists as a multiplicity. My participants used their bodily experience as a compass to guide them in navigating this medical pluralism. In doing so, I link this chapter to my main argument that the body is a fluid construct and the experience of depression highlights the fluid way a body can be experienced. My participants' experiences of their bodies while living with depression problematized the theoretical constructs of the body: internal/external, subjective/objective, body/mind. These experiences resulted in a re-examination of how the body is present and experienced in illness.

4.1. DISSONANCE IN BODY: DEPERSONALIZATION CASE STUDY

> *"It's like I have dead man's finger."* My participant reached her hand up to her hair and twirled a strand around her finger. *"It's like someone else is touching my hair."*

[Extract from Ginny interview]

Ginny spoke about her bodily experiences after she started a different course of psychiatric medication. She was experienced a dissonance between what she felt was her body and her material body. The skin lining her material body did not align with what she felt was her 'real' body. Nor did she feel like the space her material body occupied matched up with the space her felt body occupied. She could experience the bodily sensations and sensory experiences of this material body, but she felt that it was the experiences of a different body. Ginny likened this experience to feeling the material body and experiencing the sensory experiences that belonged to another, to *"someone else"*. Even though she experienced this dissonance, this material body still belonged to her. Her body became both separate yet attached. She could send or receive signals or message to operate this separate body of hers. Cognitively she knew that this material body was hers, but the material body parts that fell outside the space her felt body occupied was numb and was not included into her bodily awareness.

Ginny had switched to a new medication to counter the depersonalization she felt due depression. This depersonalization made her feel as if she had been displaced from her body and her being existed outside of her material body. Previously, she felt like her sense of self was located in a tunnel, which watched reality or operated her body from a detached distance. As a result, Ginny talked to her psychiatrist about starting a different treatment. The new course of treatment with psychiatric medication had brough Ginny's sense of self back into her material body, but she also experienced "*dead man's finger"*. With the new course of psychiatric medication, the location of her 'self' shifted. She could be present in her body and feel like there was space within her body to occupy with her bodily 'self'. The medication took away the dissonance between body and the location of self. She no longer felt like a third person narrator and existing outside of her body. She was experiencing the phenomenon of looking through her body, but her 'self' and her felt body was at a distance. She could participate in her material body's living and could operate her body. In addition to feeling like she was placed back inside her body, the medication gave her the energy to start taking care of herself. However, Ginny began to experience a different type of dissonance in her relationship with body, where material body parts were dislocated from her sense and awareness of body, her felt body. Ginny's sense of self and felt body were residing within her material body, but her felt body and material body were not aligning. The idea of a body is often engaged with as a singular and a material constant (Scheper-Hughes and Lock, 1987), but my participants' experiences of body, in particular Ginny's experiences of body, reveal that there was a multiplicity and layering to the experience of body.

Ginny experienced the phenomenon of a dislocated self from her material body before the medication. Then, she had a simultaneous experience of having both an objective and subjective body. She had both a felt body and a material body. This objective body was attached to her, but these fleshy bodily objects were more associated with the objects in her sensory surroundings. This material body and its fleshy objects responded to Ginny's bodily signals, but she had no bodily awareness within the moving limbs. The medication allowed Ginny to feel like she once again resided within her own body, but her residency and occupancy was shaped differently than her material body's shape. The dissonance between her felt body and material body created the sensation that she was residing with a stranger, or *"dead man"*, in her own material body, which responded to her mental signals. Ginny is a waitress and her hands were not included in her felt body. She could give the command to pick up a tray, but have no bodily awareness within the limbs doing the action. The lack of bodily awareness made her clumsier and she had greater difficulty moving this material body, since these limbs were not a part of her sphere of bodily experiences. She experienced the phenomena of being both her body and not her body. Ginny attributes this lack of bodily awareness and distorted bodily sensation to the psychiatric medication by making her numb to her body. However, it reveals the unique bodily dynamics in the lived bodily experiences of those experiencing depression.

What became clear in Ginny's experience was the altered and altering bodily experiences with depression and the treatments of depression. The notion of body is nuanced into having a felt body, a material body, and a sense of self that come into play during the bodily phenomena of depression and treatment for depression. This experience spoke to the heart of what my participants experience in both their depression and in their treatments in regards to their bodies. There was a tension between the body that was acknowledged as their own and the body they sensed or felt as their own (Ratcliffe, 2008 and 2014). There was a tension between the appearing body and the lived, experienced, feeling body.

4.1.1. A DEPRESSED BODY

My participants found that their material body felt, functioned, and interacted differently as they entered into a depressive episode. Their embodiment shifted which resulted in shifts in how they took up space and where they felt they could take up space. This 'depressed body' was the site of intersection between the person, the illness, the body and thereafter medical intervention.

Ulima brought the notion of a depressed body to attention, because she had noticed that she embodied herself differently when she was depressed. She found that depression changed her how she lived in her body and how she operated her body. However, these changes stemmed from her bodily feeling. She found her depression gave her a lethargic sensation in her body. Movement took more effort and she tired more quickly after movement. Sleep and inactivity were easier for her to perform, which meant that her bed was a space she felt she could exist within. If she could get out of bed, her shoulders were dropped and she moved slightly *"slouched"*, which would give her tension headaches. The spaces she moved through and within felt heavy like it was pressing in and down on her. Her 'depressed body' would reflect this heavy sensation with slouching, arms pulling her clothes closed, avoiding eye contact, and minimizing movement. She had the sense of being de-situated, where she was "*taking up space"* that she shouldn't and the space was trying to push her existence out of the space.

This felt body, 'depressed body', translated into Ulima's performance of action and her speech. Her speech patterns changed in that her speech became *"hazy"*, *"always slow"*, *"no interest in speaking at all"*. Depression has been associated with the decrease in performance, where depression has impaired the ability to perform cognitive and motor tasks. The impairment increases with the level of effort that the individual requires to sustain it (Cohen et al, 1982). Depression seems to impact the operations of bodily movement. However, the impact goes into a deeper level of the body and its awareness and feeling attached to the bodily movement.

Anneka demonstrated this deeper level of distortion in her embodiment with her experiences of food and chewing with a depressed body. During the act of eating and tasting, they found that *"even chewing is super weird"*. The bodily movement of chewing became conspicuous and they were hyper aware of the movement. They focused their bodily awareness onto the one activity of chewing and felt that this activity was alien to their bodily movement. The bodily association to their bodily movement were not always congruous. They experienced a dissociation from self, or depersonalization, and they experienced a dissociation within the body Alongside this, the relations the body held with the act of chewing took on a different relatedness with the depressed body. Anneka found ingesting food during depressive episodes became *"repulsive",* because food had *"lost its flavour"*. When Anneka found the motivation or the effort to eat, their depressed body felt food consumption was like an *"invading entity"*. Their depressed body did not associate it as something that could reside within their body or become a part of their body. The act of chewing was alienated from her bodily movement, which meant that they needed to trick their body into eating via smoothies.

It became apparent that a depressed body altered the ways in which a person has a body, the relationship with having a body, and a person's embodiment. My participants noticed disturbances in their embodiment and their sensory experiences as they felt their body shift and they embodied a 'depressed body'.

4.1.2. BODY ALIENATION IN DEPRESSION

> *"That was when I started attending the psychiatric ward really often, because my depression was really bad. I was still going for therapy. I was consistent with my appointments, but I had health issues in-between. I started losing a lot of weight. I don't know why. I started having issues with food. Then my doctor took bloods and*

> *she found out that I had a lot of vitamin deficiencies. Vitamin B deficiencies, Iron, Vitamin D, all those B-complex vitamins... So I had to supplement those, but I still wasn't getting enough from the nutrients. Then my doctor said I needed to go see a gastroenterologist and find out what is actually wrong... Then that is when I got diagnosed with celiac disease and IBS. I was devastated in a way, because I had lost so much weight. I think I used to weigh 50kg. I went down to 37kg in less than a month. It was really, really bad. So I stopped focusing on my mental health to focus on my bowel issues. Then I had chronic migraines on top of the bowel issues. Fast forward to 2017 at the end of the year, I had to go see the gastroenterologist, because I still had issues and I was admitted to hospital."*
>
> *[Extract from Ulima interview]*

There was a tension between my participants' material bodies and their felt bodies. Within in this tension, my participants were introduced and interacted with their multiplicity of bodies and notion of body in varying manners.

My participants brought two cases to my attention during the interview process, where they had a unique relationship with their material body and their felt body. In the first case, Ulima had to learn about her biological body and understand its operations from a new perspective in regards to its impact on her depression. Ulima found that depression and trauma entered into her biological bodily experiences with it manifesting as bodily issues. Ulima developed psychosomatic symptoms in her digestive tract, nutrient deficiencies, celiac disease and Irritable Bowel Syndrome. Her mental illness shifted in its area of operations in that it was no longer just 'mental'. It changed her bodily biological makeup and operations, which resulted in new embodiment and a new navigation of her lived body.

The gut has been found to be an integral part of the mental health operations as it is the main contributor to producing serotonin in the biological body. Research has found that there is a gut-brain axis (Evrensel and Ceylan, 2015). The gut microbiota is important to the development of brain systems, which are capable of delivering neuroactive substances. This microbiota could activate the nervous system, the neuroendocrine system, and the immune system (Evrensel and Ceylan, 2015). These studies demonstrate that the gut health and mental health do not perform independently of one another and have ramifications on each other. Gut health and mental health are interconnected by various bodily symptoms. However, it was Ulima's engagement with this gut-brain relationship that drew attention. She held this tension between her felt body and her biological body. Her connection with her material body was not simply one she lived through or with. She perceived it as a living object connected to her and she seemed to pull away from a personal connection with this material body. The material body became a site to act upon or within. As Ulima moved into a depressive episode, she became alienated from this material body. In order to navigate this material body and the symptomatic gut issues, Ulima was given new means of understanding and managing her material body and what could become a part of this body. It meant that she had to avoid particular food and drink groups, such as dairy and gluten, but she weaponized these intolerances during depressive episodes. She purposefully placed this material body under attack and induced bodily trauma- *"I started self-harming, eating wrong foods, that year."*

In the second case, Ginny spoke about her bodily relations during one particular depressive episode. It was not so much the tension between what she felt as her body and her material body, but the alienation and disintegration of her material body in this dynamic. The material body became perceived as an object and de-personalized. However it seems in this particular depressive episode with Ginny, she disassociated her sense of self from her material body – *"I don't buy into mind-body dualism, but there is a point where your body means nothing".* The experiences of bodily living in her material body seemed to fade out of Ginny's felt body. Ginny becomes severely alienated from her material body in that she feels like there is no longer had a material body to embody – *"you might as well be dead".* She rather embodies the experience of 'being dead' in her material body. During these depressive episodes, Ginny experiences severe de-personalization and de-realization with her body and her surroundings. She called depression a place of non-recognition and similar to *"absolute apathy*". She continued that it was a *"non-differentiation"* occurring between her body and *"every atom in the universe"*. In her experiences of depression, the concept that her material body was categorically separate from her environment seems to disintegrate. Her material body was disassociated and assimilated into the environment beyond the body. Her body rather becomes alien, *"nothing",* or *"dead"*. It becomes a part of the external world. Accompanying this non-differentiation, the external world also loses form and becomes molecular 'stuff' floating around, which her body becomes a part of. Ginny elaborated on this, *"it is all atoms floating around, You can build a horse out of Lego and you can build a castle out of Lego, but at the end of the day it is still Lego*". The experience of a disturbed embodiment and severe alienation from her material body caused her material body to become a part of this external world, where it is merely an assemblage of 'Lego' attached to her – *"I look at me and I look at a brick and I feel the same thing".*

Ginny had experienced a severe degree of alienation and de-personalization with her material body, but thereafter she transitioned out of her depressive episode and regained a sense that her material body is a part of her felt body. After seeing the external world and her material body as similar molecular 'stuff', she claimed that it did something profound to her, when she ‘came back’ to herself. The perspective she gained during her depressive episode enlightened her to her bodily operations and the multiplicity of body. Ginny went on to explain, *“When you genuinely don’t care about yourself, it erases the boundaries between what you hold sacred and what you are used to discarding. When you are able to see the connection between yourself and the trash you throw away, you are able to see that it is fundamentally equal in value.”*. Ginny began to re-evaluate how things became a part of her material body and then her felt body, which changed her relationship with *“stuff”*. The most significant impact of this changing relationship with *“stuff”* can be seen in her eating and food habits. In the depths of her depression, she could look at a broccoli and think that she was the same molecular stuff as the broccoli.

> *“It does something really profound when you come back to yourself, like when you come out of that state. You are able to assess yourself and your surroundings in a profoundly new light like the most radical changes. I have never seen anyone happy and sustain it. I have seen people go through depression and change themselves and sustain that. I have never seen anyone saying "You know what I should do. I should exercise more, because I am going to be skinnier and have that work out well for them". I have seen people reach the depths of depression and be like "I am the same as this broccoli I am eating".”*
>
> *[Extract from Ginny interview]*

With the perspective she held, her material body and the broccoli were fundamentally the same. Ginny found it amusing that losing parts of yourself or yourself can help you better understand yourself. Once Ginny’s material body regained personalization, she retained this profound connection with food. She felt the connection between food, her material body, the environment and herself. This has had a longer lasting and sustainable impact on Ginny in regards to her dietary requirements for wellbeing. The disturbance in embodiment and the tension between material body and felt body caused my participant to build a new gaze onto the body and understand the complexity of body. In addition, she used this gaze as a means to navigate the complexity of a depressed body. Ginny termed this navigation “*hacking*”, where she would use food to tap into her bodily operations. *“I found that understanding these mechanisms has been really helpful. Your neurons need potassium to fire and they don’t fire properly without it. That is a crazy thing. You can hack your psychology by eating more avocado.”, says Ginny.*

Ulima reiterates a similar sentiment, “You have to work towards changing your brain structure”. This statement made by Ulima illustrates my participants’ approach to their bodies. My participants viewed their bodies as malleable in its biology, chemicals, psychology, and so forth. There is this plasticity to their bodily make-up and bodily perception, which they could *"hack"*. In order to navigate their lived bodies, my participants needed to become familiar with the mechanisms within their body.

4.2. UNREALITY FROM A SENSORY GAZE

This section aims to examine the depressive experience and dissociation from a phenomenological framework and uses a sensory gaze. Dissociation is the term used to indicate a detachment from reality that manifests across a spectrum of severity (Niciu et al, 2018). Dissociation can include depersonalization or detachment from self, as explored in the aforementioned section, but it can also include derealization, or 'unreality', which is the detachment from surroundings (Niciu et al; 2018). My participants introduced me to this sensory bodily gaze during their explanations of their experiences of depression, in particular the experience of 'unreality'. This gaze influenced how they related to their bodies and navigated their multiplicity of body. In turn, this gaze and navigational ability influenced their understanding and choice of treatment. Disassociation creates the experience of disconnecting, departing, and *"taking a break"* from 'reality'. This particular depressive experience and phenomenological experience made my participants aware of how 'reality' was perceptually and subjectively constructed. Throughout various depressive episode, my participants came to hold both a 'reality' and an 'unreality'. Both 'reality' and 'unreality' can be understood as a sense of 'reality' rather than being true or false, because both experiences have a tangible phenomenology in the sensory body. My participants have a heightened awareness and sensitivity to their senses and sensory experiences. They used their heightened awareness and sensory experiences to navigate depression and treatments. In addition, they used it to monitor a treatment's effects and their state of being.

4.2.1. UNREALITY IN SIGHT

> *"I return to the same place. I recognize depression by the scenery, by how things look. Everything looks like a cardboard cut-out of itself. Things loose shadow. Things loose depth. Shapes blend into each other…"*
>
> *[Extract from interview with Ginny]*

In perceiving her surroundings, the scenery for Ginny lost its depth and flattened into two dimensional representations of itself. Her surroundings lost their substance, properties and spatial relations. The scenery lost its tangibility and feeling of realness to Ginny in her perception and experience of 'reality'. Ginny attributed this phenomenon to her depression, or depressive episode, because she felt like depression makes her experience *"some other kind of reality"*. She feels and experiences a shift in her sense of 'reality', where she feels like a departure from a 'reality' experienced by others into a 'reality' of her mind. In this shift, depression contributed to a particular shape, feel, and construction of 'reality'. It was not that the scenery itself changed, but rather what appeared and how it appeared in her sense of reality that changed in its phenomenological experience. As depression manifested, the properties and substance to 'reality' and experience of it altered alongside her shifting sensory experiences, bodily state, and bodily feelings.

In Ginny's *"returning to the same place",* she experiences a different sense of reality when she is depressed. However, she does not mean it figuratively. Ginny explained that it is a *"super tangible phenomenon"*. Her body geographically and phenomenologically moves through dissociation to this *"same place"*. How she is situated and how she relates to her 'place' shifts in her connection to her sense of 'reality'. 'Reality', as referred to in this paper, denotes the phenomenological state of things and how those things exist in our experiences, sensations, and perceptions. The quality of being lifelike and the experience of realness is integral to the conceptualization of 'reality' (Merleau-Ponty, 1964). The term 'realness', in either alteration or in diminishment, is a referral to the overall status of the world in experience (Vagra, 2012). Ginny found that 'reality' is not abstract or independent from her, her subjectivity, or her body. Neither her body nor reality were a fixed backdrop or site for experience or depression to play out. We are participants in a 'reality' and connect to a sense of 'reality' rather than moving through an abstract 'reality' as a voyeur (Ratcliffe, 2008, 2014). My participants connected to their fluid 'reality' through the medium of their bodies, which their sensory experiences facilitated.

These sensory experiences simultaneously made Ginny a participant, situated, and belonging in a world. Secondly, sensory experience played an important role in constituting and constructing her sense of reality. It turns the abstract 'reality' into a connectedness, relational, relatedness. Ginny's senses were a means for her to encounter and experience a reality. Perception, sensory experiences, and bodily sensations give content, context, properties, substance, and subjectivity to the experience of 'reality'. It is within this experiential field that a world or 'reality' gains realness (Ratcliffe, 2014; Merleau-Ponty, 1964). Each sense and type of sensory experience contributed to an understanding of the living with depression and different ways of understanding living in a world with depression. Thereafter, this sensory information contributed to different ways of engaging and experiencing the depression, 'reality', or my participants' bodies.

Ginny could, as she put it, *"see depression"*. Ginny focused on the perceptual qualities and sensory experiences of 'reality' in explaining, describing, and recognizing this *"super tangible phenomenon"* of depression. In particular, she experienced visuals shifts. Her perception of the external world informed her about her relationship with her depression. Ginny's visual experiences of depression in her surroundings illustrate the phenomenological 'affect' on her sensory ability of sight. However, it was not so much as her losing her sensory ability to see and gaining blindness. Rather, it is the 'affect' of depression, or how it felt to inhabit a world structured by depression, on her sensory engagement and the role of sensory experience in producing realness and illness. The tangible aspects of a world lose their realness in her sense of reality, when their properties changed in the perceived substance. The experience of depression created the experience of warping senses and perception.

Ginny described how her bodily states and bodily feelings relate to her perception. She argued that there was a link between her sense of 'reality' and her bodily state. It impacted what aspects gained attention, realness, and relatedness during depression, or a depressive episode. Ginny held the understanding that what is perceived resonates with bodily feeling and the bodily state. She used the example of colour in her visual sensory experiences to explain this resonance. "*It's because it loses its tone. Colour…it's not like colour means nothing. It's not some philosophical, abstract meaning…Green looks the same as blue. Blue looks the same as green. It is monotone.", Ginny explained,*

Ginny found, aside from losing depth and dimension, that the visual world and her 'reality' during depressive episodes became devoid of colour. Ginny feels as if she loses the sensory receptiveness and connection to colour in a depressive episode. In other case, Ginny found her sensory experiences reflected her emotional or bodily states. She used example of the emotional and phenomenological experience of sadness . During this experience, 'reality' was perceived in colours of blue, which is why she understood sadness being termed as *"having the blues*". She found a connection between colour and depression. She termed depression as *"the colour of no hope"* to reflect the lack of resonance with colour and dissociation with the external world in her sense of 'reality'.

Ginny came to understand, monitor, and experience depression through and with her sensory experiences, perception, and the impact on her felt body, because for her it is a *"super tangible phenomenon".* The unfolding of depression would manifest in her sense of belonging, situatedness, and engagement within a world. It changed her the sense of realness and reconstructed her sense of reality.

4.2.2. UNREALITY IN THE VARIOUS SENSES

Ginny brought attention to the change in the sensory experiences of depression. While Ginny found that depression became tangible in her visual perception of the world, sight is not the only sensory contributor to a sense of 'reality'. My participants found that their various sense of taste, touch, smell, and hearing became implicated in the experience of living with depression. Each sense and sensory experience gave a different understanding of being and belonging in 'reality' with depression. These sensory experiences also provided different understanding, properties, and substance to 'reality'. With each sense, my participants demonstrated the 'affect' and aspects involved in the phenomenology of living with depression.

While each sense contributes to an understanding and sense of reality, my participants found that the warping of their sensory experience and engagement often leaned towards one particular sense. This could be taste, touch, smell, hearing, sight. In one case, Maria found depression affected her auditory sensory experience, engagement and the attached bodily feeling. She attributed this 'affect' to how she encodes her memory through sound and how she remembers *"the sound of things"*. It was this vital role of sound in her embodiment that attuned her to the sensory experience of depression. She used her auditory senses to monitor her depression. It was during a discussion about monitoring her depression that Maria made the comment: *"One of the first real warning signs of depression for me is when I stop feeling music. When I can't get a song stuck in my head, that is really worrying*".

My participant's bodily sensation and bodily feeling, in regards to auditory sensory experience, was the first *"warning sign"* of her changing experience of being and the onset of a depressive episode. This *"warning sign"* signals a disassociation or disconnectedness that occurs in her experience of depression, but it also signals a disconnect and de-situatedness from a particular sense of 'reality'. Thereafter, it was her sensory engagement with her auditory sense that became affected during a depressive episode. As she moves further into a depressive episode, her engagement with auditory sensory experiences lessen. She found that in her depressive episodes that she did not listen to music at all. In addition to this sensory disengagement, she found that the qualities or substance of sound lacked differentiation in her depressive episodes. She compared the phenomenological experience of music to that of silence – *"it might as well be silence"*. In this comparison, music and silence became synonymous in its sensory experience.

However, Maria found the reverse could also occur, where she became *"super sensitive"* to auditory sensory stimulation or experience. This paradoxical experience refutes the notion that it was a diminishing or loss of sensory engagement, but rather depression changed the experience of sensory itself and how my participants engaged with the sensory. Sensory experiences are a constant that either moves to the fore or background of the experiential field of being, or of ‘reality’ (Ratcliffe, 2008, and 2014, Merleau-Ponty, 1964). Depression changed the dynamic engagement within this experiential field of being, which can either be disengagement or an over stimulus of sensory experiences. At times, my participant found auditory sensory experience to be jarring and produce uncomfortable bodily sensations and bodily feelings. Maria stated that it could become *“too much to handle”.* If the sensory experience did not resonate with her bodily state and bodily feeling during a depressive episode, it caused feeling of agitation and feeling overwhelmed. It became compared to, or felt as, an intrusion into her sense of reality. She found this often occurred in settings where she could not control the elements entering her auditory engagement and experience .*“I used to go to shopping centres with my own music, because if the shopping centre was playing something I didn’t like… it affects me”*, says Maria.

This sensory sensitivity changed how she had to engage with her body and, as a result, how she engaged with her surroundings. She could no longer move through these spaces without being conscious of the sensory sensitivity, her bodily feeling, and the ‘affect’, or interconnectedness. It meant that she had to carry her headphones around with her. She had to match sound and the bodily sensations that it produced with her bodily state or bodily feeling. Depression does not remain within the physiology or the psychology of the body, but its interactions with the sensory create the experience of ‘living’ with depression. The relationship between Maria and things within her ‘reality’ were affected as depression manifested. In her sensory phenomenology, Maria experiences ‘reality’ through the medium of her body, but there is not a distinct boundary between what is ‘body’ and what is the external, or the ‘reality’. Sensory experience does not end at the limits of a corporeal body or build its experiential field on the surface of the body (Ratcliffe, 2008 and 2014). Our sensory experiences also extend into and from what is felt as the body, how that feeling relates to the bodily, and the bodily sensations it induces. There is a fluid interconnection as they both create and affect one another. Bodily sensations reveal this fluid interconnection and relatedness between body and ‘reality’. Maria monitored, regulated, and had to navigate these sensory experiences and her bodily sensations from ‘living’ with depression.

Maria’s auditory experiences with depression bring bodily sensations to the fore in her experiential being, but is not just the bodily sensations of these experiences that change in between the self and ‘reality’. Anneka spoke at length about her bodily feeling and the bodily association to things in ‘reality’, particularly food in their case. Anneka, who uses their sensory engagement with taste to connect with the world, had their relationship with food change. They love to cook, feed people, and try new recipes. Food plays a central role in connecting with the social and their personhood. They would often host dinners or cook for people. Food was their means to centre themselves within their community and build a support network. However, they found ingesting food during depressive episodes became *"repulsive"*. In their sensory engagement with food, food *"lost its flavour"*. Food did not produce different sensory experiences of taste and bodily feeling. Food tasted similarly and as well as *"without flavour"*. They also spoke about their bodily feeling and association to the body while eating. When they found the effort or motivation to eat, their body found food physically repulsive like an invading entity. This bodily feeling meant that Anneka had to trick their body into eating by liquidising their food and having smoothies. Alongside the bodily feeling of repulsion, the bodily movements associated with tasting and eating were altered. They found *that "even chewing is super weird".* The bodily movement of chewing becomes conspicuous.

4.2.3. FEEL OF DEPRESSION AND UNREALITY

My participants brought attention to the sensory experiences, bodily sensations, and bodily feeling in the phenomenology of depression. It is during these descriptions of differing sensory experiences in depression that my participants brought up the notion of different types of depression. They established how depression changed their experience of being, but there were particular changes in this being and their experiences that had them categorizing depression into different types or manifestations. More than simply being a bodily occurrence, depression has a 'feel' to it and each type of depression had a particular 'feeling' to them. By 'feel' or 'feeling', depression would manifest in their being, but it would be accompanied a type of bodily feeling, bodily sensations, and sensory experiences. In turn, my participants would experience a particular sense of 'reality' and particular manners in which they relate, connect, perceive and belong in a 'reality'. It could be the 'dimming' of the world's colour or the 'flattening' of the scenery, where tangibility and the 'realness' of a world changes. The world might become overly loud and chaotic. 'Reality' might become flavourless. My participants within their depressive episodes experienced a differing experience of being and sensory experience of 'reality', or 'realities'. While Ginny was trying to explain her visual experience of depression, she spoke about how it was a *"super tangible phenomenon"*, but she found that depression was a *"demon that changes shape"* or a *"shapeshifter"* in how it manifested in her experiences. While depression remained a *"tangible phenomenon",* she would and could experience depression differently.

> *"I have groundhog day depression. When I say groundhog, it is the word that is most apt metaphor. There is that one and there is the flat depression, which is kind of an*

> *apathetic…I look at you and I look at a brick and I feel the same thing. Then there is the anxious, neurotic one, which is like having static in your head, like radio static"*
>
> *[Extract from Ginny interview]*

Ginny elaborated on this 'shapeshifter' phenomenon of depression. Each phenomenon was accompanied by a particular sense of 'reality', bodily feeling, and sensory experience. What Ginny termed as her *"groundhog day depression"* was the experience of desynchronisation with time and the accompanied bodily feeling of being weighed down, buried, and stuck. She would experience discontinuity between her sense of 'reality' and her sense of other people's 'reality'. In these depressive episodes, the external world becomes uncomfortable. Ginny contrasted this phenomenon of depression with her flat depression and her neurotic depression. Ginny's flat depression stands out to her by the sensory interference with realness in her sense of 'reality'. This type of depression presents her scenery as *"cut-outs"* of itself and a loss of its sensory substance. She found that her flat depression was accompanied with a disengagement and disassociation of her sensory experiences. In addition to recognizing this depression by the sensory perception of flatness, she had prevailing experience of apathy within her bodily emotions, undifferentiating bodily feeling, and a lack of bodily sensations.

The greatest contrast in her depression experiences is between her flat depression and neurotic depression. Ginny's neurotic depression manifested as the opposite of her flat depression. Her bodily feeling and bodily sensations were the most noticeable in this experience. She experienced a sensory sensitivity and an over stimulus of sensory experiences. In these sensory experiences, she founds that her bodily feeling and bodily state clash with the bodily sensations produced by these sensory experiences. This lack of resonance between body and 'reality' caused her anxiety and bodily discomfort. Aside from the produced bodily sensations, her felt body was experienced like *"radio static"*. In this neurotic depression, she felt as if the external world took up occupancy in her internal world, or her "*head"*, which left her with the experience of having no space in her body for her 'self'.

> *"Looking back on my different types of depression, my suicidal depression is very different from my worst depression. I could be suffering and I know I could be really, really be suffering, but each time I have been suicidal it has been a different experience. The one time I decided to actually try was when everything became nothing. The time, space continuum, what people meant... It was just nothing. It felt like it was just fading away. I am done… this is my time now"*
>
> *[Extract from Maria interview]*

Depression can ‘feel’ different as my participants “*go into it”,* as quoted by Ginny. My participants experienced a shift in their sense of ‘reality’ and their experience of being While each depression had a ‘feel’ or ‘feeling’ to them, different aspects in my participants’ sense of reality would become malleable at different times or in different ways. In Maria’s explanation of her types of depressions, she spoke about her suicidal depression with its dissociative experiences. Maria found that her dissociative depression had a particular ‘feel’, but she disassociated with different aspects in her sense of ‘reality’. During her years at university, she found that she could play around with the meaning of the world and the way meaning was constructed. She attributed this particular formation of her dissociative depression to her Nietzschean and nihilistic beliefs at the time. Nihilism is the belief that all values are baseless and that nothing can be known or communicated (Luis and Vazquez, 2020). Additionally, Nietzsche argued that there is only an aesthetic phenomenon or supa-sensory reality that the world eternally justifies (reference). Nihilism is then the awareness that every belief is necessarily false because there is no one true world or one true meaning (Luis and Vazquez, 2020).

Maria could play around with the meaning attributed to a world by society and how she should relate to the world. Despite *“everything”* becoming a malleable construction to her in her perception, she found that her emotional ties to people were the only thing she couldn’t play with. However when she started working, her dissociative depression changed in that the physical world became more pronounced and her social connections were the malleable elements. In Maria’s dissociative depression, *“different things lose their meaning at different times”*. It was during one of these dissociative depressions that Maria attempted suicide. She experienced an extreme degree of dissociation from her ‘reality’, where “*everything became nothing”* and there were no tethers to ‘reality’. Maria experienced ‘reality’ fading away from her. In Maria’s *“worst depression”,* she experiences *“suffering”* and pain in her bodily feeling and felt body. However in her suicidal depression, she experienced the bodily feeling of non-existence and felt blocked off from her emotions.

Maria attributed these shifting malleable connections and constructions within a particular ‘feel’ of depression to the most destressing factors in her life at the time of a depressive episode. These destressing factors influenced how depression would manifest in her ‘reality’. Maria used the example of existential dread arising from her nihilistic perceptive to demonstrate this point. Existential dread would commonly manifest in her depressions during university, where she would question the nature of things, and this manifestation would impact all her attachments. This dread used to cause her a great deal of distress, because the world would turn into *“nothing”* and it was *“empty”* during a dissociative depression. In this destressing factor, there was a particular premise from her nihilistic perspective that caused the most destress - *"that nihilistic perspective of genuinely nothing means anything and you ascribe emotion to it"*. During her episodes of dissociative depression, Maria found that she wanted to escape 'nothingness' and escape the sense of 'reality' wherein she existed, which brought forth her suicidal feelings and suicidal tendencies. However, this desire to escape 'nothingness' and her manifestation of dissociative depression changed as her stressors shifted. As she came to peace with *"the uncertainty of it all"*, the feeling of existential dread was no longer the stressor and the predominant feeling of her dissociative depression. While she still experienced disengagement and unrelatedness, the previous stressor become a navigation tool and a sign of her bodily state for her forth coming dissociative depressive episodes. She no longer wanted to escape a world that intrinsically had no meaning, but rather she wanted the world to regain meaning - *"I used to believe that nothing had meaning apart from the meaning you give it. Now, I believe that everything has meaning. You just have to be in it or not"*. The previously destressing factor became a source of comfort and changed how she related and perceived her sense of 'reality' in dissociative depression. She moved from a sense of 'reality' that held 'nothingness' to a sense of 'reality' where she could not access its meaning.

Distress, fatigue, apathy, suffering were some of the experiences ascribed to 'feeling' depression However, this *"shapeshifter"* had multiple manifestations in feeling and experiences of "living with". The DSM-5 includes particular emotional experiences in depression and 'feelings' of depression in its symptomatic criteria, but my participants spoke about experiences and 'feelings' within depression that were not in this diagnosis description. There is a selection process of experiences, feelings, and emotions in the construction of the DSM-5 criteria for depression. The 'feelings' and emotions of Major Depressive Disorder are described by hopelessness, apathy, persistent sadness, loss of interest, fatigue, worthlessness, and excessive or inappropriate guilt (American Psychiatric Association, 2013). Within this framework, emotions and 'feelings' are ascribed meaning. Alongside this, these emotions and 'feelings' get classified into good/bad, important/unimportant, and acceptable/unacceptable. In the psychiatric gaze, the 'feels' and 'feelings' of depression are classified under the category of emotions and bodily feelings to be rectified, but only particular 'feels' and 'feelings' of depression are considered in the psychiatric gaze.

While depression as an illness is disruptive in my participants' lives, they had also experienced particular senses of 'reality' and 'feelings' that do not fall into either good or bad category in their depressive episodes. Ginny spoke about one of these 'feels' of depression. In this particular 'feel' of depression, she found it a profoundly spiritual experience, which she called an *"almost psychedelic"* experience. Her sense of reality felt *"otherworldly"* and *"mystical"*. She became aware of the beauty in the impermanent, transient, imperfect things and developed this empathy or connection with it - *"You tap into some beauty that you* *wouldn't otherwise… that you wouldn't see. There is pure connection, pure just being with people, pure just being… and it has nothing to do with you. It has nothing to with your ego".* This 'feel' of depression often occurred between Ginny's decision to die and when she plans to *"actually go through with it"*. She experiences relief, bliss, and a sense of peace. It was the accompanying sensory experience, where she revels in the temporary beauty of the world, that made her decide to continue with life and endure the reoccurring depressive episodes – *"Every time I have made up my mind and I start to say goodbye, I am like 'oh…I see'."* Through this spiritual 'feeling' of depression, Ginny brought to light a typecasting of how depression should 'feel'. Rather, Ginny depicted a range of 'feeling' and experiencing depression in her 'reality'.

As my participants would *"go into"* a depressive episode, there were particular 'feels' and 'feelings' to the experience. These manifestations within a 'feel' of depression would adapt, shift, and change accordingly. It led them to call to depression a *"beast with many faces",* a *"shapeshifter"*, a *"demon"*, but it was also a *"journey"*, a place of *"enlightenment"*, a *"loss of ego"*, a *"shifting of priorities*", and a *"great transformative thing"*.

4.2.4. THE EXTERNAL SELF AND UNREALITY

> *"My hallucinations were actually showing me how I was actually feeling. If I wanted to self-harm, I would hallucinate. I would have visual hallucinations or auditory hallucinations that would encourage me to self-harm. Or I would see images of people harming themselves. That is how I began to understand how I am actually feeling".*
>
> *[Extract from Ulima interview]*

Ulima experienced a disembodied self in her surroundings through her hallucinations that informed her about her bodily state, emotions, and feelings. These hallucinations for Ulima mostly appeared during times of suicidal thoughts or during self-harm urges. She would see people hurting themselves or people trying to kill themselves in her hallucinations. Ulima's sensory experience and perceived 'reality' prompts the question as to how and where one can experience their body and their 'self'. She had a sense or presence of her body in the world through the perception and sensory experiences with her sense of 'reality'. Ulima found bodily sites and bodily states within these connections of world and body. In Western frameworks of thinking, there is a dichotomy and separation between body and world (Scheper-Hughes and Lock, 1987), but my participants do not experience this static boundedness and separation of world and of body. Ulima experiences of her bodily state and bodily feeling became reflected in the 'external' world. She 'externalized' what and how she felt. While depression was mediated through the body, Ulima found that her biological body was not her only bodily site.

Rather, her body could be and was experienced in the sensory relationship with an ‘external’ world. In this relationship and connection, the perception and sense of ‘reality’ became a reflection of her bodily state like it was also a disembodied/detached, or an embodied/extended, site of her body.

Ulima made the comment that she had become hypervigilant of her surroundings, because depression had made it hard for her to navigate her own emotions. She had Major Depressive Disorder with mood-congruent psychotic features. Mood congruent hallucinations are particular to the phenomenology of depression. It is considered a subtype of a severe form of depression (Maj et al, 1990). Her perception of her surrounding became the markers of her bodily state and bodily feeling. She would write down her hallucinations and use them to examine and understand her health . Ulima explained, *“If I felt suicidal, I would really look at my hallucinations and write them down in my journal that made me understand ‘I am feeling this way’ or ‘I am feeling that way’. Sometimes when you are depressed, it is really hard to navigate your own emotions”.* Ulima’s hallucinations and sensory experiences were a part of her experiences of depression, but she turned them from symptoms into coping mechanisms to navigate her depression. As the hallucinations were mood congruent, this symptom of depression, or manifestation of depression, allowed her to track her moods.

These mood congruent hallucinations appeared through the sensory experiences of an external ‘reality’, whether it was visual or auditory. It challenges the assumption that an illness resides and is experienced within the body. Rather the phenomenology of depression occupies the spaces wherein a body can exist and the interconnection between body and ‘reality’.

4.3. CONCLUDING THOUGHTS

This chapter examined my participants changing experiences in regards to dissociation a symptom of depression. My participants experienced dissociation through depersonalization, disembodiment, and derealization.

In the first section of this chapter, I present the case study on depersonalization, where my participants’ relationship between depression and the body was addressed outside of a cognitive lens. My participants, through their depression and their treatments, had changing experiences of how they lived in their body. Secondly, they had changing experiences of how they experienced their bodies. There was a dissonance between their material body, what they felt was their real body, and the situatedness of themselves in relation to their body. While they navigated living with depression, they found that their relationship with their body and how they related to having a body changed. Furthermore, this changed how they, the subject, was situated in relation to their body. Ginny's subjectivity was detached and she felt at a distance to her body before starting the new medication that caused "*dead man's finger*". Her experience ruptured the notion that the body is singular or a material constant. The body is both layered and fluid in my participants' experiences with their bodies during depression.

Secondly, my participants continued to experience dissociation through disembodiment. This dissonance translated into varying ways my participants had, performed, moved, or inhabited their bodies. My participants' mental health and mental illness affected their ways of embodiment, bodily expression and bodily engagement. While living with depression was disruptive to my participants, they couldn't categorize the experiences of depression solely into good or bad. Depersonalization and disembodiment became a tool for my participants to navigate their bodies. Ginny found that depression helped her reimagine her body. She began to relate to her body in new ways, which helped to create sustainable change to maintain her well-being.

In the latter section of this chapter, I further present my ethnographic data. I approached the body from a phenomenological gaze and introduced a phenomenological framework to understand disassociation, in regards to derealization and 'unreality'. I illustrate my participants' sensory experiences and experiences from an 'unreality'. Ginny sees depression as she enters a depressive episode. Depression was a *"tangible phenomenon"* rather being restricted to cognitive or behavioural operations. This tangibility of depression manifested through my participants sensory experiences and their shifting sensory engagement. These experiences problematize the site of depression as being an internal and bodily phenomenon. My participants sensory sensitivity and sensory engagement highlight the interconnectivity that existed between them, a body, and their environment. This interconnectivity was made murkier with Ulima using her hallucinations and her external environment to understand her health. Ulima did not experience the static boundedness of a body, nor the dichotomy between an external/internal environment. My participants used dissociation and their subsequent experiences to navigate their depression and their well-being.

CONCLUSION

As they shift through dissociation and these various bodily states, my participants take note and monitor their bodily fluidity. They develop a bodily awareness and use it to inform their agency. They used their self-monitoring to seek out treatment and navigate their bodily experiences to achieve or maintain well-being. Additionally, my participants' bodily experiences broadened their understanding of health and their approaches to well-being. My ethnographic chapters demonstrate how my participants' phenomenological gaze, combined with their experiences, broaden the approach to and understanding of depression. My participants build upon the depressive symptom of dissociation – depersonalization, disembodiment and derealization. The body is often a taken for granted factor in research. However, through living with depression, the relationship with a body is problematized both theoretically and experientially.

While living with depression, my participants experienced having a body, their body, and the relationship with a body that broke down the subject/object, body/mind, and external/internal dichotomy. They came to experience the body as layered and existing as a multiplicity. The body was not solely material, nor did it end with the skin barrier. They experienced depersonalization and disembodiment, where at times they were not the full occupants of the material body, or they subjectively felt detached and existing outside the material body. Additionally, there is a distinction between their material body and their felt body. They drew attention to where they or how they experienced a body rather than had a body.

My participants experienced a multiplicity within their body - felt body, sensory body, sense of self, material body, dis/embodied body, medical body, etc. These layers of having and experiencing a body did not necessarily align as a unit. At times, their sense of self was not centrally located within the body due to depersonalized. They were outside or detached from their bodies, or they did not fully occupy their material body. At times, they experienced a displaced or external sense of self, where they monitored themselves, or their body, through changes in their environment. This could be done through hallucinations or through changes in their sensory experiences.

They experienced their bodies as a fluid construct upon which they applied various medical gazes to navigate medical treatments. Their interactions with various medical practitioners and medical systems exposed them to various medical gazes, but their experiences from living with depression had them gazing upon their bodies with new perspectives and forming new relationships with their bodies. This arose from changing forms of embodiment, or ways of occupying a space, which required my participants to adjust how they moved through a space or interacted with an environment. This was pronounced with the changes in sensory sensitivity, where their sensory engagement changes as they moved in and out of depressive episodes. They developed a heightened receptivity to sensory stimulation resulting in sensory overstimulation. In other cases, they experienced a sensory deprivation, which signaled the arrival of a depressive episode. My participants found that they needed to complement their body's sensory experiences with the sensory experience of the surrounding environment. The distinctions between internal and external in their experiences of their body were not clear.

My participants viewed the biopsychosocial model as one model in a complex system required for care and treatment for those living with depression. They have offered insights into how to expand the medical system in the Cape Town context, to shift from a reactive approach to responsive and giving care approach. Ulima suggested approaching illness as a phenomenon rather than isolating it to a particular location in the body and a singular specialized doctor. She argued that the body is an eco-system and that there is a need for a more dynamic approach to health, where there are teams of doctors collaborating from their various perspectives to build a treatment strategy. In addition to reimagining how to administer treatment, my participants also reimagined out-patient care and community care. It was suggested that there be depression sponsors. Those, who have achieved a level of maintenance, sponsor and advise someone adjusting to their diagnosis, or living with depression. This idea was taken from the recovery sphere of addiction treatment. My participants argued for a system of care and healing beyond the current frameworks of hospitalization. The proposed inter-disciplinary and medical pluralistic approaches are a means to address the needs of out-patients in the mental health services and community-based care. They made suggestions on how to restructure mental healthcare services and gave solutions to address the treatment gap in mental health services. There is an opportunity for further research in this context. This future research could be used to respond to the mental health system and treatment gaps for depression in Cape Town.[3]

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[3] Word count: 28 481

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