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"Crippled", Creeping and Crawling towards Enlightenment in this Life

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ABSTRACT

The objective of this study is to disseminate the value of my own unique body and seek to be liberate it from the constraints imposed on the disabled by our culture and society. Auto-ethnography is a tool for self-empowerment that guides me to enjoy the journey of self-reflexivity and recovery. Three themes have emerged after the activity of self-reflexivity: i) "disability" is not the problem, ii) "disability" is a hidden or untapped strength and iii) "disability" can be turned into a journey enroute to discovering meaning and the purpose of my existence. My critical, innermost thoughts liberate me from the socially constructed normativising identity traps that try to put the blame, hinder and burden of my unique body, I imprisoning the mind around the identity of a disabled person. This study may become a source of inspiration that helps many others to appreciate and reappraise their own bodies, and discover their individuality as a form of power and impetus for socio-personal and socio-structural transformation.

Keywords: Autoethnography, disability, self-identity

INTRODUCTION

Auto-ethnography engages the externally constructed and maintained, but also internalised, voices-in-dialogue with individual personal experience as a disabled person but also as a person with a different condition of body and being. I see myself involved in multiple levels of socially constructed consciousness to re-contextualise and recover my true worth and true self-identity. This is a process that engages a critical self-reflection as a means to comprehend how one's self-identity is constructed by and embedded in society and culture and subsequently internalised by the self (Ellis & Bochner, 2000). This is also the inward self-reflection to redefine and reassign meanings. The

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outward and inward reflections enhance self-understanding through the gaze as both insider and outsider to mirror what is dialectically “me and you” and what is “not me and you” (Yuval-Davis, 2010).

Engaging in the reflexive writing process allows the past and present to be more visible. This paper is a recovery and reconciliatory exercise to analyse my past and understand my present and the future.

Writing this paper is intended to trigger your inner resonance to challenge and to nourish your thoughts and empathy.

Thus, I will start by describing my background following an accident, which altered my life and shattered my dreams. Throughout this innermost critical self-reflection process, the interrelationship of “disabled” embodiment, social structure and culture comes alive. This situation enables me to reflect sharply on the meaning of disability, how it is constructed, used, structured and justified as well as the living hell that it creates for people like me.

Personal narrative

Part 1. When I was 16, I had a motor accident. I became a quadriplegic. My life changed completely and for the worse because of this accident.

> *“I cannot do anything by myself. I cannot dress myself. I cannot write. I cannot sit. I cannot walk. I cannot manage my daily affairs….”*

In my case, the impairment, from the medical aspect, is considered to be a high-level of impairment, incurable and therefore a permanent disability. I have been categorized into the disability group based on these two points, deficiency of my physical being and incurable by medical intervention.

> *“So everyone around me felt pity for me… I cannot describe how helpless I felt…and my parents’ desperate desire to find a medical cure was overwhelming…”*

> *“I want to be normal…I want to not be disabled. But my life is deemed not worth living because of my new physical condition as it is institutionally constructed, maintained and mislabelled as a disability…”*

The remarks such as “you are crippled”, “you are useless”, and “you are abnormal”, “so pitiful” and by implication, a useless non-productive burden were used to describe me. These remarks rubbed salt to my wound and directly negated my interpretation on the actual meaning and mission of my life. The new state of my physical condition was mislabelled as a “disability” and reduced me to a state of irrelevance, weakness, condemned to stay and live either in isolation or in a welfare institution for the disabled in this so-called civil-minded society in which we live. I was totally lost and had no idea what I wanted to do with my life in the present but especially in regard to my future as well. Am I condemned to live as a dependent and parasite forever? Or do I have to find ways to prove all the critics wrong? Where should I go? Thoughts like “I cannot do it” or “I am not good enough” were deeply impressed upon me, imposed externally and deeply rooted internally into my mind, my heart, my spirit and my psyche.

The disabling perceptions devalue our quality of “being” and undermine our psycho-emotional well-being (Reeve, 2002). It is because disability contains both spoken and unspoken assumptions to mislabel the identity of disabled people. It is because our society has a set of the hidden rules to classify and justify the differences between the abnormal and normal merely based on physical traits. Thus, we construct our identity according to having or lacking certain physical attributes to represent ourselves and assign the meanings to our performance (Goffman, 1959). Consequently, spoken and unspoken assumptions produce a strong sense of inferiority that governs our mind not to believe in ourselves as capable and able persons and entirely “normal” in our range of capacity.

Part 2. In 2000, my parents sent me to a Handicapped Centre, a special place to accommodate disabled persons. They hoped that I would learn some skills and get some training so that I would become less dependent as well as economically productive. To my great despair, the Centre treated us as dehumanised and pitiable objects at best and as goods and commodities useful for raising funds to run their institutions and provide jobs for themselves. No effort was ever made to know and to understand the residents as unique and able human beings; there were no programmes nor skilled professionals to help us to live independently and with the dignity due to human beings. We were disabled by the very institutions that were set up ostensibly to comfort and empower us.

> *“Awful! Once upon a time, I took it for granted that I deserved to be treated special…I thought the Handicapped Centre would be the best place to train us…But that was not to be the case...”*

To be sure Centres such as those I was admitted to contribute to greater disablement and discomfort to those who cannot live independently, creating the illusion and misperception of dependence in order to survive. This constructed identity of disability is imposed upon disabled persons causing them to become nihilistic, self-negating, self-disabling identities that define who we are, how we understand ourselves and expect to be treated (Stets & Carter, 2011).

Thus, when a body has been marked “disabled”, a social stigma is automatically imposed and attached to it (Link & Phelan, 2001). People perceive us on the basis of our disability without distinguishing us as having other characteristics such as gender, race, age and sexuality that make the same subject unique (Linton, 1998).

Part 3. After I left the Handicapped Centre, I went to college in 2006. It was here I realised how the able-bodied misperceived and mislabelled us.

> *"I had a hard time when I applied to study for my diploma in the college. At the beginning, the college did not accept my application because of my disability. They assessed my ability of writing with sprint hand and the speed of typing on a computer."*

Inevitably, my writing and typing was slow. My physical ability and performance to write and type was challenged. I was slow, needing more time on homework. However, they suggested that I find a special school tailored to my situation.

Following much persuasion and a written not to further my studies to the Advanced Diploma level at the Kuala Lumpur campus was accepted.

Society defines disabled people as "victims of misfortune", "otherness" and exploits them as "object of charity", "special" or advertises them as "inspirational" (Cameron, 2008; Lawson, 2001; Peters, 2010). It is how our social system has brainwashed and continues to brainwash our bodies, hearts, minds and spirits to believe that we do not belong to the "normal" world.

Present studies

In this study, I had to struggle to be free and to be liberated from the socially constructed and structurally maintained normativised brainwashing traps so that I could articulate and reflect the reality of a person in my condition. I asked myself repeatedly "Who am I and who are we?", "How do we name and interpret ourselves?" and "What are our rights and privileges as human beings?"

As argued by Shakespeare,

> *"Identity is an aspect of the stories we tell ourselves, to others. ... Previously, there was a limited range of narrative devices and themes available to people with impairment: now, new stories are being told, and we are creating ourselves for ourselves….* (1996, p. 95).

This study fills in the gaps by assessing the subjective experiences of disabled persons and their disability, to raise self-awareness and freedom from disabling self-identities (Griffo, 2014). Raising positive self-enabling and self-empowering critical self-awareness that focuses on the positive capabilities of disabled persons can liberate them from normativised, socially constructed disabling mislabels. In the stories below the traditionally constructed misperceptions of "disability" are challenged. This exercise is in accordance with the principle of nothing about us without us.

METHODOLOGY

This study applied the auto-ethnography method. Auto-ethnography is a qualitative method that is useful to reflect my unique story, not only to challenge the assumptions about disability, but also to rethink and consciously revise about our lives (Jones, Adams & Ellis, 2013). As a researcher, we observe ourselves and review how we position ourselves to make our knowledge accessible and transferable to readers (Franks, 2015). It is more explicit to say that the researcher moves from the backstage by immersing into the pattern of thoughts and feelings of inner self-consciousness and brings it to the front stage in order to engage the reader's reflexivity. Throughout auto-ethnography, there was the process to construct, deconstruct and reconstruct my identity (Custer, 2014). This is how I articulated and rearticulated my experiences in order to see my past, reshape my present, and create my future.

RESULTS AND DISCUSSIONS

The three themes generated after my in-depth self-reflection are as follows i) "disability" is not the problem, ii) "disability" is the hidden or untapped strength and iii) "disability" is the journey enroute for discovering the meaning and purpose of my existence.

"Disability" is not the problem

As stressed by Oliver (1996), disability has nothing to do with the body. If we cannot accept the reality of our disability, we are unable to appreciate our inner capabilities. It is because of our negative perception that makes us more incapable. Therefore, disability is only the problem if one easily accepts defeat or totally gives up.

Disability is not born but produced by our society (Finkelstein, 2001). For example, if everyone prefers a straight-edged shaped nose but you have an aquiline nose, the aquiline nose is defined as unattractive and automatically you become an "oddball" in the eyes of the majority. You are disabled and disadvantaged by your difference (Baciu, Alexiu & Bîrneanu, 2015). Inevitably, the ways society defines and classifies what is able-bodied or disabled, attractive or unattractive, worthy or worthless hinges on a majority consensus and preference. It is how our society treats people with different body conditions.

Our social, cultural and political systems are exclusively privileged to serve able-bodied people. This is because the disabled are perceived to be unproductive and do not contribute to the national economy and are not "tools" of political interests. It is always a direct consequence of a disabling system that robs the disabled of self and self-confidence. This is how our society sustains the power of superiority to reinforce inferiority of the disabled.

Therefore, disabled people themselves are not the problem but it is the mind-sets of the able-bodied and how they see and think about disability. Is disability seen by the able-bodied as a disability or is it a differing ability that able-bodied cannot accept?

"Disability" is the hidden or untapped strength

This is precisely the body I have, which has given me the power and ability to discern the richness of strength and understanding of life. It is the physical trait of a human being that warrants the embracement of accessible and inclusive systems to enable and empower the participation of the disabled.

It is not an exaggeration to say that brainwashing traps direct us to believe blindly that disabled people are a homogeneous group that need to be managed. . This is what I went through. After being categorised "disabled", the main task becomes normalising my disability by seeking medical intervention and institutionalisation in a Handicapped Centre.

The value of our lives is not defined by how the society defines our physical psycho-social condition/state. Thus, we need to build up a mature, stable and well-defined identity to strengthen the strong sense of self (Erikson, 1994). Strong sense of self and oneness enables us to express ourselves.

"Disability" is the journey enroute for discovering the meaning and purpose of our existence

We, as individuals have our missions and roles to play too.

> *"If you see our environment, you can find out that there are always some imperfections within perfections. The flowers are beautiful because of the presence of leaves and grass."*

However, most people would focus on the beauty of flowers without realizing that it is because the presence of leaves and grass enhances and magnifies the beauty of the flower. The conclusion is clear: imperfect and perfect would collude with beauty.

Things became lighter and positive when I started to accept myself as a person with different condition of body and being. I realized that I am unfortunate because of my imperfection. I also realised all individuals have a role to play despite their imperfections.

Inevitably, accessibility and inclusion are the capacitors and facilitators for the social engagement of disabled people (Cepolina & Tyler, 2004). This indicates whatever the body functions of the person, the inclusive and accessible environment enable their involvement in the desired activity. There is the need of the strict enforcement to encourage the integration of the accessibility and inclusive practices into every sphere of social development and system (Griffo, 2014). The aims are to enable the disabled and empower the disempowered.

CONCLUSION

I value my unique body and my "self". Self is liberated through new understanding, and then others too can be liberated through sharing of ideas. Thus, loving, affirming and celebrating individual uniqueness. I develop my own sharpness and analytical ability to reclaim my dignity, and liberated. It is not my body condition that is disabling.

It is the social structural system that is disabling as it tries to prevent me from being all that I am and can be.

Just like the Leaning Tower of Pisa, people like to travel and see new things because they want to know why this tower cannot fall and also to wonder when this tower will fall. I will not fall down. I want to be the Leaning Tower. It is because I fully understand,

> *"One will only suffer temporarily if he or she changes, but one will suffer permanently if he or she does not change. I will not fall and will not be seen to fall."*

Indeed, accessibility and inclusion are the common needs for human beings. Poor connectivity from the built environment, public transportation to the facilities of destination remains inaccessible to disabled people and the temporarily disabled, elderly, pregnant women and small children in strollers. Architectural barriers such as stairs, absence of elevators, ramps or steep ramps, etc prohibit participation of disabled people and others in need of accommodation.

Thus, the contribution of this paper is to refresh our self-awareness by sharing the strong beliefs that tie us together and to liberate us from the disabling system and initiate meaningful social change.

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