

Otherness and Mothers of Children with Disability

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Abstract: This paper addresses the way disability is lived and constructed by mothers of children with disability as recounted in their narratives. It focuses specifically on the mothers' relationships with their family members and society after the disability diagnosis of their child. 'Otherness' is a crucial theme in this paper. In fact, the paper explores the narratives with a view to exposing processes of 'othering'. It shows that the way we tend to organise lives around particular norms restricts and pushes people with disabilities and their mothers to the margins. This paper also provides insights into my own sense of otherness since I wrote it while pregnant.

Keywords: disability, mothers, otherness.

Introduction

This article is based on a dissertation presented in the Euro-Mediterranean Centre for Educational Research in the University of Malta for the degree of Master of Arts (Comparative Euro-Mediterranean Educational Studies). In this dissertation, entitled; *The Incoming of the Other: A Comparative Study of Published Narratives of Mothers of Children with Disability*, I compare narratives written by mothers from different countries about having children with disability. The main focus is the impact of this reality on their lives. Published narratives were chosen as the ideal means to enter into the lives of these women because, according to Sikes and Gale (2006), "the limits of my language are the limits of my world" (p. 1). They give a good understanding on how "mothers construct narratives of disability and how disability can construct narratives of motherhood" (Frantis, 2011, p. 129). This exercise is held under the philosophical lenses of Edward Said and Jacques Derrida.

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This paper explores the theme of 'Otherness' derived from these philosophers vis-à-vis two particular realities mothers of children with disabilities face after the disability diagnosis. These are; otherness and the mothers' relationship with her family members and otherness and the mothers' relationship with the society in general. In this paper, I shall also present parts of my otherness during this journey because this study is also a personal diary of my otherness as a mother-to-be in face of the many discourses about the struggles of disability, perfection and the so-called normality. In addition to the literature and the discussion, this paper captures the thoughts and feelings of five different mothers of children with disabilities in order to help the reader put everything into context.

Otherness

Otherness constitutes one of the main pillars of this paper for a particular reason: it helps me and hopefully the readers to detach from normalcy by giving me divergent ways of acknowledging the Other and avoid close reading of texts. This helps to make more sense of the way mothers from different parts of the world experience the reality of having a child with disability away from "a preconceived understanding of identity as self-sufficient presence" (Biesta, 2009, p. 27). This theme continuously shows me that by resorting to the usual linearity, which place the Other at the periphery, there is a greater possibility for knowledge to become a source of power (Kang, 2009). Hence, it opens up a whole new discussion on the "covert layers of assumed 'truth'" (Danforth & Rhodes, 1997, p. 358) and gives me the drive to go beyond the borders even if this demands discomfort and frustration (Morris, 2004). Said and Derrida are central in this journey because together they give me seven philosophical ideas which help me dislocate the other from the margin. These include deconstruction, contrapuntal reading, orientalism, logocentrism, post-colonialism, being an exile and justice. In different ways, these themes are about allowing the texts speak, moving the reader away from a dominant role and thus allowing a close-reading. They are crucial because they assist in resisting the linear kind of thinking which usually frames children with disabilities, who are often subject "to a great fear, disconcerting and isolated, to a prodigious act of negation" (Stiker, 1999, p. 7). Additionally, they provide me with "a new space of reading" (Wood, 1992, p. 3) and also help me bracket my identity in ways that allow other voices to emerge and be heard. Derrida denotes this approach by arguing that we should question what we are comfortably accustomed to (Wood, 1992) and Said similarly talks about the need to allow the discourse of the Other to come into mainstream (Burney, 2012). By following Derrida, the intention is to promote "alternative meanings which have usually belonged to minority groups and which have often been marginalized, to reclaim their rightful place in the market place of ideas" (Sweetman, 1999, p. 3). Moreover, Said's philosophy aims to reveal "the hidden structures of power and knowledge"

(Burney, 2012, p. 46). Altogether, the idea is to allow a shift from established and normative discourses about children with disabilities “toward releasing unheard-of, undreamt-of possibilities *to come*, toward cracking nutshells wherever they appear” (Caputo, 1997, p. 31).

In the following part, the theme of otherness comes across the two particular moments in the mothers’ life.

Otherness and Family Members

“No cards and flowers arrived in the days following Matthew’s birth because those around me had no idea how to react” (Enriquez, 2011, as cited in Camilleri, 2011, p. 1)

When parents learn about their child’s disability they face moments of disappointment (McGill Smith, 2010). However, this is not only experienced by the parents, by the mother in particular, but also felt by the whole family. Brown, Goodman and Köpper (2010) write that, “The terrain families must travel is often rough in places” (p. 1). These authors explain how there are many factors which change in families upon the discovery of a disability, among which they list: the well-being of the family; the emotional and physical health of parents; the parents’ relationship and tension in the family. They add that, “Marriages undergo change with the birth of a child, any child. But when a child in the family has special needs, this change may be even more profound” (p. 1). Increase in exhaustion, little or no time for each other, lack of family cohesion and adequate support and financial burdens are among the countless demands related to having a child with disability (Green, 2007; Cullen & Barlow, 2002). To lessen this burden, a number of family-centered services are usually provided (Evidence Network, 2003) but Parette, Meadan and Doubet (p. 382) argue that, despite the list of services, very often “fathers are treated as an afterthought” (p. 382) which according to them should not be the case. They add that much the same like the mothers, fathers of children with disabilities have also reported feelings of stress and disappointment. The mothers in the narratives referred to in this study have written about how the discovery of their child’s disability affected their relationship with other family members. They expressed particular reference to their partners and also their reaction to this situation, as shown in the chosen quotations below.

All the mothers write that both fathers and other family members mentioned in the narratives exhibited different disconcerting reactions upon the discovery of a child’s disability; ‘tear the place down’, ‘patting my back for reassurance’, ‘we accused ourselves’ are among the different examples drawn from the experiences. These are in line with the study by Goddard, Lehr and Lapadat (2000) and Camilleri (2013) who also listed an array of feelings

including guilt, denial, optimism, trauma, frustration, confusion, sorrow and acceptance. These feelings may be read in light of Said's Orientalist theory. Much like the way the Orient has been stereotyped by the West as "exotic, static, irrational, remote, barbaric and primitive" (Burney, 2012, p. 29), society has also marked the disabled as "different" or "abnormal".

England (Wyn, 2009)

The Partner – Before the diagnosis

"When Alex (*Nia's husband*) comes to visit me here he holds me in his arms and says that all will be well. He tells me that Joe (*their son*) will be fine and that we will be closer than ever." (p. 10).

The Partner – After the diagnosis

"Alex has been crying when I get back to the car" (p. 18)

"One night Alex sits up all through, staring out at the flat, wet stars, and next morning he says: "It's like death," and slams the door." (p. 44).

"We've lost intimacy, Alex and I. We're out of balance. He says I've disappeared into a world that he can't access and that I only think of Joe these days. He says he feels left out, as if he's running ahead or falling behind, as if we're journeying without him." (page)

Other family members

"I have called my father from the phone box in the corridor. "It's the brain," I told him, and then he couldn't speak and I couldn't speak and we just stayed there like that, just hanging, the line pressed up to his ear, and to mine." (p. 15)

"Before she goes to bed, my mother sits with me in the summer-house, watching the sun set. She says her pain is "double", because she feels it for Joe and she feels it for me." (p. 37).

Australia (Robertson, 2012)

The Partner – After the diagnosis

(*Parents' agreement on how to control Ben's fixation on numbers*)

"Robert and I finally agreed to 'quarantine' Ben's numbers. But instead of limiting him to using them once a day, we did the reverse" he was not allowed to talk about numbers at dinner. (p. 21)

"He's a fighter," remarked Robert, patting my back for reassurance. (p. 132)

(*During a school concert*) – Robert looks at me sadly and says, 'He's so different from the other kids, isn't he?' 'Yes he is,' I say, 'but he did so well.' Unlike Robert, I feel quite happy with today's experience. (p. 154)

Marriage Break-Up (After the diagnosis)

Our marriage seemed so unimportant compared with what our son was experiencing that it withered away in a few years. That's part of the story, anyway." (p. 99).

Other family members

"My mother – like me – was still coming to terms with the idea of Ben being autistic. She wanted to focus on his abilities, not his disabilities. Then my mother said, 'You know, Rachel, you can't really call Ben handicapped. He just has a very particular genetic inheritance". (p. 15)

Lithuania (as cited in Elvikyte, 2008)

Parents angry at each other

"At first we were thinking that we were not alcoholics and we did not have such people in our family, and we did not know why it happened to us. We accused ourselves, each other. ... We were very angry. At first, we didn't know with what we were angry. Then, we were angry with each other. Then, with ourselves. (librarian, 35, daughter with CP, 9)(p. 43).

Other family members

"The worst reaction was by my so called family, my husband's relatives. They said that I was guilty that I gave birth to that child. They rejected me. It was my fault that I had that child. I was guilty..." (unemployed woman, 43, daughter with CP, 17).

Malta (Enriquez, 2011, as cited in Camilleri, 2011)

Husband's Involvement

"My husband and I were still under shock when they brought him out of surgery, it broke our hearts to see him so helpless and for the next month I spent nine hours a day next to him in hospital.

Other family members

"When my family and friends found out how I felt (happy to have him), the cards and flowers came pouring in and, feeling more positive, I prepared myself for the challenges ahead" (p. 1).

Egypt (Shaker, 2002, as cited in Lababidi, 2002)

Family members

"When I was able (after the shock of the diagnosis), I wrote to my family in Egypt of Tamer's diagnosis, and everyone wrote back that the doctors in the United States were wrong and the diagnosis was nonsense. I remember when I came back with Tamer, one of the older relatives came to visit and Tamer was sitting on the floor. She instructed him, 'Go to the bathroom and bring me some toilet paper so I can clean your hands.' He went and returned with the toilet paper and handed it to her. And then she exclaimed, 'Now can that be a severely handicapped child? He has done this without any help; it is not true he is mentally handicapped'.

"The good intentions of relatives trying to shield a parent from a painful realization by denying the condition delays the treatment that could have helped." (p. 65).

Due to society's "desire for assimilation to the norm", "rhetoric of sameness", "erasure of differences" and "the promise to restore an individual back into the fold of "normal" life" (Stiker, 1999, p. xii), the birth of a child with a disability is not considered as part of the "standard of normalcy" because "people with differences are positioned as having less power" (Kang, 2009, p. 1). They are generally "perceived as deviations in kind, rather than examples of human variety" (Bost, 2011, p. 166). Consequently, this leads to an additional burden on the family, pushing them to the periphery and inflicting on them and their families the feelings mentioned above. Foucault (1979) emphasises that this fixation on 'normalization' makes it easier to measure gaps and order levels which only pin-point differences further, and that this "power of normalization imposes homogeneity" (as cited in Baker, 2002, p. 693) which excludes and includes. Indeed, the feelings mentioned above by the mothers are mostly attributed to the fact that, "Disability talk is often conducted in terms of a 'problem', a conundrum, or if you like, a headache that simply won't go away" (Campbell, 2000, p. 309).

This lack of recognition that "human capacities vary greatly from one another" (Stiker, 1999, p. xiii) and the normative references that constitute perfection in a child have imposed on fathers and other family members the feeling of being "kidnapped in another world" (Wyn, 2009, p. 44). In Derrida's words, this force for things to be "ordered, systematic and clean" (Mercieca, 2013, p. 202) hinders fathers and other family members from being open to the unexpected towards an "otherness which is excluded and suppressed" (Biesta, 2009, p. 27). All this adds an extra strain on familial relationships, possibly leading to marriage break-ups. Derrida acknowledges that "the road towards the other is not an easy road" (Biesta, 2009, p. 16) but he still emphasises the need to look for "what is unforeseeable from the present, of what is beyond the horizon of the same" (Biesta, 2009, p. 15) and move away from the urge to "locate a fundamental ground, a fixed permanent centre" (Biesta, 2009, p. 20). This urge stultifies and fortifies the creation of an "an inside and an outside" (Caputo, 1997, p. 108).

In parallel to this, in the study by Goddard, Lehr and Lapadat (2000), parents who do not fall in the trap of "others' reductive assumptions" (p. 274) and deconstruct the "dominant discourse on disability and its effects on parents" (p. 285) are able to tell a different story. They resist "the persistence of reductionist stereotypical view of physical and mental impairment" (p. 284) and this allows for a redefined experience of what constitutes "normal", "disabled" and "lives worth living" (Landsman, 1998, p. 93). This follows Derrida's creed to be "open-ended, porous, experimental, nonprogrammable, vigilant, self-questioning, self-revising, exposed to their other, inventive of the other. In a nutshell, deconstructive" (Caputo, 1997, p. 70). Simultaneously, in the study, parents who, like Said and postcolonialism, make a "consideration of [how] alternative, suppressed discourses and realities"

(Crossely & Tikly, 2004, p. 149) avoid closure and give more space to a deeper relationship with the other family members. This is also experienced by some of the parents in the narratives: "Joe's changed the way we see things, Alex and I. He's changed the way we think and the kind of places we find meaning. He's changed the way we grow. I think we feel things more deeply, Alex and I" (p. 182); "I would say that we became even closer, although we were close before. But now there is a deeper understanding between us" (manager, 28, son with Down Syndrome, 5 months) (as cited in Elvikyte, 2008); "At night I would often wake up crying and my husband would reassure me that everything would be fine" (Enriquez, 2011, as cited in Camilleri, 2011, p. 1).

Derrida explains that by only engaging with these philosophies of otherness, one is allowing space for what is usually overlooked, out of sight, omitted and excluded (Caputo, 1997). He stresses the "concern for the other as other, for the otherness of the other, for an otherness that, by definition, we can neither foresee or totalize" (Biesta, 2009, p. 31) in order to avoid closure.

Otherness and Society

"The staff did not believe in the potential of mentally retarded persons" ... "He is well adjusted and integrated in society" (Shaker, 2002, as cited in Lababidi, 2002, p. 65-67)

Prior to discussing how society has affected parents, it is worthwhile to clearly understand what is exactly meant by society and why it is given importance in this article. Mayer (2004) describes that society forms an integral part of human lives because our lives are "embedded in social contexts and are powerfully regulated and constrained by such context" (p. 169). He adds that history, society and institutions all play a major role on the lives of individuals. Correspondingly, McAdams (2008) explains that narratives not only represent the individual's experience but also "its most important and intricate relations to culture and society" (p. 242). Sikes and Gale (2006) confirm this in claiming that narratives are a way of making "sense of the world as we perceive and experience it and we use it to tell other people what we have discovered and about the world, or more specifically aspects of it, are for us" (p. 1). Stiker (1999) is of the same opinion and adds that in whatever we do we disclose society's norms. Therefore, through their stories, parents are not only representing their individual, unique experiences but also show aspects of their society (Newman 2013; Ferri 2011) making it impossible not to tackle this issue further.

Despite deriving from different backgrounds and cultures, all the mothers in the narratives seem to encounter the different social meanings, society's

demands, society's expectations and the various social definitions attributed to disability. This resonates with Landsman's (1998) claim that "Mothers of children with disabilities make their way within a society that devalues their children and in which motherhood has "failed" to follow the culturally appropriate trajectory" (p77). The mothers' narratives clearly indicate that they react differently to these constructs. Robertson (2012) questions these societal norms and rejects the idea of 'curing' her son to come to terms with what society promotes. Wyn (2009) seems less determined than Robertson (2012) and admits that she still compares her son to the measures which society imposes, although, at one point, she seems eager to explore the 'new' world with her son. Similarly, some mothers in Lithuania compare their children with others and with the standards which society enforces and feel awkward when their child acts 'strangely' in front of others. Enriquez (2011, as cited in Camilleri, 2011) seems to be struggling with the situation, trying her best to cope in such circumstances, while Shaker (2002, as cited in Lababidi, 2002) uses her son's disability to make up for the lack of information and proper services she encountered in her society.

England (Wyn, 2009)

*Mother's reactions towards society - .
(Comparing herself with her friends)*

"It's as if we've lost our timing now. Julie's had Freya, Joanna's had Callum, and I've had Joe. I can't keep up with them. Each time I try it's like treading water, while they're powering past me, doing butterfly" (p. 27).

Reactions from people towards her son
"A girl from the paper came to check out the gossip this morning and stood on the doorstep asking me questions as her eyes crawled all over him. She asked how I was feeling. "It's every mother's nightmare," she said. (p. 29).

"Now I can't amble through the parks and passersby unnoticed, I see our reflections everywhere. I see how no one ruffles his hair the way they do to other children. I see them look the other way, I see them stare." (p. 67)

"Yet the views and words society uses to define them still have the power to single them out" (p. 68).

Australia (Robertson, 2012)

Mother's perceptions on society and autism

"In the way that people with cancer are told to 'fight' the disease, so too are parents of autistic children told to 'fight' autism, to rid the body and self of the autism that afflicts the child.

"Perhaps there is a kind of stain of shame that attaches itself to someone with autism, like someone with cancer, a shame connected to the feeling of incurability, their supposed proximity to non-being" (p. 51).

"We construct autism as 'other' and therefore valorize and stigmatise, idealise and demonise" (p. 53).

"Of course, most parents adore their children, autistic or neurotypical, but it is surely partly the message that autistic children are a burden to their parents that supports the search for a cure" (p. 62).

Malta (Enriquez, 2011, as cited in Camilleri, 2011)

People in Society

"Many people tell me that I am doing a great job and their words move me to tears because they remind me that even though life can be hard, somehow I will find the strength to carry on" (p. 2).

Louisa Enriquez, (2011)

"Autism is still only a socially and culturally constructed concept; it's simply a list of behaviours that are classified as symptoms of a medical 'disorder'" (p. 186).

"The structures of society, however, continue to be ordered around the typical, or perhaps ideal, developmental path and so there are continual pauses and reconfigurations in your life. In a sense, you live against the story told by society." (p. 90).

Egypt (Shaker, 2002, as cited in Lababidi, 2002)

Children with disability and society

"Mentally handicapped people were never seen and families kept them hidden in a back room or on a farm, so that the knowledge of this handicap did not spoil the chances of the brothers and sisters for marriage" (p. 64).

"When we thought of the mentally retarded, there was much information that we did not know about." (p. 65).

"When Tamer was young and we were stationed in Europe, I was always worried about returning to Egypt because Tamer would not get help and training" (p. 67).

"Starting the Right to Live Association -

Some people said that they had enough problems without getting involved, some denied they had a mentally retarded child, some people were too tired, but some quietly assented, 'Yes, when do we begin?' (p. 68).

Lithuania (as cited in Elvikyte, 2008)

Mothers of children with disability and society

"If every family had a child with disability there wouldn't be any problem" This very nicely echoes the idea that disability is a social construct rather than a biological condition" (p. 28).

"There is no public discussion about children with disabilities. Thus, women are not ready for the birth of a "less-than-perfect" baby" (p. 33).

"You go on a bus and you feel it. And you try to correct your child. Always. You try to put him into standard. Either he behaves or looks strangely. And you correct him always because you don't want him to stand out in the crowd. You try to compare him with others. But it comes because others try to compare. And then we try to compare. ... This complex appears because of other people, not because it's bad for you. We are used to him. ... If people do not pay attention you also don't. The complex comes from people who do not understand. And if they don't want to understand they will never understand. (museum worker, 46, son with CP, 25) (p. 41).

Additionally, most of the parents in the narratives have also commented on the way people in society reacted to their son's disability. Wyn (2009), for instance, writes about how people look at her and her son pityingly "I didn't see what the other mother, who gave me a pitying look as we passed the gate, saw" (p. 185) or judgmentally, "A disabled child disables a family," she says, over her cup of tea" (p. 137) (*referring to the occupational therapist*). Roberston (2012) similarly explains how people still relate a sense of other, stigma and strangeness to one's disability. This is also confirmed by one of the Lithuanian mothers who, before having a child with disability herself, used to look at other disabled individuals in detrimental ways (as cited in Elvikyte, 2008).

These different reactions confirm that society plays an imperative role in the way people perceive disability. Despite the numerous debates, papers and discussions in relation to this topic, it seems that society still regards disability as the "abnormal other" and Stiker (1999) writes that "yet none to this point in history has committed themselves to a belief in the "naturalness" of physical and cognitive differences to the normative human condition" (p. xi). As society still emphasises categories (Baker, 2002) and "negative attitudes" (Landsman, 1998, p. 78) it is difficult for people not to look at such people in these disapproving ways. The parents in these narratives note these societal distinctions by writing comments such as, "Society separates us. It seems to fear the vulnerable" (Wyn, 2009, p. 67); "What is it that makes people afraid of contact with a person with autism? Difference, embarrassment, confusion?" (Robertson, 2012, p. 51), "the birth of a disabled child is experienced by a mother as a great loss of all plans" (as cited in Elvikyte, 2008, p. 33), "I began to visit centers for the mentally retarded, but they were like a storage for safe keeping, with no support systems or programs" (Shaker, 2002 as cited in Lababidi, 2002, p. 66).

In line with these, Danforth and Rhodes (1997) reaffirm that "disability is individually and socially constructed", "disability as a reality is made by people in words, thoughts and social interactions" (p. 358). This disallows parents from seeking "alternative thinking as well as the imagining of more empowering ways of being" (Fisher & Goodley, 2007, p. 68). It is also forces parents to "locate their children along a narrative of progress" (Landsman, 2008, p. 78) constructing stories of hope. This happens to Wyn (2009) when comparing her son to her friends' while still dreaming of a "choreographed" life (p. 27), to some of the Lithuanian mothers who feel edgy when in public and also to the Maltese mother who describes her situation as a struggle and needs strength to carry on. Simultaneously, this urge to "'pin' race down and create an 'index'" (Aberdeen, 2000, as cited in Baker, 2002, p. 670) makes these mothers feel as outsiders. Indeed they declare, 'I spend all my time on the

margins' (Robertson, 2012, p. 100), 'no public discussion on people with disabilities' (as cited in Elvikyte, 2008, p. 33), 'much information that we did not know about' (Shaker, 2002, as cited in Lababidi 2002, p. 65), 'life can be hard' (Enriquez, 2011, as cited in Camilleri, 2011, p. 3), 'the odd one out' (Wyn, 2009, p. 185).

Said experiences the same sense of displacement because throughout his lifetime he has been exposed to different cultures (Jerusalem, Palestine and Cairo) but never feels part of them. He writes how this experience of being an exile or, true to the title of his memoir, 'Out of Place' (1999), inflicted him with a sense of suffering but it also formulated his world view. In his essay 'Reflections on Exile' (1984), Said describes this experience as "strangely compelling to think about but terrible to experience" (in Barbour, 2007, p. 294). However, it gives him his contrapuntal awareness to read back "from the perspective of the colonized" (Ashcroft & Ahluwalia, 2001, p. 92), showing a particular awareness of the subjected and concealed. Through this ideology, Said is able to take into consideration all the dimensions involved when reading a text about the colonized and not only the leading one. His target became that of revealing power and making the "code visible" (Ashcroft & Ahluwalia, 2001, p. 93). From the narratives, Robertson (2012) seems to be the closest to this ideology. She declares that she feels alien in her society but this exile experience allows her to continuously question the power which society valorises, "independence over dependence, non-disabled people over people with disability" (p. 96). In Said's terms, she is "cutting against the grain, questioning received ideas [including his own], and treating the critical encounter" (Mitchell, 2004, p. 3).

In fact, Said's exile and contrapuntal analysis and also Derrida's deconstruction invite society and parents who still cling to a "linear narrative" risking "higher pressure situations" and "superhuman criteria" (Fisher & Goodley, 2007, p. 71) "to think and choose" (Danforth and Rhodes, 1997, p. 38). Derrida's call for deconstruction also demands that society 'overturn', 'critically analyze', 'open up', 'reveal covert layers' (Danforth & Rhodes, 1997) and to shake and re-evaluate that which is usually taken for granted (Sweetman, 1999). According to these philosophies, making the familiar strange, being open and uncertain, "enables mothers to enjoy their children in the present" in ways that "transcend categorization of normality and abnormality" (Fisher & Goodley, 2007, p. 78). These also empower societies to avoid totalising, yet instead opting, for the sake of justice, "to keep the surprise of the invention of the other open" (Biesta, 2009, p. 31), "always becoming and [which might] never be completed" (Fisher & Goodley, 2007, p. 78). Mercieca, (2011). Likewise this encourages professionals who tend to work within these confined spaces which society imposes, to engage with the theory of otherness and realise that, "Although professionals are expected to be certain and to possess a font of knowledge on which to draw in their work,

it is possible that learning to tolerate uncertainty makes a better professional, especially when the work involves dealing with people and children” (p. 33).

The final part of this paper will now focus on my journey in this study. It gives a brief description of my venture with otherness in my mother-to-be status which has an impact on my thinking and writing.

My Journey

My role at the start of this journey was completely different to its final stages. In my first proposal I had declared that one of my challenges would be that I am a stranger to the subject because I was not a parent. Consequently, I had also stated that, ‘The fact that I am not a parent and have no relatives with either a physical or a mental impairment gives me the opportunity to view the stories from an “objective” point of view, allowing me to remain uninfluenced’ (May, 2013). However, all of a sudden, comes, the moment which unexpectedly introduced me to “an affirmation of what is ‘wholly other’”, “An affirmation of what is unforeseeable from the present, of what is beyond the horizon of the same” (Biesta, 2009, p. 15). Amidst my struggle to engage with the literature, to read the stories and to question that which is usually taken for granted as part of the process to become a better professional (Mercieca, 2011), I discovered I was pregnant. This otherness gave my role a complete twist. I was no longer the non-mother, the complete alien, writing about mothers of children with disability but, as a mother-to-be, I became part of their stories as well. This new status gives me the opportunity to be caught in-between the narratives because it now also became a study of my journey of being pregnant with a child who one day could possibly also be excluded and labelled. The subsequent paragraphs give a very brief description of the otherness that I encountered in relation to my family members and society.

My Otherness and Family Members

In this part of the dissertation some members of my family are mentioned. It is important to acknowledge that their consent was gained. We also discussed the ensuing part to make sure that what I wrote does not underestimate their feelings or attitudes.

My husband has not walked this journey of otherness with me and thus found it very difficult not to be part of “the neutrality and the boredom that linear thinking brings with it” (Mercieca, 2009, p. 6). This makes me realise and reflect how similar to him I was, had I not been part of this journey, of this whole new idea of the impossibility of the other. I would similarly be attuned “to secure knowledge and skills” (Mercieca, 2009, p. 171), ignoring

the other, the excluded. Nevertheless, due to my continuous engagement with Said and Derrida and the mothers' narratives, during my pregnancy, I continually deconstructed and overturned fixed meanings and perceptions (Royle, 2000; Kang, 2009) about disability, normality and linearity. This strenuous voyage was not at par with most of my family members in terms of how they look at disability. It has created a continuous struggle between my family members and I making our relationship, "a puzzling combination of emotional closeness and estrangement" (Barbour, 2007, p. 297). This is very similar to the way Said felt when he also felt 'Out of Place' (1999) and exactly like him, this experience of being an exile has helped me develop a "scrupulous subjectivity, independence of mind, critical perspective and originality of vision" (Barbour, 2007, p. 295).

My Otherness and Society

My attempt to deconstruct linear discourse and attitudes about disability has also rendered my role in society as that of an exile. This mainly happens because of the considerable amount of importance society still gives to labels and to the "ability - disability dichotomy" (Danforth & Rhodes, 1997, p. 360). For instance, when reading about pregnancy and birth, it was quite common to read statements such as, "After nine months of hoping for a healthy, perfect baby, it is devastating to give birth to a child who is anything less than that" (Eisenberg, Murkoff, Hathaway, 1989, p. 475). Through such subtle messages, society portrays children with disability as a burden or strain (Shah & Priestly, 2011) creating a powerful discourse which I want to strip down to its "logically insubstantial bare bones" (Danforth & Rhodes, 1997, p. 358). This journey, especially through the Orientalist philosophy has made me aware that this perception towards people with disability is very much similar to the way Orientals are described by the Europeans as "depraved (fallen), childlike, "different"; thus, in contrast, the European is rational, virtuous, mature, "normal" (Said, 1978, p. 40). For example, I still recall the moment when my friend had told me that since I was pregnant I should change my dissertation topic. Even if, at the time, this seemed like the most viable option, the journey of "the unforeseeable, the incalculable, indeed the impossible" (Royle, 2000, p. 6) which I was experiencing taught me that by changing the topic, I would be removing one of the main aims to this study; that of having a sense of responsibility towards the other who is usually excluded or marginalised.

Moreover, this does not mean that by deciding to follow this path I did not yearn for everything to turn out 'well' and fall within the realm of 'normality'. Nevertheless, due to my in-depth reading of these philosophers I tried my utmost to shed off any constraints or borders which tried to entrap me and my expectancy.

Conclusion

This article has drawn a number of insights learnt from the journey I embarked on during my study. Said and Derrida have given me complex theoretical tools to make sense of how disability is lived and constructed by mothers of children with disability with particular reference to how this affected their relationship with family members and society. This perspective is recounted in the mothers' writing, and the process of writing itself continues to construct and reinforce the lived experience. The mothers' narratives have indicated how 'disability' is a social construction which tends to suppress people diagnosed with disability and put them in a nutshell. The seven philosophical ideas, related to 'Otherness', have specifically emphasised on this fact. They come across these "frameworks of meaning-making" (Fisher & Goodley, 2007, p. 67) in various ways often dislocating the Other from the margins by "seeing, gleaning, exploring other meanings that had not been overtly obvious in the text" (Burney, 2012, p. 128). Otherness breaks open and disjoins that which family members and society tend to gather and close (Caputo, 1997) in their definition of 'disability'. Furthermore, all this has also contributed to a very deep and personal reflection about 'disability' throughout a very sensitive period in my life. 'Otherness' enriches me with alternative ways to value children with disability and get beneath most of the clichés associated with it. Moreso, it also empowers me to reflect that there are no conclusive stances apart from offering me a new kind of 'response-ability' (Rocco, 2004) to answer to the needs of the other and to continuously think again.

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