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Caregivers and people with disabilities: relational embodiment of stigma and concern in Egypt

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A Thesis Submitted to the Cynthia Nelson Institute for Gender and Women's Studies

In partial fulfillment of the requirements for the degree of Master of Arts in Gender and Women's Studies in the Middle East/ North Africa

Specialization in Gender and Women's Studies in the Middle East/North Africa

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DEDICATION

I dedicate this thesis to my parents, Dr. Magdy Omarah and Dr. Wafaa Zada

For all their love, support and continuous encouragement and faith I LOVE YOU

BOTH THANK YOU FOR EVERYTHING

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ABSTRACT

Caregivers and People with Disabilities: Relational Embodiment of Stigma and Concern in Egypt

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This thesis explores disability as a relational model and how stigma is produced within an Egyptian domain. This study focuses not only on People with Disabilities (PWDs) but rather on their primary caregivers i.e. parents and siblings. I examine how stigma affects the relationship between caregivers and their disabled family members. I also explore how some relatives run the risk of being stigmatized themselves by association develop a 'stigmaphile response'. Thus, exploring the notion of concern that is inevitable in caregiver-PWD relationship and how this embodies individuals into new subjectivities under society's control. Furthermore, this thesis aims at finding a way to combat the stereotypes that arise from being associated with PWDs and also aims at shifting people's perspectives into considering that disability should not be categorized it is too diverse and many aspects which differ from one disability to the other thus cannot be categorized in to a "new gender". My goal is to help find a way to eradicate the "shame" that surrounds the word "disability" in order for individuals to be able to enjoy a quality of life without fear, blame and exclusion.

ABBREVIATIONS

Americans with Disabilities Act - ADA

Conventions on the Rights of Persons with Disabilities - CRPD

International Classification of Impairments - ICI

Disabilities and Handicaps - DH

National Organization for Women - NOW

National Council of Disability Affairs - NCDA

People with Disabilities - PWDs

World Health Organization - WHO

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Chapter I

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Introduction

Understanding Disability

Disability has no boundaries, ethnicity, religion, gender or social background. It is part of the human condition. Humans have basic needs such as food, water, shelter, medical care, and education. However, there are other basic qualities that are necessary in their lives to live with dignity such as parental love, trust, friendship, and progress. This desire has no exceptions of country, culture or even class (Lababidi 2002). Disability is usually understood to mean people with disabilities, however, caregivers and family members who share their journey with them are underrepresented. Both People with disabilities and caregivers are intertwined in the diverse world of disability. It is very vital to deconstruct disability mainly the language that is being used to describe disability as a "social fact and norm, as a static identity" (Friedner & Weingarten, 2016: 485). We must understand what it means that disability is becoming a norm especially in communities not conventionally defined as disabled.

Interpretations of disabilities have varied throughout history. Disability theory is embedded in many social scientific engagements with the body, culture, society as well as subjectivity. Disability is gaining global interest, as the stigma around it is diverse, varying from place to place. Even though many struggles regarding legislation and

policies have been made, still disability remains a social problem. The disabled individual still remains marginal and excluded. Thus, it is necessary to enhance our understanding of the opposing concepts of disableism and ableism that is central to help unpack the experiences of disability and focus on finding an end to the inequality caused by society's oppression. Disability is recently increasing in becoming normalized as an identity; it is starting to be the "new normal" due to the fact that many people are living with disabilities due to advanced technology in the medical field. The development of the disability studies field is diverse and has explored disability as a concept and set of practices that has shaped our lives and how we understand ourselves. It is important to understand the stages in which disability studies went through, it was seen at first from a medical model. In the era of modern medicine, disability was understood to go hand in hand with impairment and handicap. People considered it as an ailment that should be 'cured' because it was understood from a medical perspective: that of fixing the individual so he/she may return to the community and become like 'normal' people. The old definitions used in the *1980 International Classification of Impairments*, *Disabilities and Handicaps (ICIDH),* describe disability through three classifications: impairment, disability and handicap; these categories were also cited and defined in Benedicte Ingstad and Susan Reynolds Whyte, in *Disability and Culture* Researchers and Lawmakers struggled for years to reach an acceptable definition that did not de-humanize people with disabilities. Many developments took place to provide a specific common term that would help provide identification to help common people and social programs in understanding the exact requirements of individuals with disabilities.

From a medical model, the field shifted to include a social construction model and a minority model. Disability became a social state that is determined by society based on an individual's circumstances in life. It is a condition brought on by society's expectations and fear of difference (being different). According to Michele Friedner and Karen Weingarten, disability studies have viewed disability as a "social, cultural, and political construction that is defined by the interaction of physical environments, political and economic structures, and social interactions with individual bodily impairments" (Friedner & Weingarten, 2016: 483). As disability became more a concept of diversity because bodies were no longer seen from the medical model of an illness that requires fixing but rather as another way in which bodies are categorized and organized by society. This shift helps in understanding why marginalization, discrimination and violence occur towards PWDs. (Friedner & Weingarten, 2016: 488). Therefore, by shifting the field from the medical model to the social enhanced our understanding of the conditions and challenges of 'disablism' as a result of social exclusion. There is still an ongoing fear of what is considered outside of the normal and labeling individuals by categorizing them based on the lack thereof, of certain body parts or cognitive abilities. The main reason is that people with disabilities are considered 'untamable' and out of control, there is no specific rule to follow when dealing with one; being disabled is a conundrum in itself. What does it mean to be dis- abled? Who is to blame for this imperfection and why is it considered being less of a human to be disabled? By understanding the social theory of disability, culture and society allows new perceptions of how to improve the quality of life for Persons with Disabilities (PWDs). This also allows them to move forward and openly talk about inclusion, as well as rehabilitation

and formulating laws that should guarantee the rights of people with disabilities and citizenship; but also take actual steps in order to accomplish that.

I see that the field of disability in general, has mainly focused on the situation in the United States and Western Europe paying less attention to other contexts for example Egypt and the Middle East. It is time to shed light on disability on this side of the world as it is vital to share more about the narratives of the experiences of Egypt as it will be different from those of the US and Western Europe. Helen Meekosha (2011) stated, "Contemporary disability studies extend well beyond academia. As estimated 80% of the world's disabled people live in the Global South". She is referring to the ways in which agencies such the UN, the World Bank, and The International Monetary Fund. Finance and frame their disability related programs on the Western Models of development and rehabilitation without fully understanding the differences that exist in the local community practices of non-western cultures.

Egypt and Disability

Families kept it a secret if they had a disabled child as they feared judgment from other people and because at the time it was a condition to be ashamed of, people were shunned for having a 'disabled' member in the family. This helped stress the concept of difference and being 'outside of the normal' and the concept of having to fit in and birthed the concept of social exclusion. People with disabilities in Egypt, and in most of the Arab world in general, were quite neglected and stigmatized by the community (Lababidi & El Arabi, 2002). There was lack of knowledge about the disability situation; some were perceived through the lens of superstitions for instance, having a child with

disability was seen as a punishment from God because he is angry with the parents or due to envy. People felt ashamed and stigmatized thus were compelled to hide their children. On the other hand, others perceived disability through the lens of religious charity. For example, the Islamic faith encourages Muslims to help the disabled people, the less fortunate and poor in society through giving 'Zakah'. 'Zakah' maybe considered as a form of income tax however, it is actually considered an obligation of duty in a religious context. As well as teaching people with disabilities mainly the blind in Al-Azhar mosque and Al-Azhar schools called the 'khattatib' (Hassannein, E.E.A 2015). During the nineteenth century, as the number of individuals with disability increased and so did their needs and demands, society and state began to take interest in promoting activities for people with disabilities. At first the government adopted a medical approach to disability. For example, the Ministry of Health treated children with disabilities as though they had a disease or an illness; they mostly adopted methods of treatment via isolation into asylums or hospitals...etc (Lababidi 2002). Rehabilitation was primarily to help the individual become 'normal' so him/her could 'fit in' within the society. Ministry of Education in 1978, issued a law that special sections and schools should be created for the blind/visually impaired, the deaf/ hearing impaired and lastly for the mentally disabled. However, the education system was and still remains lacking in the facilities as well as the learning programs that are provided to children with disability. In addition, the Labour Law of 1959 introduced a 2 per cent quota for employers to ensure the recruitment of workers with disabilities in the workforce. This law was made to ensure that people with disabilities receive a fair chance in securing a job and a proper means of living. Also, for the people who acquire impairment through work related injuries or

diseases must receive compensation and pension, the Egyptian Ministry of Social Affairs (MoSA) introduced the Rehabilitation Law 39 (1975), but was later amended under Law 49 (1982), which allowed the quota to rise from 2 to 5 per cent. It was apparent that disability issues were excluded from other policy initiatives. However, this is due to the definition that was used by members of the government issuing the Rehabilitation Law "The citizen that one or more disabling barriers have resided in, which weakened his/her ability and made him/her in serious need for outside help or institutional support based on scientific and technological basis to render him/her to normal level or as close as possible to normal level" (Abdel Nour 1973:157).[1]

This definition that clearly refers to the notion of "normal" is actually labeling people who are different as "abnormal". The government has had a narrow view and only saw disabled individuals as 'different' and 'sick'; their rights were practically non-existent. The fact that "outside help" is needed and without clarifying the type of help needed further implies that the disabled were constituted as dependent individuals, unable to perform social duties within their community; thus endangering their citizenship and banning their inclusion in the community. Shedding this negative light on PWDs implies that they are a burden; just like using the term "otherness" which emphasizes a sense of abnormality. This attitude engenders a separation mechanism that divides the community, creates tension, and erects barriers. This leads the rest of society to view Person's With

[1] Hagrass, Heba. (2005). *Definitions of Disability and Disability Policy in Egypt.* '

Social Model of Disability: Europe and the Majority World', Leeds: The Disability Press, pp. 148-162)

Disabilities (PWDs) as different, thus requiring special treatment "The policies affecting the disabled in the last fifty years have grown out of charitable organizations, religious piety, individual initiatives, and government schools, associations, athletic programs and health care" (Lababidi, p.23 2002).

However, as the social model of disability grew popular globally and was similarly adopted in Egypt, it highlighted the role that society plays in stigmatizing those who are seen as a burden in the community. This permitted more legal successes for people with disabilities, such as the 2010 Labor Law requiring that both public and private sectors should hire people with disabilities and abide by the 5 percent quota; those who refuse would face fines and jail sentences. In addition, Egypt ratified the UN Convention on the Rights of Persons with Disabilities in 2008. The most prominent shift in disability in Egypt however, came with the 2011 revolution. This revolution was very important as the number of disabilities have increased substantially due to the injuries that affected and changed many lives moving them from the realm of "able-bodied" to " disabled". Moreover, since the 2013, 30th of June Revolution, Egypt has made many improvements to achieve a strategy compliant with the 2007 UN Convention on the Rights of Persons with Disabilities. The Central Agency for Public Mobilization and Statistics (CAPMAS) announced on 30/9/2017 that people with disabilities make about 10.7 per cent of the total population. As the number of people with disabilities increases so do their needs and demands.

Although laws are being amended and rights of the disabled have been included in the constitution, society's perception has not altered very much. Disability is still seen

as unwanted and feared in Egypt. The quality of life of a disabled individual in the Egyptian society, like other societies as well, is obstructed by the cultural and social stigma that is imposed on him/her by their families and society as a whole. The abled have the 'power'; they are in charge through the invisible lens of social representation. They push out people with disabilities and make them feel like they are unwanted. Parents are very important in this regard as they are the primary caregivers and the first part of society the PWDs is exposed to. If parents pity them and think that they are less, then disabled individuals have no chance. If parents surrender to society's fears then they have been stigmatized even before leaving the confines of their home and so called "safe zone". Some parents trap their kids in virtual prisons out of their fear of society's ideals; while others are able to resist and attempt to help their children adapt as well as take their place as rightful citizens in their community. It is important to know that family is the most significant unit of Egyptian society and plays an important role in virtually all-social relations. Arab societies start with family and is patterned on it as was observed by French scholar Pierre Bourdieu after living in Algeria for many years that:

" The family is the alpha and omega of the whole system: the primary group and structural model for any possible grouping, it is the indissoluble atom of society which assigns and assures to each of its members his place, his function, his very reason for existence and, to a certain degree, his existence itself; the center of a way of life and a tradition which provide it with a firm foundation and which it is therefore resolutely determined to maintain; last but by no means least, it is coherent and stable unit situated in a network of common interests whose permanence and security must be assured above all else, even if necessary, to the detriment of individual aspirations and interests" (Abudi,

D. (2011): 27 quoting Bourdieu).

Research Objectives

As disability is seen through a social construction model it is analyzed as a product of cultural and historical practices and ideas. The field has always focused on PWDs, their disability and the experiences of disability. However, very little attention has been given to families with disabilities and especially caregivers whom I believe are the most important people in the lives of PWDs. The caregivers I speak about in this thesis are parents and siblings who have mainly been appreciated in the role they play in the lives of the family member with disability. Many studies have neglected the part in which disability itself plays in caregiver's life and shapes the way they experience it.

This thesis is a study of how families of PWDs experience disability, along with the people with disability in a variety of ways. I will be focusing on the Egyptian context and how disability is seen from an ableist Egyptian perspective. I will be explore how disability is embodied in other bodies i.e. caregivers, spaces between bodies and the elements that connect or separate bodies. I also explore the concept of disability as a ' relationship' mainly in terms of family and on a larger scale the society, using the social relational disability model. I will explore how disability is simultaneously a stigma, an embodiment and a relational category. This thesis attempts to answer the following questions: to what extent are caregivers affected with their relationally centered association with PWDs in the Egyptian society? And how does stigma and concern affect the caregivers' quality of life and wellbeing? How are caregivers embodied along with PWDs in social categories that determine their identity due the close relationship they

share? Answering these questions may provide answers about ways in which we can strengthen the relationship between family members, eliminate the 'shame' of the ableist community and make it's relation with PWDs more positive and productive.

Conceptual Framework

The social model of disability reinterpreted the perception of disability that was presented in the medical model by radically shifting the attribution of 'disability' from the individual (body) to society, 'which is reluctant to accept disabled people' (Morris1991: 34). Thus concluding that disability is seen as a social injustice and a cultural identity. Erving Goffman's (1963) formulated the notion of stigma and what it is like to be a stigmatized person. He argued that stigmatized people are those who do not have full social acceptance primarily based on their appearance of difference for example race and disability. Goffman further argues that stigmatized individuals share common values such as belief in receiving equal treatment, which leads to feelings of shame, self-hate, and even agreement with their exclusion from society (Goffman, 1963:38). Baffoe 2013, like Goffman argues that the factors that contribute to the formation of stigma such as ignorance of lack of knowledge, superstition, and involuntary exclusion of individuals who are perceived as different or deviants from the society (Baffoe, 2013). Such social stigma creates discrimination among people and how they treat each other resulting in labeling, isolation, shame as well as deprivation of the person's rights such as the right to education and employment (Baffoe, 2013). This concept however is changing as more contemporary debates are currently emerging, arguing that the social model has become "an outdated ideology which does not attend adequately enough to the subjective and embodied nature of disability" (Meekosha 1998; Thomas1999). Therefore, disability is

positioned as an embodied, lived and bodily form that is equally socially constructed through cultural and physical barriers within society.

This thesis uses the social relational model of disability approach in explaining the disability stigma in terms of caregivers' experiences. It is important to understand that the relationship between caregivers and PWDs is formed through the process of socialization i.e. social control. The notion of social control plays a key role, which is the social order that regulates our behaviors, appearances as well as thoughts to fit in the laws, norms, and social structures of society. An example of social control is family and primary caregivers who teach or pass on norms, values, and belief system of a given society. Another example of social control is that which is produced and enforced by the government and it's officials. Hence, to unpack the power dynamics of such relations I deploy theorization of the concept of body, power and embodied subjectivity and disability. Relying on Michel Foucault's work on power I explore subject formation and how power is used to understand and respond to society's ideals, laws and institutions. [2]There are networks of power; this is seen in the distributions of resources that mainly produce as well as play a key role in maintaining the ways we think about those who are marked "normal" according to societies standards and those who are classified as "abnormal", not fitting; the 'other' (Tremain. 1978). This creates tensions between both abled and PWDs and how both struggle to create a way of life. For example, the feeling of shame about being different from what society deems 'normal', due to this fear of being seen as different PWDs develop avoidance, self-consciousness as well as an air of

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[2] Foucault and the Government of Disability, Tremain, S, 2005

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hostility (Goffman, 1963). Similarly, the caregivers might share the same feelings as they too become marginalized due to their association with a disabled person. Moreover, caregivers struggle with blame; they blame themselves for being born 'whole' or if they are inadequately able to help their disabled family members. Another form of blame would be that caregivers would blame PWDs for how society discriminates against them and excludes them merely due to their association with PWDs.

As this thesis focuses on the relationship between caregivers and PWDs as well as how both are affected by the stigma of disability and are marginalized by it. I use Margaret A. Mclaren examination of Foucault's work in her book *Feminism, Foucault and Embodied Subjectivity* (2002) She states that Foucault's work mostly deals with questions about knowledge, power and subjectivity. He believes that subjectivity is basically produced within power relations that results in a concept of the subject wholly determined by social forces. The notion of the body is central to Foucault's work, as he identifies the body as a site of power. It is through this that the concept of subjectivity emerges and how it is shaped by power. "**Power is everywhere**: not because it embraces everything, but because it comes from everywhere. ... Power is not an institution, nor a structure, nor a possession. It is the name we give to a complex strategic situation in a particular society" (Foucault 1978:93). Moreover, I use Tremain Shelley Lynn's *Foucault and the Government of Disability* (2005) where Foucault argues that a way to manage people is to practice division, classification and ordering which has become a primary means to individualize people who understand themselves as well as are understood scientifically in that manner. For instance, the caregivers objectified in terms of the disability in their household rather than merely being perceived as another abled member

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in the community related to a PWD; both in this sense become disabled. Also, Foucault (1980) introduced the notion of bio-power, which is networks of power and knowledge in our everyday that create subjectivity; power-knowledge networks produce, regulate who we become, the conditions under which we live as well as create a way of life for us. In this case the caregivers of PWDs are against the abled-bodied who shame them. Hence, work on bio-power and the dual nature of the subject can help us to "discover how it is" that disabled subjects "are gradually, progressively, really and materially constituted through a multiplicity of organisms, forces, energies, desires, thoughts, [and so on]" (Foucault 1980a: 97). Here Foucault talks about how bio-power can mold human beings into subjects through regulating political life as well as prohibiting, controlling the subjects hence guiding, influencing and limiting their freedom.

For example, applying this to the topic of disability, if all PWDs were viewed as passive, weak bodies and abnormal, this representation contributes to their devaluation within the community. It is here that resistance has risen to counter and challenge the normalizing power that can affect transformation in the social as well as individual bodies. PWDs and caregivers in association end up represented within the same frame. It is important to understand the external power formation that constructs the lives of disabled individuals and caregiver as well as the internal power formation that the caregiver and disabled individual experience within their relationship to each other and the outside world. Only by understanding these categories we can resist the barriers that society has constructed for them.

Foucault (1982) determines that although modern power appears to be regulating political life through negative repressive terms by prohibiting as well as controlling subjects, this opens up space for resisting these governing regulations and conditions. Furthermore, Foucault defines power as dependent on resistance; basically where there is power there is resistance. "We are never trapped by power because it is always possible to modify its hold in determined conditions and following a precise strategy" (Sawicki, 1991:25) From his perspective the social and the historical field form a battlefield of struggle. It is here that power circulates and is exercised on as well as by individuals over others and themselves. The most important and interesting question is who is struggling against whom? The answer is everyone is fighting one another in one way or the other, be it fighting for more rights, for education, space, money, mobility, prejudice, stigma and there are even internal struggles within ourselves. In addition, Foucault examines the effects of social and cultural norms as well as how resistance developed to combat normative practices. The notion of emergence views the body as well as the treatment of the body as a site for struggle and contestation; subjectivities emerge out of political struggles. Moreover, Foucault argues that emergence is dynamic and that as long as the institutions and practices that forms the body continue, so shall the struggles. [3]'His work marks a radical departure from previous modes of conceiving power and cannot be easily integrated with previous ideas, as power is diffuse rather than concentrated, embodied and enacted rather than possessed, discursive rather than purely coercive, and constitutes agents rather than being deployed by them' (Mclaren, 2002). This power if we look at it

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[3] Gaventa, J. (1980). *Power and powerlessness: Quiescence and rebellion in an appalachian valley*.

in the case of disability in Egypt, this power normalizes behavior; I use disability within the social, domestic sphere as the example in which society has managed to create the 'disabled family'. "We must cease once and for all to describe the effects of power in negative terms: it 'excludes', it 'represses', it 'censors', it 'abstracts', it 'masks', it 'conceals'. In fact power produces; it produces reality; it produces domains of objects and rituals of truth. The individual and the knowledge that may be gained of him belong to this production" (Foucault, 1995:194).

Literature Review

People with disabilities have always faced negative perceptions i.e. stigmas that have always been a key to their marginalization and a barrier to their integration in society. What is being somehow neglected in the disabilities field is the recognition that caregivers of PWDs too are affected by the same social stigma due to their familial relation, especially in Egypt. This thesis will discuss the work on stigma, concern and embodied relationality to examine the extent to which the experience of the caregiver and disabled individual can be understood in the specific context of the person's life and relationships.

Oliver (1990) argues that the social model of disability is built on the binary opposition between bodily impairment and societal disablement. He also argues that the medical model classifies people as healthy or unhealthy dividing normal from abnormal and matching the illness with its treatment. Thus he concludes that both medical and social models, actually in a way aim to 'cure' disability, the medical by curing the impairment while the social by curing social attitudes and the environment. Klein (1932,

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1948, 1975), Fairbairn (1952, 1954), Winnicott (1966, 1971, 1975c, 1986) and Mahler (1965; Mahler *et al.*, 1975) use a psychoanalytical approach known as the relational model. Psychoanalysis focuses on subjectivity: "who we are, where we came from and where we might go" (Goodley 2012). The Relational Model is based on the concept of transition and interactions of PWDs and their primary caregivers, which offers an understanding of the emotional development of PWDs. The relational model shows links between the experiences both internal and external of PWDs and the effects that disability has on the non-disabled i.e. the caregivers.

The relational model of disability was studied through different aspects for instance, the studies done by Melaine Klein (1932, 1948, 1975), relies on the unconscious interaction between the disabled child and the caregiver in the earliest developmental stages. She argues that a child's sense of self as good or bad is "related to the predominance of good and bad objects in its internal object world" (quoted by Wilson, S. 2003:25). Klein provides an example of breast-or bottle- feeding where she clarifies that if the child has difficulty feeding then the caregiver might feel frustration about her lack of success in nursing the child. This feeling may then be transmitted to the child and in turn the child will feel both its own frustration for not being able to nurse and the mother's concern, thus intensifying its feeling of persecution. Klein's observations on the early interactions between the child and the primary caregiver is supported and is similar to Fairbairn's (1952, 1954), who mentions that a child is born with a structured and functioning ego has defense mechanism in dealing with non- satisfying personal relationships. This is referring to an incident where a caregiver reacts differently to a child because the child has a disability for example, by acting cold toward the child,

overcompensating or by merely avoiding the child. This results in the child with disability employing a defense mechanism such as the creation of splits within the individual of object and ego as a result of negative experiences imposed by an external object (caregiver). Moreover, Winnicott (1966, 1971, 1975c, 1986) compliments Klein's and Fairbairn's arguments by adding the concept of 'put into hiding'. This concept Winnicott calls 'the hidden self' which appears if the primary caregiver or mother fails to adapt to the child's needs. For example, if the caregiver is unable to adapt to the severe nature of the child impairment or also if the caregiver develops a negative reaction to the child's disability such as embarrassment, repulsion or a feeling of hopelessness. Therefore, the child goes into 'hiding' and develops a false self to protect itself and face the world in order to comply with the demands of the caregiver and the surrounding environment. Furthermore, a true self develops when a child receives adequate adaptation of its needs from the caregiver. Finally, Mahler *et al.*, (1975) believe that the notion of 'personhood' is not innate but has to be achieved through adaptation to the environment, the first environment being family i.e. mother. Mahler argues that the child should eventually function on its own and cease depending on the mother, but at the same time the child "will retain an interpersonal tie to the mother" (quoted by Wilson, S. 2003:28) However, if the child's physical need for help does not change and still requires life long support, this greatly affects both child and mother's quality of life as the relation between them becomes immersed in frustration, fear, guilt, and over all concern over the child's future. This adds a new perspective that could be used to understand the personality development and reactions of disabled people, which is intertwined with caregiver attitudes and the relational environment causing it (Wilson 2003).

The concept of care is related to survival and is reflected in health and quality of life. Moreover, attitudes of care are always associated with relations of love and friendship, devotion and concern and stress about a loved one "care is a way of being in the world, a way of existing and co-existing, of being present, of navigating through reality and relating to everything in the word" (De Azevedo and Santos 2006:772). The primary caregiver (mother) who is known as the informal caregiver is responsible for the basic care whereas secondary caregivers are people who deliver occasional care. An informal (home) caregiver is defined by De Azevedo and Santos (2006) as a social subject who absorbs not only the scientific knowledge of the disability but also the socially and culturally shared values and beliefs in the social group that the caregiver lives in. With care there is always an urgent need to take care of the family member with disability, thus caregiving always comes hand in hand with concern, the growing fear of not adequately taking care of the PWDs due to the deficiency in services provided by the government as well as ableist stigmatization of PWDs. Shewchuk and Elliott (2012) explain that there is a complex relationship between personal and environmental characteristics that occur over time which affect a caregiver's adjustment in terms of depression, anxiety and health. Therefore, care and concern are closely associated with the notion of quality of life. "It is a multidimensional concept that reflects the conditions of life desired by a person in relation to eight needs: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion and rights" (Schalock, 1996:12). The quality of life of people with disabilities contemplates the same factors and dimensions, which are considered relevant for people without disability. Schalock (1996) explains that quality of

life is emerging in family centered domains such as within the sphere of families with disabilities and is achieved based on family interaction, daily family life, parenting, financial, emotional and social well-being as well as productivity and advocacy, health and physical environment i.e. safety, space and comfort.

Caregivers of PWDs are considered a homogenous group due to their shared experience of the social stigma resulting from their association with any type of disability (Lawson 2011). To embody means to put into a body an idea or a spirit, to give a concrete form to or to express (principles, thoughts or intentions) within institutions, art, action, and word combinations. Hence, embodiment of an idea or principle is its physical form, realization or expression or even the incarnation of that idea (Oxford dictionary, 2003). Embodied relationality is the binary divide between caregiver and PWDs. It creates an interpersonal connectedness relating to mind/body, self/other, internal/external, and nature/social. Blackman and Venn stress the idea that 'bodies should be defined by their capacities to affect and be affected' (2010: 14). Descartes (1995) theorizes the body as an assertion from the mind meaning that an individual may feel comfortable with his self-sensed self, while Lacan (1977) argues that the notion of selfhood maybe seen by an outside object for example through looking at a mirror to see oneself. Foucault (1982) however, rethinks both the Lacanian subject as well as the Cartesian man from the morality of the body as well as the social constraints of the mind. While Merleau-Ponty (1995) highlights that body is a unique medium "it both sees and is seen; our bodies are sensory objects and objects to be sensed"(Hansen, 2003:173). Thus, emphasizing that the caregiver/PWDs relation is an embodied relational self where the bodies become objects of social practice such as the stigma. "Sometimes we may be both agents and objects at

the same time" (Meekosha, 2010:11). This better describes the interdependent nature between individual, family and community life and how PWDs and caregiver within family experience stigma, concern and embodiment.

Stigma is a social aspect of disability and those associated with it; it affects caregivers as well. Different kinds of disabilities are viewed differently in different societies and cultures (like blindness is more respected than other types of disabilities). For example Micheal Warner's (1999) examines stigma and the emergences of politics of shame brought on by society's conceptions of the norm and what is accepted socially. Thus creating a space that Warner refers to as "stigmaphobe", a world where these dominant 'faceless' majorities stigmatize those who are different and outside the 'norm'. Another space is made where those who are stigmatized find commonality amongst themselves, this space of "stigmaphile" (Warner, 1999:43). This creation of political stigmatized groups result in raising tension and hierarchy as social power struggles emerge between people, each forming different perspectives without trying to understand the different perspective of the other side. Warner's queer theory and the "stigmaphobe" sphere of society are very relevant to this thesis as it examines how stigma is integral in the lives of both PWDs and their caregivers.

Furthermore, Bill Hughes (2012) relies also on Nussabaum's notion of disgust as an emotion that is core to people's everyday relationships with their bodies. This consequently affects our social interactions thus causing social exclusion. This is where the stigma takes root thus resulting in disabled people being hidden away and cut out. This is better explained as Hughes argues, " the threat posed by ourselves (and projected on to others), the threat of our "bodiliness and same and anxiety associated with it is a

product of ableism, of the 'tyranny of perfection'. Ableism makes the world alien to disabled bodies and at the same time, produces impairment at the same time, produces impairment as an invalidating experience" (Hughes, 2012:24). Catherine A. Marshall et al (eds.) (2009) Focuses on Arab societies as an example, where disability is associated with oppression and hierarchy of stigma, where children and women with disabilities are more stigmatized compared to the older people with disabilities. Moreover, she argues that in most cases poverty is associated with disability more as it fails in servicing and including PWDs in the society due to economic and cultural reasons. Similar studies conducted by Warner (1999), Das, Hughes (2012), Stiker (1999), Marshall (2009), Mead (1982) and Turner (1992) to show how this system of fear and exclusion exist across many cultures.

In addition, Carli Friedman (2017) emphasizes that the notion of ableism, like other "isms" such as racism and sexism describes the discrimination towards a social case like disability and describes how certain ideals are both valued and not valued. Similarly, Phil Smith's (2004) argument of the similarity between whiteness and its relationship with disability and how fear places both outside of the normative boundaries. He also examines how 'otherness' creates a feeling of 'revulsion' accompanied by a sense of fear. Like racism, ableism also rises from the same unexamined "assumption of biological Inferiority" (Smith, 2004: 202); Smith claims that this means that people without disabilities are considered 'normal' and those with disabilities are somehow not considered equal. For instance, race is inherent in the body, it cannot be changed similarly like almost all disabilities; thus both are being 'manufactured' by the society by being invisible in the social sphere. Like ableists, whites do not see that they are raced,

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because according to Smith (2004) 'Whiteness' in itself is socially, historically and culturally constructed the same way as disability. This notion structures many lives such as the lives of blacks and whites, similar to how the lives of men and women are structured by gender. In a similar manner, the life of PWDs and their caregivers is structured by their impairments. "Discrimination does not occur because of difference, but instead that taxonomies of difference are created by processes of discrimination" (Mclaren and Torres 1999:46). The literature used in this thesis shows how embodied relationality of caregiver and PWDs are affected by their lived relational experience of stigma and concern within the social construct of disability. There is scarce analysis concerning Arab countries and Egypt, most studies focus on western concepts of disability, caregiving and rehabilitation. I believe that more studies should be conducted on caregiving and the relational model of disability in non-western contexts because prevention and rehabilitation models will vary based on the country's services and cultural situation.

Methodology

Words create identities and realities; by understanding them people can then reclaim and reevaluate the words that have derogatory connotations that hurt such as spinster, hag, disabled, dwarf, retard, blind...etc. These types of words create images and realities that end up shaping people's lives in a community. The use of discourses can frame possibilities of subjectivity, which is important to my thesis. Everyone is seen as an active agent however; some might vary based on whose strength surpasses the other. Language and culture and how they are shaped by contexts have a long history in

anthropology. [4]"The pragmatic relevance of words is greatest when these words are uttered within the situation to which they belong and uttered so that they achieve an immediate practical effect. It is in such situations that words acquire their meaning" (Malinowski, 1942:19). Similarly, Volosinov, argues, "All social signs, including language, emerge from social interaction where language use is always motivated and framed within the struggle between different groups"(Kellogg, 2009:84).

I am using a qualitative method to study how social representations and relations impact the lived experience of care for physically disabled persons from the perspective of both caregiver and PWDs. I interviewed 16 people total; 12 were caregivers: 5 mothers, 5 siblings and two wives of men with disabilities. The remaining 4 were persons with disabilities. I am not focusing on a specific type of disability; I am more focused on the relationship within a family between disabled members and the caregivers. However, I chose on purpose families with different disabilities, as I wanted to prove my thesis's argument that the lived experience and embodiment of caregivers dealing with different disabilities is similar. I show how within the Egyptian communities and cultures that the burden of caregiving falls mostly on women. I found my research interlocutors through friends and friends of friends who either had a family member with a disability themselves or knew of a friend who did. My initial aim was to interview an entire family: parents, siblings as well as the member with disability to study the family dynamic as a whole in the formation of the embodied subject and quality of life. However, only two

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[4] Malinowski, the founder of modern British social anthropology, is usually credited with being the inventor of ethnographic fieldwork, a fundamental research method throughout the social sciences. Malinowski, Bronislaw, 1884-1942

families were open to talk and share their experience. As for the rest they were divided, some cases the mothers had young children with disabilities so obviously I couldn't interview them but the fathers were not interested in sharing their experiences. Siblings of PWDs were willing to talk and share their family experience but not all their parents were willing to do the same. However, the adult PWDs themselves were willing and eager to talk to me about their life and family. Some interviews were conducted at their homes; others were conducted as per the request of some of my subjects in a café, or near their place of work. All interviews were conversational in nature and interactive. All of the interviews were transcribed, and then the texts were analyzed and the names were changed to protect their identity. Some interviews took more than one session; hence I had to meet some of my subjects multiple times. Furthermore, I also used interpretive repertoires to examine the power of language and words on shaping people's lives and experiences. All my research interlocutors were interested in my topic and willing to share information because they wanted to shed more light on the disability issue in Egypt and they were concerned about their families and their future.

Chapter II

Stigma: Symbolic Struggles through the Lens of Society

Social Representation of Stigma in Egypt

A friend of mine was pregnant with a boy and I was thrilled for her when I first found out, yet when I went to congratulate her I found that she was petrified. Her joy was shadowed by her fear that the baby would not be born normal. Normal was a word that captured my attention, what is normal? When I asked, she responded with, "That he would be weird; perhaps, he would have something in his brain or deformed somehow". This made me think about what has ignited this fear within her. She went to three doctors trying to take tests in order to confirm that she would have a 'normal' baby. That inexplicable fear fascinated me and I began to wonder who gets to decide what and who is normal and who isn't? I wanted to find the reason behind this inexplicable fear, the fear of being different. I wondered whether this was due to the fact that if she in fact found out that the baby had a disability her life would change, as she would take on the role of caregiver with all its challenges. I wanted to also understand it, did she fear her own life changing or was it also an external fear of society and being shunned. This made me question why these differences between abled and disabled individuals are seen as faults to be hidden and considered shameful rather than recognized and made visible. I wanted to examine the disturbing ideologies behind disability within the Egyptian community.

An undeniable fact of life is that disability could happen to anyone; anybody could be born with a certain type of disability or give birth to a child that possesses one.

Anyone might wake up one day and find himself/herself put into a different category due to an accident of some sort, disease or merely old age. Anyone can become disabled or a caregiver at any moment. In the Egyptian domain, disability remains culturally stigmatized because rather than encouraging people with disabilities to become active members of society. Egyptian cultural norms have often led families to hide their disabled members and care for them at home where they are not visible to the public. Now families consist of caregivers where some of them may feel embarrassed because their child or sibling has a disability and out of fear hide them or avoid facing the disability thus, resulting in adding to the stigma internally within the walls of their home.

An example of this is the case of Sabrine, a 23-year-old girl suffering from Cerebral Atrophy. Her family originates from the rural part of Al Sharqiya. The doctor said it occurred during birth, which left her with muscle impairments affecting her right arm and left leg as well as her urinary bladder functions and speech. Her family did not understand what that meant and did not care to ask. Her mother, Om Seif, whom I interviewed said " Ehna falaheen manefhamsh fil hagat di, khalas 'amr allah, hane'mel eih" (we are peasants and we do not understand these things, it is God's will, nothing to do". The fact that's she said 'God's will' implies that Sabrine's family belief in superstitions and this allowed them to not give Sabrine the adequate care needed for her function. They never followed up with doctors about her case and how to handle it. Sherine Hamdy's work on superstitions in "Our bodies belong to God" look at how in poor areas the belief that out bodies belong to God and that he is in charge to do with them as he wishes aids in many horrific cases such as selling of their organs. Here, Sabrine's parents acceptance of their daughter's fate without bothering to understand

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further or seek a cure in their misguided understanding of the quarn.   I must make clear first that I did see Sabrine but I did not have an interview with her, I was not allowed to be with her alone. Her mother, Om Seif, the primary caregiver, spoke with me. She does not work and mainly cares for Sabrine with the help of Sabrine's younger sister Dalal. According to her mum, her father is a plumber and is always kind to Sabrine and buys her sweets. It is important to mention that Sabrine was taken out of school at the age of 13; she was bullied severely at school, as students did not quite understand her case. When I asked about why she was taken out of school and how does she spend her time "She does not know how to do anything, I did not teach her because I did not want her to burn the house down if she tried cooking, she just stays home all day with me" (Om Seif).

Stigma has crippled the way Sabrine's caregivers were supposed to teach and support her. Her family believe her presence is a test from God, "Ibtelaa" " Affliction"; they assumed that she will not be able to do anything and proceeded to do it for her and let her do nothing, thus making her incapable of taking care of herself through their interference. She was seen as a burden someone they had to care for and a burden that the younger sister will carry on after the parents die 'heya ta'bana, bentena taa'bana w khalas' "she is sick, our daughter is sick and that's all there is to it". Om Seif said that they did not take her out a lot because they feared people would ask questions again and "it's enough that they know we have one sick girl, what if people thought the other one is sick too!" They sentenced her to a life sentence with them and her sister, not once thinking of any remote possibility of something that could be different and the resentment that Dalal might feel in her relationship with Sabrine because she has to continue the care process after her parents. Here the caregiving process was affected by the social

representation of disability Sarah Eleanor Green (2007) argues that stigma has an important impact on both dimensions of burden and, through its impact on 'subjective burden', thus decreasing the perceived benefits of caring for a child with a disability.

Stigma and a Caregiving Spouse

Bill Hughes (2012) traces the story of disability through modernity to show that there is a deficit of credibility brought upon by the power exerted by culture. "Disability is not only culturally mediated but is constituted through culture" (Hughes, 2012 p.5). Moreover, Hughes argues that the social sites of power surrounding disabled bodies and minds are epistemologically rooted. Hence, the notion of disablism itself emerges from the fact that disabled individuals are unable to match up to the ableist community ideals. Caregivers project the ableist ideals of the community, if they allow stigma to stick they subconsciously or even consciously project it towards the disabled member in their family. This is portrayed in the next case of Ragab and his wife Basma and how Ragab's disability became Basma's disability too. Ragab is a 28-year-old man with dwarfism who lives in a mechanic shop in " the garage" area somewhere in between Gesr el Suez and Al Fangari. It is a very poor area, yet it is considered the biggest and best mechanic's zone in Cairo. Most people who live there are the mechanics and their families. Ragab works as a helper, he brings tools and fetches items for the other mechanics and only fixes minor issues in the car. He is married to Basma who is an "able-bodied" woman. He finds public transportation very challenging, he has to always be accompanied by someone to help him get on and off the bus. It is easier to get around inside 'the garage' area, as his movement is not hindered due to the shortness of his size, he is employed by El Hag Mamdouh, who is the owner of that mechanic shop called "el warsha". When I

interviewed his employer El Hag Mamdouh about Ragab's job status he said, "Ragab is like a son, he is a 'sabi men sobyanai' "he is one of the workers". His workers get paid based on the cars they fix, but Ragab does not, he is always helping someone work. He does not get paid for a whole car since he did not fix a whole car. He mostly lives on tips from the customers and El Hag. Ragab lives in a single room under the stairs of a building next to the 'warsha'; El Hag owns this building and Ragab stays there with his family for free. It is a tiny space that is not enough for a family with two kids, but it is what is available to them. On my fourth visit in a span of a few months, I learned that after two years of waiting Ragab finally received the pension that he applied for in the Ministry of Social Solidarity. Ragab told me "this was possible because one of the shops' customers had connections and called some acquaintances in the ministry to get my paperwork done."

Hughes maintains that part of the reason for the disabled's exclusion is society's aversion to impairment and the feelings of disgust, pity and fear that they are subjected to. There is an underlying need to eliminate the disabled individuals or fix them. Society's view matters, they are the outside world that affects the inside world (family as well as the individual self). If every time a person leaves the house people stare and point it leaves a scar and affects negatively with how one would perceive him/her self. If people only emphasize 'difference' then that is all that registers in a PWDs mind as well as the mind of their caregiver. Ragab needs assistance for transportation when he is seen together with his wife, people whisper, and point at them not in a subtle manner. One incident that Basma shares and says affected her strongly.

Basma:

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Ragab and I were getting on to the micro bus because we

needed to go get my son, Yasen vaccinated, I always help

Ragab climb on, I carry him. When the driver saw us, he asked

me "Is he your brother?" "No, husband." He said "rabena

yegaziki ya benty enek etgaweztih, akeed hateksabi fih sawab"

roughly translated as " God bless you for agreeing to marry him

surely, you will be rewarded for your kindness". I was upset that

he said that and especially in front of Ragab. Also, there were

other incidences where we would hear people loudly whispering

comments like "Why didn't she marry some one like her? How

did she manage to have children with him? Poor girl, did she

even have a choice? They are probably related that's why! Her

parents made her maybe? How do they even go about doing

'that'? I didn't think he could have kids?" Because of this,

Ragab doesn't like to go out anymore or go anywhere far from

where we live. Every time we try going somewhere new that

required transportation we came back upset. We only go to a

nearby park called El Badr where people from the neighborhood

go and know us.

Here we see how the phenomenon of disability is seen as a problem of how the

human body is affected by the community. As Bill Hughes stated that disability is an

ontological problem and that many people with disabilities feel that many of the people

they interact with treat them as though they were either 'invisible, repulsive or 'not all

there" (Tichksoky and Michalko: 127). I must admit that I learned more about Ragab's

life from his wife Basma, all the information he gave me was vague and made to show

his live in the best possible way. However, with Basma's help so many things were

revealed about their lives and the struggles that they face everyday. People actually tell

Basma that they are upset that she chose to marry and live with Ragab. According to

ableist society, which likes to emulate the norm, she is seen as disrupting the norm and

creating a commotion. [5]By incorporating Goffman's notions of how identity and selfhood

are performed in life this shows how disabled identities are experienced and expressed.

Hence, the body becomes a 'performing body' as it is in commotion, which indicates

"disturbance" and "unruliness". This being the case in all these families living together

and 'moving together' performing in a culture that seeks to service 'normal' individuals.

Similarly, is the case of Om Batta who is married to a blind man, they are a

slightly older couple. Like Ragab, Mohamed never worked because he is blind neither

did Om Batta; Mohamed's family father provided for them. Now Om Batta works as a

janitor at a university, she went into work after her father-in-law died and there was no

more income. Om Batta has three children two girls and a boy who are all grown up now.

Om Batta and her husband Mohamed are distant cousins, her parents urged her to marry

him when she was young with the promise that Mohamed's father will take care of their

living expenses. Mohamed is significantly older than her by 23 years. She married him

when she was 20 and he was 43. Now Mohamed is 73 years old and his youngest

daughter takes care of him while Om Batta goes to work, as the eldest daughter is

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[5] Carrie Sandahl & Philip Auslander's *Disability Studies in Commotion with Performance Studies*

married to another family relative. Om Batta has been the primary caregiver of her entire family as wife and as mother. They lived in a building that was owned by Mohamed's family so no one mocked them. However, around the neighborhood, little kids used to put rocks in Mohamed's path to see if he will be able to avoid them with his cane. Mohamed didn't finish school neither did Om Batta, and his family never encouraged him to work. He just goes to his father's shop, his father owned a grocery store Mohamed used to help out there but was never given an actual job. She was not allowed to work earlier as her father in law forbade it. She was at home raising the kids and caring for Mohamed, she never ventured far because Mohamed wasn't comfortable with new places. She usually went to visit her family and the surrounding areas. When a spouse suffers from a physical or mental injury the relationship between spouses becomes dependent on the fact that the other spouse will take on many more roles and responsibilities. This can leave the caregiver feeling exhausted, stressed and overwhelmed at times. The spouse that is offering care to the other spouse may find the role gratifying and rewarding, but there are times where it can also make the caregiver resentful, lonely, and hurt. The relationship between spouses is put to test because if a spouse is suffering from a disability it makes them aware that they are not performing in some areas as other people. Therefore, this might affect their self-esteem and self worth. The stigma seen in these cases is 'percieved stigma "which is the stigma that a person feels that they experience and their anticipation of discrimination" (J. Goodall et al 2018).

Adding Jack Goodall's notion of 'percieved stigma' to Basma and Ragab's story, Basma is not only Ragab's spouse but also his caregiver. She is considered a caregiver as she takes care of him and helps him for example in transportation and with other needs.

However, she does not work because Ragab will not allow it. Basma says "I think he feels like people will talk about how I become the money maker of the family, because Ragab's friends some times tease him about how useless he is, I personally do not think it is funny but he says they are just joking". The way Ragab is treated as though he requires kindness and charity in terms of how he makes a living and his incapability in performing certain tasks at work reflects how Basma is treated as well. She is considered disabled as well, she heard this form of talk many times whenever Ragab and her walked together "she must be disabled also, that's why she married him, why would she agree if she wasn't sick also". Basma admits that this led her to wear a niqab because people used to stare at her too, especially the men in the neighborhood. " Here comes Ragab's wife". "I can feel them looking at me, making comments about needing a real man, I knew this would create trouble for me so I told Ragab I'm going to wear a niqab". It was assumed by almost all the neighborhood that "Ragab cannot father children because he is a ' dwarf'' according to what Basma's mother and a few people said to her when they first announced that they are getting married. Basma says "I believed them that dwarves cannot have babies and I prepared myself that I will not have children, everyone was shocked when I became pregnant". This entire negative stigma affects Ragab and Basma's relationship in the sense that it is filled with frustration; Basma becomes upset from people's words against her and Ragab. Ragab in turn feels frustrated that he is exposing his wife to this. She says " I have to constantly assure him that I am not upset or else he refuses to go out with the kids and I also think he feels ashamed that I hear this about him". This creates a strain on their relationship as it surpasses that of mere spouses or partners, but add to that the fact that one takes care of the other. One is actually

dependent on the other; thus care here is seen as a burden when we mix this with the cruelty of the outside world the quality of life experienced by the caregiver is lacking.

Stigma of Siblings

Though there are different types of disabilities, the feelings and interactions between siblings are the same. Most of them share the same feelings of resentment, guilt, embarrassment, anger as well as pride regardless of the brother or sister's disability. According to Mary McHugh (2003) she argues that sibling resentment comes easy with small families as household chores as well as the brunt of babysitting falls on the sibling, mostly the oldest daughter. In terms of the Egyptian community that mainly perceives a woman as a caregiver, this is her predetermined role whether as mother, wife, sister, or daughter. Most importantly there is fear of families with disabled members, the fear of influence of a sibling's disability on potential relationships. As indicated in Nagham's case her and her younger brother Omar. An error at birth caused serious damage to the brain that left Omar with hearing impairment and eye impairment as well as severe damage to the muscles, he had no control. When her parents asked the doctors what his condition was, they said that there is no name for it " Rabena khalao' keda/ this is how God created him". Nagham's father is a diplomat, so when he received a post in the United States and another in Tel Aviv, they took Omar for check ups in both countries to see what the doctors would say. The results were not conclusive in both, however all the doctors said that as he grows older he would develop epilepsy and won't survive long. He had corrective surgery to the eyes and wore a hearing aid as well as received physiotherapy to try to teach him how to walk and use his body's muscles. Nagham said they were able to provide adequate care for him due to her dad's position, which covered

the treatment expenses. When the posts ended and the family returned to Egypt, they struggled living in Egypt, as the facilities were neither as developed nor as good as it was abroad.

Nagham:

Mohamed needed to be on a stroller type chair whenever we went out and people stared and also it was a hassle trying to take him to parks or malls like we used to in the states. My Dad took him out of school because he would come back home bruised, beaten and even burned but the teachers never admitted anything and said the kids were playing. Omar used to wear diapers always because he had no muscle control so he couldn't control when he needed to pee or poo. He always came home from school without anyone having changed his diapers. When we tried moving him to other schools they refused to take him in, they said they didn't have facilities for his special needs and they refuse to change the diaper of a 10-year-old boy. So, Dad took him out and we moved to Obour city and bought a house there so Omar could walk in the garden because we couldn't go out much. In Egypt we practically never could. Omar was always in a wheel chair or mostly crawling because his legs only carried him for like a minute. Someone had to always be with Omar, my sister, my mum, and me we took turns changing his diapers and feeding

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him. My mum was mainly responsible for taking care of him.

We loved him but it was very hard living with him. We

couldn't bring any friends over because when he was 12 he

started touching his body and would kind of masturbate and

he would not know or understand and there was nothing that

we could do because he couldn't understand us. Also, I was

scared to bring any friends over and have them see that. Only

very few family friends knew about Omar and they used to

come over. They accepted that he acted strange, especially

that at this stage he would grab people's breasts, thighs and

pinch them. So only the few who knew about him came. But

Omar started having seizures when he was 14 and they kept

getting worse till he died of a severe one at 17 years.

I use Baffoe's (2013) argument that states that myths, superstitions as well as

negative labels contribute significantly to the social exclusion of PWDs. As I have shown

through these cases that both caregivers and PWDs are excluded due to the stigma

portrayed by the Egyptian society, which results in the family's inability and difficulty in

participating in activities in society that will ensure for them a good quality of life. The

reason why some families keep their disabled members a secret is related to self-blame,

grief, maintaining privacy as well as stigma. In most cases there is the question of

marriageability and in Egypt, this pushes suitors away for fear of having a baby with the

same disability due to genetics. Another part is the care; no one wants the burden of care,

since most caregivers are women. Men do not want to enter into a marriage with families

with disabilities, as they will be required to participate in the care of the PWD at the very least financially. A very similar case like Nagham's brother, Mahitab has an older brother with a serious form of Spina bifida that resulted in paralysis below the cleft area, loss of sensation, and loss of bowel and bladder control. Their cases are very similar minus the diplomatic father.What is noteworthy is that due to the fact that both women have a brother with a disability that their romantic relationships were affected. Mahitab broke off her engagement with her former fiancé because he suggested that they should find a replacement home for her brother if her parents die because he did not want her brother to move in with them and he did not want a disabled individual inside his home. It is very important for people to realize that family bonds are strong and in Egypt like other Arab cultures the notion of kinship is paramount (Campagno, 2009). An individual's social identity is closely linked to his or her status in the network of family relations. The concept of marriage is also considered a life-step. Even in today's modern times, it is basically almost every Egyptian home's goal that their daughters get a husband, children, status, and new house (Campagno, 2009). This is how most Egyptian families measure the sense of security for a child future. Nagham's first relationship was ruined when her suitor's mother saw Omar as the families were meeting to discuss the engagement and wedding plans. There was fear of Nagham carrying a gene that would result in her having a baby with a similar disability even though Omar's disability was due to a problem that occurred at birth. As a result, Nagham, even after the death of her brother she never mentioned Omar's disability to suitors or to her second fiancé. In fact, only very few family and childhood friends know about Omar's disability, her work friends do not. This might be due to the stigma that comes with it, when people know you have a member

with disability feelings of pity are always evoked. This sense of pity creates a sense of discomfort, makes people fear to ask actually curious questions about the situation; they fear offending or hurting a family members' feelings. Hence, people assume that the family is struggling and is living a difficult life. These feelings projected by the outside community affect the consciousness of an individual and create tensions within the household between parents, siblings both abled and disabled. A person with disability already feels different from others due to his/her disability and suffers from issues related to self-esteem. Depending on the type of interactions within various households, some embraced the disability and worked on adapting to it, while others denied it. No matter how the family is closely knit, the community plays an important part in easing the life they lead or making it more difficult depending on the severity of the stigma received "the norm is something that can be applied to both a body one wishes to discipline and a population one wishes to regularize" (Foucault, 2003). Thus concluding that siblings of people are in fact a unique population from which we are able to elicit more understandings of disability due to the fact that they experience disability in a variety of ways and as they get older they take on increased caregiving roles for their disabled siblings.

Chapter III

Caregiver and Relationships of Concern

Poverty and Disability

Parents have trouble talking about disability because they want to maintain the illusion of normalcy to themselves as well as the rest of the world. Another reason would be because they find it painful to discuss disability as feelings of guilt, frustration, concern, anxiety and sadness arise. Their minds are filled with worrisome scenarios of the burden they carry in maintaining a good life to their children both abled and disabled. They fear that one may feel slighted if the other receives more attention. This is mostly the case when the child with disability receives more care and attention not just from the parent but the abled siblings too are required to help and share in the responsibility of care. Concern is a dominant and constant emotion that parents feel from the moment they discover their child has a disability and it never fades. Sigmund Freud explains that there is "an existentialist view if anxiety, anxiety is central to the human condition, and that our mental life is characterized by psychic conflict" (Ainsworth et al., 1978: 35). Parents first concern will be about their child's disability, what is means for him/her and how to live with it and the type of help he/she will require. Parents will worry about their child's future in terms of education and services that will be required for him/her to live a good life. For example the very similar cases of Om Anas and Om Mohamed; both have young children with hearing disabilities.

Both women's husbands work as bawabs, they came from el Menia to Cairo; Om

Anas works as a maid in a nursery, has a little girl named Asmaa who is 7 years old and had to have Cochlear implantation when she was about 3 and a half years old. They had the operation done in Moa'lemeen Hospital; 90% of the surgery was covered and the rest they had to come up with through borrowing from the tenants of the building they worked in. They borrowed from the other bawabs in the area and through Al Orman organization where she and her husband went to get money as well. At first, Asmaa went to speech therapy sessions assigned to her after the surgery and her mum was keen on taking her to every session. The speech therapy sessions cost 50 L.E per session, and they were scheduled three times a week. Furthermore, the maintenance of hearing aids batteries was 1,000 pounds and the wires if they need change is another 500 pounds and they must be changed every five months. She has two batteries, she wears one and charges the other. Asmaa is not allowed to go out and play any physical game because her parents fear that she would fall or hit her head and ruin her earpiece and they cannot afford to buy her another one. At first she was rejected from a public school because the school did not want the responsibility of taking care of Asmaa and her ear device. The school's principal asked Asmaa's mum to take her to a deaf school because no body has the time to waste to teach a 'problem child'. After a lot of pleading, the principal agreed to admit her if Asmaa's parents were willing to pay a 400-pound donation. When Om Anas told the principal how poor they were the principle knowing that Asmaa's mum is illiterate made her pay 200 and sign (finger stamp) waiver that the school is not responsible if the earpiece breaks. Now Asmaa still cannot speak very well but she has memorized the meanings of certain sentences in order to function around the house but has learned nothing at school, as she requires extra attention and the teacher does not

have the time to spare. Similarly, Om Mohamed lives in the same area as Om Anas, they both live in sector 8 at Nasr City. Her five-year-old son Mohamed suffers from the same situation as Asmaa, only his speech is worse, they go to the same speech therapist, Om Anas is helping Om Mohamed by giving her the details about her daughter. Both families rely heavily on charity organizations to keep up with hospital bills as well as personal gam'eyat that they form to save up the money and of course from donations from the tenants in their buildings.

For these two women their biggest concern is money, their children's disability is considered as a financial burden. Disability and poverty are intricately linked as both a cause and consequence of each other. Both mothers primary target is the safety of the hearing aids as they are the most fundamental items for both their children's ability to function and live. In this case their concern and stress over money outweighs the personal needs that Asmaa and Mohamed need. They are only allowed to play together; both mothers decreed this. Asmaa is no longer allowed to play with her younger sister so as not to ruin her device and the same with Mohamed he is the youngest and his older sister is not allowed to approach him at all. Both Asmaa and Mohamed are now expected to live within a fragile invisible bubble because their parents cannot afford to give them a chance to enjoy a regular childhood. When Om Mohamed said "I am not worried about him being hurt I am worried about the device, where will we get another one if anything happened to it, it is a catastrophe". It is evident here how social class plays an oppressing role by creating social inequality. Poor economic performance creates a "low social stratum" that is associated with restricted access to social and economic resources. This becomes embodied inequality and in case of disability especially the severe cases maybe

detrimental to health. These mother's worries are not strange, they are typical parental

concerns, yet due to the family's economic status children's quality of life will be

negatively affected. For instance, the fact that Asmaa and Anas are not allowed to play

like other kids because their parents cannot afford to replace their children's gadgets.

When I asked why not teach them sign language this way you can always communicate

and will not fear very much if the earpiece breaks. " We are too old and people will call

us crazy" "el ns hat2ol 3alena maganeen" said Om Anas, who laughingly commented on

the fact that she didn't even finish school how do I expect her to learn sign language.

They said they have enough worries of making ends meet and trying to take care of the

kids. Both mums mentioned that they take the kids with them almost everywhere they are

almost never left alone. Each community has its own measurement of what constitutes

poverty as well as the material good necessary for their ability to function within their

city. These functional limitations form a barrier for them that prevent them from fully

participating in society.

Marriage and Disability

Marriage is challenge for PWDs and caregivers and is one of the biggest concerns

that parent of disabled and non-disabled children worry about. In terms of disabled

children, parents are resigned to the fact that marriage is not a feasible result depending

on the severity of the disability. For example, Om Anas and Om Mohamed said "Asmaa

and Mohamed will marry each other when they grow up, they both have the same thing

and will understand and care for each other". Both mums are the primary caregivers; I do

not recall them saying anything about the role their husbands' play in caring for their

children. I know both mothers are the ones who take the children to the doctor and speech

therapy. Both mothers were thrilled with the idea that their children would marry each other; this way they won't have to worry about their marriageability status when they grow older. Similarly, Marian who is a young woman with dwarfism unlike Ragab, Marian comes from an upper middle class. She goes to a private university and studies pharmacy. Marian's mum tries to find her matches on dating websites for people with dwarfism. Marian admits that all her mum can talk about and actually pray for is that she would find someone to marry "Rabena yeba'tlek ebn el halal yarab". Since her older sister was able to get married and Marian admits that she heard her mum talking with her friend on the phone on many occasions about how she feared neither she nor her sister would get married due to her disability. Marian said her mum used to stress endlessly about it, she feels more relieved now that her sister got married. All her focus now is for Marian to find a husband "awza atamen aleiki" (I want to make sure you will be fine). Therefore, all Marian's suitors are also men with dwarfism. Like Om Anas, Marian's mother does not believe that her daughter can marry an able bodied man. This is due to the fact that women with disabilities in the Egyptian society specifically are doubly stigmatized even more than men. If a woman needs care how can she provide it? Carolyn Fromader and Helen Meekosha (2012) argue that there is a denial of recognition, which is not only a form of disrespect for woman, but also that it can be damaging to women with disabilities and how they see themselves. "Women with disabilities have not achieved the same level of social, economic, cultural and political equality" (p 287). This is yet another reason why parents of children with disability are prone to worry and hide the presence of a disabled child. In Sabrine's case, her mother said "we fear that she would not be able to get married nor have a job, but we are counting on her younger

sister and older brother to care of her after we die, we made them swear to look after her". That was their ultimate fear that she would be left alone to fend for herself. She does not cook because her mum never allowed her to try for fear that she wouldn't be able to handle the stove. She is not allowed to leave the house alone because of fear of embarrassment, harassment or that she would be kidnapped or worse. Her mother said "Oh no way, she is always with someone, she never walks those streets alone, her body is too much of a woman and she would attract unwanted attention". The only way is for Sabrine's younger 15-year old sister to take her in when she gets married and takes over caring for her in the event that something happens to their parents. Parents are concerned with the future of their children and always expect the sibling to take over care in their stead. Depending on the type of disability some mild cases can learn to live independently while other cases with severe disability, such as Sabrine, Omar and Mahitab's brother cannot. Disability is then both embodied, and spills over into other bodies, and the things that connect or separate bodies (Shildrick 1997).

Concern and Stigma

Disability is not just the individual but the family as well. In Egypt, disability stigma becomes the family stigma thus raising other notions of concern from parents about their children both abled and disabled. To study the formation of stigma we must refer to Goffman, who identifies three types of stigma: stigma of character traits, physical stigma, and stigma of group identity and all of these types of stigma have in common is that they each have the same sociological features: "An individual who might have been received easily in normal social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other

attributes have on us." (Goffman, 1963:38). Therefore, stigma connects the outside world (social) and the internal world (self and other people i.e. caregivers and family). Dealing with stigma inside the house is just as important as outside if not more so. Sharon Snyder and David Mitchell (2000) claim, "Disability restricts, excludes, renders one exceptional: disqualifies" (quoted by Garland-Thomas 2017). An example is the case of Noha who has a child with Down syndrome, Ali. He was her second child the older one Mostafa, was born 'normal', 'abled'. When Noha found out she was devastated and listened to a lot of friends from her work who told her that kids with this disability do not live long and cannot receive an education, and he will have a form of mental retardation. She feared that people would make fun of him so she decided to have him undergo a plastic surgery when he turns 16 to change his features. She heard that people make fun of persons with Down syndrome based on their appearance. For 3 months after his birth she searched ways in order to have the surgery performed until her husband refused and changed her mind. They searched and found out that Ali will require a lot of rehabilitation in the form of physiotherapy and speech therapy for a huge part of his life and it will be expensive. They worried about the extra financial burden. She was a housewife and her husband worked as an account at a company. Her mother, sister, mother-in law and even friends told her to get pregnant again and have a baby girl, this way she will not have to worry about him when they are old because the girl will care for him. Noha and her husband did indeed get pregnant again and alas her pregnancy turned out to be another boy. They wanted her to try for one more time but expenses were already too much; Mostafa's school, Ali's treatments and the new baby. A mother is supposed to be the source of

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security and if she adopts abeleist ideologies then before he even leaves the house and meets outsiders, he will be made to feel unequal and ashamed.

The fear of society's reaction to her child almost made Noha take huge risk and actually harm her child. She already succumbed to one form of pressure and tried having a baby now she suffers three times the financial burden that she was concerned about. According to Fiona Kumari Campel (2009), ableism is a way in which abled and disabled bodies as well as minds are merged together through their subjectivities and culture. She defines ableism as a "network of beliefs, processes and practices that produces a particular kind of self and body (corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human" (Campbell, 2009: 213). She outlines the ways in which ableism works globally in the knowledge production of disability. Non-disabled people play a major part in constructing, characterizing, projecting, repressing as well as culturally symbolizing ways in which images of disability and impairment can sometimes 'subjugate' as well as threaten people with disability as they attempt to uphold and emulate 'ableness'.

Another example of stigma that affects an entire family is Basma and Ragab's family. Basma and Ragab have two children Safaa, and Yasen. They currently live in a room under the stairs of a 4-story building. Earlier they used to live on the top floor, both rooms where given to them by El Hag Mamdouh, who owns the building. Because of the bathroom and the fact that Basma used to help Ragab climb on and off the toilet seat; he protested and started to feel uncomfortable after his daughter started growing older and began to watch him. Basma said he did not want his kids to see him being taken care of like an "invalid" "A'gez". So, they moved down where the bathroom is 'baladi style'

built in the ground so he would not require any assistance. Basma was more open about their family situation than Ragab. Ragab talked about how good everything was whereas Basma shared actual incidences and worries. As I previously mentioned they do not leave the area much due to the stares and hurtful remarks that they receive. Now a new concern is Safaa's relationship with her father, at 3 years old she is as tall as Ragab. When they were walking down the street one day, Ragab was holding Safaa's hand next to Basma when a little boy with his mum were passing by and the boy pointed at Ragab and said "look mama, big baby, baby man!" the mother laughed and they walked away. Basma recalls that her daughter looked confused and was asking why is Ragab a baby. Another traumatic incident for Basma was when Ragab's warsha friends used to joke around whenever Ragab was with his daughter. They used to tell her 'show us that you are as tall as your dad and slap his face and we will reward you with a pound'. They wait until she does and have a good laugh out of it. Ragab never reacts because he said they were joking, but not to Basma, after she found out she gave the littler girl quite a beating and told her to "never ever raise your hand at your dad again! Don't you dare! He loves you, he is good, and when people ask you again you say no!" Ragab's disability defines the whole family, his wife and kids. There is a huge chance that it will affect their kids' future especially their daughter, when she starts going to school and other kids find out that her dad has dwarfism and start teasing her about him. She feared what this will do to her self-esteem and what this will do to the father daughter relationship. Moreover, she fears that Safaa might not find a husband when she grows up for fear that she carries 'the dwarf gene'. These were some of the concerns that were expressed by Basma and she said that all she can do is talk to her kids and prepare them for what they might hear.

Therefore, the above cases prove Carol Thomas's argument regarding social relational understanding of disability "Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing" (Thomas. 1999:60).

Chapter IV

Embodied Relationality of Caregiver and PWDs

Relationship of Attachment

The relational and experiential proximity to disability is essential to this thesis as I explore the relationship between spouses, siblings and parents of people with disabilities and how their understanding of disability, along with the values they hold and their attitudes towards, it affect the way they live their lives. Brett (2002) argues that no model of disability is adequate unless it takes account of the experiences of parents and children. To understand more about how PWDs and their caregivers live and embody disability is through examining their relationship. Using Ainsworth (1978) theory of attachment to understand reactions to other's needs and value orientation, states that attachment is dependent on the kind of attention he/she receives. This is extremely important in parent-child relationships however, mothers and fathers form different attachments with their children. Mothers form a primary attachment as the primary caregiver, while fathers form a secondary attachment yet, both are important for the development of the child "Attachment has been most commonly defined as children's inborn need for a sense of security between themselves and their primary caregiver, where they feel safe exploring and learning about the environment" (Ainsworth et al., 1978:37). There are four types of attachments: secure, resistant, avoidant and disorganized/disoriented. These attachments mainly show the different patterns of behavior between caregiver and child and whether the caregiver meets the child's needs or not. Children with a sense of secure attachment share a bond with their caregiver that provides comfort and safety. While a resistant

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attachment is where the child is unsure of the caregiver, sometimes he is clingy other times the child is not interactive. Avoidant, on the other hand means basically that the child is ignoring the caregiver and 'avoiding contact'. Finally, disorganized /disoriented attachment means that caregiver projects both a sense of safety and fear as well, due to inconsistent behavior from the caregiver. By understanding this attachment we can better conceptualize the many stages and forms of relationship that connects PWDs with their caregivers. The relationality of disability means that the presence of impairment does not only have meaningful effects on a disabled body, but on other bodies as well (Kafer, 2013).

I will use the attachment theory as an example in the case of Mrs. Amal who has two daughters, Merna and Hadeel. Hadeel, 27 years old, has a hearing impairment; she has been gradually losing her hearing ability since she was 14. She was supposed to wear hearing aids but refused and her parents completely dismissed the issue, so did she. They just bought the hearing aids for her; and by silent mutual agreement never discussed it again. She refused to wear them for almost two years because they used to hurt her; she used to shut them off due to loud noises that she wasn't used to. She was bullied at school and called "stupid" because she did not hear the other kids or answered a different answer than the questions they were asking so, they called her an "idiot". At the university, she had to wear the hearing aids because her condition deteriorated and the doctors said that it might affect her language because there were new words that she was not introduced to, as she could not hear them. She wore them during university, and people as usual would whisper in the seats behind her saying 'poor girl' or "what's that in her ear". She was self-conscious about that and would always wear her hair down to hide them. She

actually failed a course because she would not ask or inform the professor that she could not hear him during the lectures and never said anything; she was scared of the attention she would get if she said anything. She went into a state of anxiety and depression as the doctor later told her that she is continuously losing hearing in both ears and that he fears if this continues, there is a possibility that she will lose all hearing completely. Upon hearing this, Mrs. Amal screamed hysterically "my daughter, my daughter, I am losing my daughter!!!" As a result Hadeel refused to go see the doctor again and began suffering from severe anxiety and later had to go to therapy and receive treatment for it. Mrs. Amal did not like to talk about the Hadeel's disability but after Hadeel broke down since she was rejected from a boy she loved because she was "almost deaf" and had to go to therapy. The family opened up about her condition. Mrs. Amal keeps referring to her as " Hadeel taa'bana" '3ayana'" sick". Mrs. Amal used to and still does give her a lot of money to buy anything she wants and constantly buys her presents as a way to compensate her for her suffering. Hadeel does not do house chores because her mum does not want to pressure her more. Merna is responsible for all the house chores as well as errands. Every time Merna has a birthday, Hadeel receives a gift like her sister so she would not feel bad. This family is an example of an insecure attachment, where caretaker avoids the disability and does not address it as well as ignores the other sibling for fear that the disabled sibling might feel jealous. Mrs. Amal has embodied the safety and fear that Hadeel experiences. She feels that she is different because of the way her mum treats her and many times Mrs. Amal mentions Hadeel's condition without realizing that Hadeel can hear her. Even though Hadeel has a job and friends, still in her mother's eyes she can sense the anxiety and concern, which affects her self-esteem. Mrs. Amal admits

that she too has undergone depression due to Hadeel's condition, because she does not know how to handle it.

Furthermore, Hadeel is an example of how micro-sociological perspectives play a part in the power structuring that is continuously reproduced. She was bullied. Hadeel lived in silence and had to manage in a world where people decided to ignore her condition rather than simply talk about it and explore options, which can improve her quality of life. When asked why they did not acknowledge it, Mrs. Amal said 'we didn't want to make a big deal out of it and make her feel different so we bought her the hearing aids and acted like she was okay, so that she doesn't get negative attention from people". This need to overprotect from some disabled families is just the sort of dangerous action that results in weakening the person with disability and creating the marginalized, oppressed body. Hadeel's family misrecognized her needs and erected barriers and tried to go with society's ideals of the norm. They could have rehabilitated her and empowered her to be in control of her life. Therefore, she would have been less prone to suffering low self-esteem and fear. She was denied the use of her prosthetic, her earpiece that would have cleared many obstacles. Her older sister interfered and took her to therapy and encouraged her to meet new people, who helped raise her self-confidence a little; Hadeel's situation may have spiraled down and she would have embodied the helpless, sick girl that her mother believed and feared she would be.

Both Hadeel and Merna embodied the concern projected by their mother Mrs. Amal. Hadeel is concerned for her self and her mother's constant state of anxiety that she feels is her fault. Merna is concerned for both her mum and sister and she must carry the bulk of the responsibility as very often her mother surrenders to fits of anxiety. A person

with disability is able to accept and perceive his/her body as a whole. However, it is usually the mothers (primary caregivers) who have difficulty accepting that. Like so many mothers Noha, Marian's mum, Sabrine's mum, Om Anas and Om Mohamed they are overcome by strong feelings of grief, disappointment that later turns into shame, anger and guilt over their inability to help their children and worry about the kind of life they will have to live. This is why, these negative feelings are transmitted to other family members i.e. the disabled child and siblings creating tension among family members and that is when the feeling of burden emerges and settles its weight on the family. This could also end up creating rifts between siblings' relationships, for a 'shadow sibling' is created because the disabled child occupies the center of the family. Growing up at the periphery does not help identity formation either, thus further proving the embodiment of projected fear that dictates the lives of families and affects quality of life. Therefore, examining how disabled people may come to understand and situate themselves and their own identity is a key matter relating to inclusion and exclusion [6] *'Being* an impaired subject is not an all-encompassing identity. In that light, Biesta (2011: 145) differentiates between identity and subjectivity. Achieving an identity refers to the belief that 'only a stable and positive identity [can be] obtained through identification with an existing socio-political order'. Subjectivity, 'a process of subjectification – a process in and through which political subjectivity is established and comes into existence or, to be more precise, a process through which new ways of doing and being come into existence' (Biesta,

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[6] Griet Roets and Rosi Braidotti, *Nomadology and Sunjectivity: Deleuze, Guattari and Critical Disability Studies.* P.174

2001:145). Thus we see here the subjective experience of being and becoming and how disabled subjects exist in a world of barriers.

Roles of embodiment

Das (2001) examined the notion of domestic citizenship, kinship and family to show that stigma is not on the body but in fact 'off' the body, it is within the networks of family and community in which an individual becomes embedded with the domestic or excluded as she has clearly depicted in her previous article. This is important to my thesis as I explore the power of narration of caregivers and PWDs and with their embodied subjectivities within their domestic sphere (family) in relation to their public to show how they are made and remade based on each individual experience. Mead (1982) thought of the self as interacting phases called the 'I' and the 'me'. 'Me' is the social phase of the self. It is the internalized social order that promotes stability, predictability and social control (myself as others see me). The 'I' is the novel, creative, unpredictable phase of the self. This all occurs within the self-consciousness, which is a trait only humans possess, which Mead refers to as mental life, this is done using symbols such as gestures and responses to said gestures. This is how the formation of the "other" comes to be. He further argues that even though the self and body are different, the body can never view itself as a whole where as the self emerges from social communications with others and that one can view oneself through the others' perspectives. The theme lack of independence emphasizes the perception that disability is related to reliance on others. This theme shifts the focus from a function-oriented focus to a relationally centered meaning. The body becomes affected and in turn affects change in sibling relationships such as Merna, Nagham, Mahitab and Sabrine's sister Dalal. At some point the

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relationship becomes resentful especially during adolescence; siblings of disabled people suffer from parental neglect because all the attention goes to the other child. Another interesting emotion is feeling guilt over the fact that they were born healthy while their sibling has a hard life and a 'defect'. They also feel affected by the social stigma and are exposed to harsh comments from people thus worry about bringing friends home and they also worry about what they will say to and about their brother/sister. Moreover, they also may develop low self- esteem like their disabled sibling due to stressful conditions at home such as Merna and Hadeel's case. Later on, as they grow older and gain more maturity the role changes; they become over-protective over their siblings' feelings and well being as well as become very compassionate toward other people due to their understanding of the world of disability and being stuck in between. For example, Mahitab is very protective of her brother and once broke up a relationship with a suitor for saying a negative comment about her brother. Simiarly, Merna and Hadeel are actually very good friends, they moved past the resentment phase and are now each other's support line. Merna is very conscious about protecting Hadeel's feelings and always ends up reacting aggressively if someone upset her sister. Nagham, complained about Omar's disability and was ashamed from inviting her friend's home. She loves him and loved taking care of him, yet she hated the changing of the diaper part but she talked about how he loved music and water, so she used to play her violin for him and used to support him against the kitchen sink to play with him in the water. She was more afraid of people's reaction to him than of him actually embarrassing her. She later realized that as she grew older she overcame the resentment. Dalal too said that she loved brushing her sister's hair and playing make up with her. She didn't mind feeding her and the house

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chores she said that she would have been required to perform the chores even if she was an only child. Dalal also admitted that she would not trust any one else with her sister, thus does not mind her living with her when she gets married, "we have been living together my whole life anyway, it won't be new". Therefore, siblings of disabled individuals become a whole new category where they are not disabled yet are different as they break the norm of ableist community; they exist on the periphery of society. Das (2001) "the domestic and it's various publics of the relationships through which defect, disability, and impairment are embodied, performed, projected, and narrativized, to create the delicate work of the creation as well as separation of different body-selves through which the subject is made and remade" (p 529).

Disability needs to be thought of as general difference rather than based on impairment or illness. Moreover, studies are proving that by focusing on relational spaces as sites we enable obtaining an understanding of lives of PWDs and their caregivers. As Turner (1992) conceptualizes the body not only as an embodied subjectivity in the medical model but also as an organism, as a lived experience as well as a potentiality and also as a system of representations. He states that in writing about the body " we can talk about having a body, being a body and doing a body" (Turner p.16) The concept of body has been a focus of many social practices, it is bound into society as well as regulated through culture. Like sibling relationships, parental relationships are most important, as parents are the foundation of family. They provide security, love and nurture. In examining the mother-child relationship studies show that "maternal sensitivity has an impact on the child's feelings of security and cognitive competence" (Posada et al., 2007; von der Lippe et al., 2010). In families with disabilities, disability is a challenge that the

entire family faces not just the disabled individual but every single member is involved and is affected as well as affects another. When parents have a disabled child, their lives change and they have new roles and adjustments to make. They are exposed to financial worries as therapy and rehabilitation is quite expensive especially if the child has severe disability and will require care for the remainder of his/her life. Parents face guilt, as in society's eyes they get blames for their child's disability and as well behavior in public. Parents are expected to find balance in work and care; must be fair between all siblings but cannot because the disabled child will always be the priority due to his/her needs. Parents feel guilty over neglected their abled children and for expecting them to help and care for their sibling. Moreover, parents must educate themselves on the disability and its requirements in order to be able to provide adequate quality of life for their children. There are behavioral challenges that disabled children will undergo due to their frustration with their own bodies and condition. All these factors adds strain on parents especially parents of severely disabled children are also more restricted in some social activities than those of lightly disabled. An example is Omar, Nagham's brother, and his disability. The family could not go out and was obligated to move and buy another house and he required 24 hours care. The strain of such a responsibility and the fact that the whole family felt helpless during his seizures and could not relieve his pain was devastating for the family and the worry of which seizure will be the one to end his life. Nagham said, "It was my mother's ultimate nightmare and greatest fear". The strain of stigma that affects the children both abled and non-abled and having to worry about their futures such as Basma, that her children will be bullied because of their father as well as Mrs. Amal whose fear of society made her avoid addressing and admitting that her

daughter needed special care. Moreover, in case of Om Anas and Om Mohamed, they had to restrict their children because they could not afford to buy them new equipment, thus ended up suppressing them the way the rest of the society did and highlighting their difference. This why it has been reported that many mother's especially because they are more involved than father's, they end up suffering from depression. Society already has it's own preconceived notion of what is 'normal' and what isn't yet, however it can start from home, this is where that child learns how to communicate and establish relations with family members first, then community in school etc.

Acquired Disability and Quality of life

Friedman (2017) suggests that the majority of the people actually hold unconscious prejudice towards disabled people. "The norm is something that can be applied to both a body one wishes to discipline and a population one wishes to regularize" (Foucault, 2003: 37). Since disability can happen to anyone at any given moment, one might actually say it is inevitable. For example, the cases of two abled men who acquired disability, they had undergone surgery and had their limbs amputated and hence moved into the disability realm. Omar, a 26-year male who was in a motorcycle accident and as a result needed to amputate his leg; Mario is 23 years old had cancer and had to amputate his arm to stop the cancer from spreading. Both men tried the Egyptian made prosthetic but sadly the quality was not good. They travelled to Germany and received their prosthetics. Both men went through severe emotional and physical trauma as well as rehabilitation and support. They lost many friends after their operations; some of these friends did not wish to be close to them anymore. Omar lost his girlfriend; she could not handle his new situation and accept his new life. Needless to say both men's

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self-esteem was shattered. They had trouble becoming dependent on their families after reaching an adult age and experiencing independence. Having to rely on their mothers to help them put on their clothes, move and carry things was very difficult for both of them and their parents. Omar and Mario never met yet their stories could not be more similar. Their mothers and the rest of their family members became overprotective and clingy. Their mother worried over their future, Omar works at a bank and continued to work in it even after the accident. His mother feared they would let him go due to his disability, but they did not. Mario on the other hand, has just freshly graduated from college and as he was a business student, who wanted to work in the accounting field, feels like he cannot get a job. He has not yet applied for any job for fear of rejection though he claims he is waiting to undergo more rehabilitation first since he is learning how to write using his other hand. Both men were exposed to stigma and a sense of helplessness yet due to family support they are learning how to adapt. Social constructionism has been criticized due to the fact that the physical and mental impairment and oppression that PWDs face is unrecognizable " If the able-bodied saw the disabled as potentially themselves or as their future selves, they would be more inclined to feel that society should be organized to provide the resources that would make disabled people fully integrated and contributing members" (Wendell 1997: 247).

Using the notion of acquiring disability, it is not just acquired physically but socially as well; mothers who are caregiver and acquire the disability burden of caring for their children. Moreover, siblings mainly the girls, are required to are and carry on the disability burden. Lastly, I will draw on Lina Abu-Habib's *Gender and Disability* (1997) to explore the status of women in Egypt as well as the Middle East and how they are

already marginalized and objectified into performing the roles that society has dictated for them such as housewife and care giver. This is important to explore as it links gender and disability. They are two aspects of social identity, which leads to double marginalization from society as they are expected and designed to live in a world that is run by able-bodied men. These women are invisible in our community as they fail to conform to traditional and social concept of beauty and strength that is considered the norm. This leads to feelings of pity, embarrassment, condescension due to how abled-bodied perceive them. Women are already facing problems in receiving basic services such as health and education and that is when they are able-bodied. When we add impairment to it, they are not being represented in any way. This is important as I explore the status of these women, not only disabled women alone but also mother's of disabled children and how they take the sole responsibility of being the sole care giver as well as the nurturers of the household without being recognized. On the contrary, mother's most of the time are blamed, shamed and stigmatized for the birth of a disabled child. For instance, we see the narratives of Basma and Om Batta who acquired a disability because they married disabled men, female siblings of disabled individuals like Nagham, Mahitab, Merna who will have trouble getting married due to society's fear that they carry the disability gene. They embody the caregiver-disabled subject, a caregiver who faces disabling oppression from the community. In Egypt it is important to examine women when we speak about family, because this is the role expected of them as caregiver. However, being a woman in Egypt is challenging enough, add a disability to it with the lack of services available we thus creating a new role of a woman in limbo state is created; like Sabrine who has a disability that renders her "useless" in the eyes of

society. Similarly, May's aunt Fatima, who became blind due to a brain tumor and surgery, at the age of 16. She acquired not just the physical disability but also the cultural disability of being a disabled woman. She spent her days at home and was not comfortable going out, she never went to school to learn Braille she just remained the rest of her days with her mother who was her caregiver who also was bound to the house for her sake. I asked May whether she thought the suitors stopped coming because she was blind?

Mai said:

"Of course, of course they did. It goes without saying ya3ni!! Because people are like this now let's be realistic so how about then? You see now if you're in your 30's or like 29 or whatever they think that this is a negative point and it takes down your chances of getting married. So how about if you have something physical because here in Egypt we are not really that open minded but maybe if you were some where else or if you were in love with a person whose is really civilized, open minded and really in love with you; then maybe.

Moreover, Turner's (1992) mention of female sexuality and how female bodies are understood and regulated. He states " my identity; however, depends in part on my occupancy of a body, or rather a particular body, namely, my body. This claim is not to argue that there is a biological conditioning of identity, since my body is part of a complex social context involving many other relevant (social) bodies" (Turner: 93). Marian who must choose a husband with dwarfism because even though it was not said

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out loud, that is exactly the type of man that she is expected to marry. Similarly, Fatima ceased to be desirable and was no longer a candidate for marriage due to her blindness, thus Fatima's lack of desirability embodied her disability. Also, Hadeel who still fears entering into any romantic relationship out of fear that she will be rejected again due to her impairment. In addition, Mahitab, Merna, Basma, Dalal, Nagham all these women's relationship with their disabled members face the possibility of being rejected by society for fear of their association with disability. Thus in a sense, they too acquire their spouses and siblings disability and it affects to an extent how they live.

This also relates to Rosemarie Garland-Thomson's "Building a world with disability" she questions how can disability be both an opportunity for inclusion and exclusion? Arguing that we live in a world that rewards diversity of all kinds, some notions about certain acceptable bodies such as LGBTQ's and individuals with disabilities prevail. People who are visibly different yet still fall outside the norm that society expects and deems acceptable. Also, Garland-Thomson's is integrating the disability scholars Sharon Snyder and David Mitchell claims which suggest that disability is restrictive and disqualifies from full membership in the human community. They introduce the idea of Eugenic world building, the ideology and set of practices that control and determine who may enter and who may participate in the shared public space; thus determining who gets a chance to exercise the privileges of citizenship. This design of the world is considered restrictive to the disabled individuals. If this system continues then basically we are eliminating the existence of certain people. Therefore, if the abled community is reference point about said individual lived experience of relational disability then, this will push the focus on the core areas to a quality of life for both

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PWDs and their families. As Wendell (1997) sum it up "No one wants the social stigma associated with disability, but social recognition of disability determines the practical help a person receives from doctors, government agencies, insurance companies, charity organizations, and often from family and friends." (P.264).

Chapter V

Conclusion

Challenges that still Exist

All this leads to negative social consequences for disabled people that embody disgust, pain, fear, loss, shame thus increasing the stigma and exclusion that disabled people. The disability scholar Tim Stainton (2001: 453) notes that 'for both Plato and Aristotle, it was reason that separated men from beasts. To be wanting in respect of reason – to be what today we would call intellectually disabled – was to be less than human, to lack value, to stand apart from and deserve to be cast out of the polity.' (Hughes, 2012: 315).

I believe that Egypt should focus on changing the perspectives of its society as well as their attitudes rather than attempting to change disabled individuals by 'normalizing' them as much as possible in order for them to be accepted back in society. It is true that laws have been made to 'equalize opportunities' for the disabled and give them a chance to improve their lives. This however, does not work. I indeed society has come a long way and yes we realize that they have rights and that society created this category but laws and awareness campaigns are not enough. There are a lot of poor people who do not understand; neither do they know their rights or how to acquire them. There are indeed laws that oblige schools, universities as well as companies to accept disabled individuals; they are still able to forge papers in order to pass the quality assurance inspection but in reality they do not hire nor accept students. I am trying not to generalize but many prestigious schools do not have programs that cater to the disabled

individual. There is progress however I consider it a slow one and not very efficient, we can spend years attempting to propose endless awareness campaigns. I believe the real issue is with the implementation of the rules and the implementation of these campaigns. Societies' views will not change through words but through actions, through students attending schools together with disabled students, through having schools being equipped. It is left for the activists and the NGO's but technically without the government's support nothing much can be done. The government speaks for the people and represents the culture and ideals of a society keeping the disabled isolated still shows that Egypt is a long way from accepting disability; though it is making progress albeit a slow one.

It took twenty years to move the disability from merely awareness and to stress on the importance of action and taking steps. However, there are still some struggles that are present today. For instance the education system is lacking in the facilities as well as the learning programs to children with disability. Especially in the government sector, which primarily relies on governmental funding, it is close to impossible to convince a teacher to allow a 'disabled' student in her/his class, as most refuse because they aren't paid enough and consider it extra work. The classes are not integrated meaning that Children with disabilities (CWDs) attend the same school but separate classes. In addition, most schools focus on workshops not academic areas: they focus on preparing them for vocational jobs, but not on learning academia. Thus, the curriculum is also below average; it is not good enough to qualify for university. Such an attitude is reflected in the lack of facilities. There is a lack of Braille books; so blind/visually impaired individuals must then rely on readers to read for them. There are only a limited number of braille

books available and the blind only learn through braille. Thus all general libraries must offer more facilities and provide more books; also, the deaf/hearing impaired must learn through sign language. Some school students need to have companions to help them in schools work. I would have liked to see that students became each others companions meaning the abled could helped the disabled as extra credit maybe, this will help increase the sense of compassion and friendship; even make both feel like that is just a regular event in school; both will then grow up used to each other's existence. Besides, there is a strange situation where schools insist on only one disability in order for them to be able to handle the 'student', which in itself is forming even new categories within the categories. In many cases some parents do not even know sign language hence this leads to a huge gap at home and isolation within the family atmosphere. Not only the authorities represent the attitude of "otherness", but also families of the disabled. Parents struggle in making decisions when it comes to their children with disabilities; some are unaware of what they must do. When parents first find out that their child is disabled, they are at a loss as to where to go to find medical assistance as well as where to look for knowledge about the disability. Hence, parents are not encouraged to seek training and counseling on how to deal with their children and what to do in order to provide guidance at home. Moreover, Cairo, or any other city in Egypt, is not accessible to disabled in most streets and building, although now changes have started to happen to attempt to make it more accessible, but still requires a lot of work such as in the public transportation services.

The Egyptian realities reflect a general trend of treatment of the disabled in the world t. The stagnation in this area in Egypt reflects ineffective approaches employed.

This research has attempted to fill the gap and focus on perception of disability, contributing to the more effective search for solutions to transform inability of the disabled to their ability.

Limitations and Ethical Considerations

I had a huge challenge finding women with disabilities and people who knew PWDs and their families were hesitant to help me get in touch with them. When I finally spoke with them I couldn't ask questions concerning roles and sexuality, given the conservative society we live in; this was tricky subject to maneuver. This was both understandable yet frustrating because there was so much information that I wanted and so many questions that I had. But could not ask for fear of offending some one by talking about matters considered taboo.

I had fun in my fieldwork conducting my semi-structured in-depth interviews, that allowed me to meet many people and visit many areas however, I also faced many challenges such as for example I struggled trying to get people to open up. I found people who knew PWD or friends whose children had disabilities and of appropriate ages but they felt uncomfortable asking them for fear that they will be upset and I believe the term "3eeb" was used often. Even when I found people who were willing to get me in touch with individuals with disabilities I was always warned to be "gentle" with them and with my questions. I wanted to find a woman who also moved from the abled to the disabled category so she would provided by telling me her story of the changes in society and how she transitioned, how did she function with such limitations. But alas, the only case I found was of a woman who passed away so I only narrate the story from the perspective

of her family not her personally. There is so much more than could be done using relational theory of disability but the community needs to be more accepting to open up and share. Some people are desperate to talk and share their family's struggles while others sadly are still affected by the shame.

Final Words

I conclude that all people with disability experience disability as a social restriction, whether those restrictions occur as a consequence of inaccessible built environments, questionable notions of intelligence, or social competence. The inability of the general population to use sign language, the lack of reading material in braille or hostile public attitudes to people with non-visible disabilities. Disability is a development issue, and it will be hard to improve the lives of the most disadvantaged people in the world without addressing the specific needs of persons with disabilities. Dr. Hagrass gave me sound advice the concept of "Nothing about us, without us". She meant that I must receive my information only from my interlocutors who were PWDs however, since I am encompassing a fairly diverse fieldwork I need to have both, because yes no one knows disability better than PWDs, but no one knows abled better than the abled themselves. As we are all one community we need to listen to what the other person says and how each person translates his or her own experience. I tried to maintain that in my work, I tried very hard to stay focused on the themes that I laid out for my self. I was challenged very much through my writing to not venture away and state endless texts. The elements on power that is because I sincerely believe that this is the core of disability studies and practically any other study. Power I believe is like an intangible invisible layer of mist that we dwell inside, thus most of the time cannot feel how it changes, molds, creates and

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recreates. I have barely scratched the surface of the disability field and how to go about affecting change. The one thing that I attempted to do that was my goal is to provide understandings and ways in which we can improve the quality of life. If we could understand the creation of labels and work against to decrease labeling as much as possible through understanding the many mechanisms that cause it. For all people not just people with disabilities; the community as a whole has needs; a city requires certain facilities' to succeed in achieving equality for all. I end with a quote from Stiker: For good or ill, the disabled were exceptions and stood for exceptionality, alterity; now that they have become ordinary, they have to be returned to ordinary life, to ordinary work. [R]ehabilitation marks the appearance of a culture that attempts to complete the act of identification, of making identical. This act will cause the disabled to disappear and with them all that is lacking, in order to drown them, dissolve them in the greater and single social whole. (p. 128)

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