



RESEARCH ARTICLE

A GLOBAL PERSPECTIVE ON MOTHERHOOD OF DOWN SYNDROME CHILDREN; EXPERIENCES IN LAGOS STATE, NIGERIA

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ABSTRACT

Purpose – Conducted in Lagos State, this research study sought to illuminate a cultural and context specific insight into the experiences of seven Nigerian mothers of Down syndrome children.

Design/methodology/approach – Adopting a feminist approach, seven mothers aged between 34-67 years were purposively sampled from mothers regularly attending the Down Syndrome Foundation of Nigeria in Lagos. Data was collected via in-depth interviewing, which consisted of open-ended questions that were used to explore the individual experiences of these mothers, within a cultural context.

Findings – There were six emergent theoretical themes from the study; birth of a child with Down syndrome - a diagnosis; challenges; positive attributes; worry; coping and knowledge gained. Findings from this research are consistent with findings on the experiences of mothers of children in alternative contextual settings. Mothers had no prior knowledge of the abnormality until they had a child with Down syndrome. The formal diagnosis was related to a process of grief characterised by depression and eventual acceptance. During the course of rearing their child, mothers face challenging situations such as financial problems, behavioural problems, and medical challenges. Moreover, mothers reported that these challenges had an impact on their health. Positive impact included family relationships, religion, and spirituality and specific support groups. Mothers indicated that the absence of government support, societal acceptance and finances made the journey of rearing a child with Down syndrome in Nigeria more challenging.

Research limitations/implications – This is a small scale study which is intended to illuminate the lives of women raising children in a culturally and contextually specific region.

Practical implications – This study highlights the stories of seven women, it highlights the need for further investigation to see how far generalisable to a wider population these findings are.

Originality/value – To date there have been no studies of the experience of raising children with Down syndrome in this culturally specific region. The study provides a unique insight from a feminist perspective into the lives of women living in Lagos State, Nigeria.

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INTRODUCTION

With a global population of approximately 7 billion, it is estimated that about 1 billion people are living with various forms of disabilities. Of these figures, an approximate number of 200 million are children, which include children living with Down syndrome (WHO, 2013). As there is an increase in life expectancy, and more women are beginning to take up career roles and give birth at an advanced age (Yashon and Cummings, 2012), the prevalence of this disability will continue to rise (WHO, 2013). WHO (2014) estimates a global incidence of 1 in every 1000 or 1 in every 1,100 live births. Though the disability equally affects all races, genders and socio-economic classes, in the US it is estimated that 1 in every

691 babies is born with the abnormality with a total of about 6000 babies born with Down syndrome annually. Furthermore, out of the entire US population, approximately 400,000 people live with Down syndrome (NDDS, 2014). However, in Australia, the rate of babies born with Down syndrome is about 1 in 1,100 with 1 in 1,700 as the average population rate of individuals living with Down syndrome.

Contextualising Perceptions

In Africa and other developing countries, there is difficulty in getting accurate data as a result of practices such as mothers giving birth in places such as churches and traditional birth homes where record keeping is lacking. Also, mothers of children with Down syndrome have difficulty in reporting such cases because there is still a cultural, supernatural stigma surrounding the birth of a child with Down syndrome. Thus,

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the available data is hospital based, which is relied on for health planning on the premise that it represents the actual population (Ajuwon, 2012). The most recent study conducted over a period of 9 years in a Nigerian hospital reports an incidence of 1 in every 865 live births.

Objectives of the study

The study aimed to

- Describe the experiences of mothers of children with Down syndrome.
- Explore the factors impacting on the experience for this group.
- Discuss this in view of the socio-cultural background of the society.

Literature Review

Published evidence suggests that parents of children with a developmental disability face elevated levels of stress in comparison to parents whose children have no disability. (Bingham *et al.*, 2012; Pillay *et al.*, 2012; Lee, 2013). Emotionally, parents contend with altered expectations of 'normality' in relation to their child (Mudhovozi *et al.*, 2012). Integrating a child with Down syndrome into the household and contemplating the potential life-long responsibility of taking care of a child who is impaired and seen as 'different' can have a dramatic influence on levels of stress (Gill and Liampottong, 2011). The long-term unpredictable life of the child, physical and mental health, functioning ability, growth and development and the family's capacity to provide for the child are stressors that further contribute to the psychological burden of the parents (Ogsten *et al.*, 2011). Physically, parents devote most of their resources, energy and patience as they rear any child (Mudhovozi, 2012). They are responsible for the health, emotional and behavioural problems of their child as well as his or her activities of daily living. Consequently many are left with little or no personal time and this is exacerbated in caring for a child with Down syndrome whose needs may be greater (Marchal *et al.*, 2013). Societal discrimination places additional pressure on those households living with a recognised disability (Gill and Liampottong, 2011). Women often sacrifice their jobs, further placing a strain on the financial security of the family as a whole (Pillay *et al.*, 2012). In a study by Mudhovozi *et al.* (2012) following an investigation into the experiences of mothers of children with intellectual disability, suggested that this creates the potential for family division as they become objects of societal gossip and ridicule. Parents of disabled children report issues of self-esteem and depression, which subsequently has an adverse effect on their health.

Bourke *et al.* (2008) investigated the health status of mothers of children with developmental disabilities, outcomes reveal that mothers had poor health with a mean physical health score of 50.2 (SD+9.6) and a mean mental health score of 45.2 (SD+10.6) which is significantly low when compared to the normal of 50 ($P < .0001$). Factors associated with this include the child's behavioural challenges, everyday functional capacity and general health status. In a more recent review of 28 studies, Lee (2013) investigated maternal stress, sleeping habits and well being of mothers of children that have developmental disability; results reveal a bi-directional

relationship between maternal stress and symptoms of depression as with between poor quality of sleep and depressive symptoms. Azad *et al.* (2013) further found an association with maternal stress and child's behavioural problems at child age six consistent with previous research suggesting that the behaviour problems of developmentally disabled children is a determinant of stress for mothers of these children (Neece and Baker, 2008). Challenges do not necessarily always lead to negative consequences for families. Ahmed *et al.* (2013) interviewed 30 mothers and fathers of children with Down syndrome to explore their experiences of parenting with the majority of the parents reported positively about the birth of their child. The majority described their child as a 'special gift' from God. Skotko *et al.* (2011) surveyed parents of children with Down syndrome on their well-being, of the 2,044 participants, 99% proclaimed love for their children, 97% reported being proud of them, 79% viewed life more positively because of them. However, 5% of the respondents reported their children embarrassed them while a further 4% wished they never had them. In another study, Ogston *et al.* (2011) examined 199 mothers of children with an autism disorder and 60 mothers of children suffering from Down syndrome to assess their levels of worry and hopes with regards to the ability to attain future ambition. Outcomes were consistent with previous research that indicates that hope provides a component of protection against suffering, anxiety and other forms of psychological distress (Colin *et al.*, 2010). Mothers of children with Down syndrome had higher hope and lower worry in comparison to those with children that have autism who reported lower hope and higher future-related worry. Interestingly, mothers who worried less were more highly educated and had older children with higher functioning levels.

MATERIALS AND METHODS

Data was collected in two phases of interviewing incorporating open and closed questioning techniques. The interview session was audio-recorded, with a digitally encrypted recording device, after obtaining the participants' permission. Field and observation notes were also taken. Content validity checks were made on the data collected. The data was manually transcribed and for a more comprehensive description, handwritten notes made by the researcher during data collection were also added to the transcribed accounts (Speziale *et al.*, 2011). The Jeffersonian method that ensured that an accurate, comprehensive and exhaustive transcript was produced (Jefferson, 2004). A vital feature of this method is the allowance for a system of symbols that denotes certain types of language features such as the use of 'um' and incomplete statements (Lapan *et al.*, 2012). The researcher employed accuracy in this process and transcribed how all words sounded including those not spoken within the conventions of Standard English. To aid the identification, analysis and report of key themes emerging from the interview (Caulfield and Hill, 2014), the data was analysed using Braun and Clarke's six stages for thematic analysis (Braun and Clarke, 2006), namely:

- Data familiarisation.
- Generation of initial codes.
- Searching for themes.
- Reviewing themes.
- Defining and naming themes.
- Producing the report.

The researcher started by first listening to the audio-taped data and reading through the transcribed information in order for the familiarisation of the data. Then, the analysis was done using a highly structured approach starting with an in-depth coding process which required working line by line through the entire data. These codes served as 'shorthand devices to label, separate, compile and organise data' (Charmaz, 1983: 186). Ethical approval was obtained from the University of Sunderland and the organisation where the research was conducted.

Sample

In a study as to explore the experiences of mothers of children with Down syndrome, the purposive sampling method was adopted, where the researcher performed a 'criterion-based' selection (Holloway and Wheeler, 2010), purposefully selecting participants who are mothers of the children in the foundation as they could provide in-depth, information-rich understanding of the phenomenon under investigation. Participants' age ranged from thirty-four to sixty-seven and though they all reside in Lagos state, they originated from different states and cultural backgrounds. States and ethnic groups such as Calabar, Ibo, Edo and Delta states were represented. Equal variance in socio-economic status was noted.

RESULTS AND DISCUSSION

Six themes theoretically emerged from the exploring the experiences of mothers of children with Down syndrome:

Birth of a child with Down syndrome- a diagnosis

The majority of mothers had never heard of the abnormality prior to the birth of their child, and even after birth it was only after sometime that the doctors were able to diagnose the condition, though the time and age at which they gained knowledge of this varied. This is outlined in Table 2. 'After the delivery, I found out that instead of adding weight, the child loses weight...the doctor... She did not understand the condition and it's a big hospital...we moved to another hospital.... They understood there was a problem somewhere but they couldn't really say 'look at the problem'... He was two years plus before we discovered his problem'. (Yemi). Although all mothers did not know of their child's condition prior to the delivery, several mothers said that they always knew something was wrong with the child as a result of medical problems which they did not experience with previous pregnancies. 'My heart sank!... I was actually very very devastated. So, I first called the nursing sister who was there at the bay, I wanted somebody to re-assure me that maybe I mistook... she came in, I told her, I said 'Take a look at this baby, have u seen anything that erm is not normal about her?' she looked at her and said 'No, there's nothing wrong with her'. So, I said I think this baby has Down syndrome, she looked at me, looked at the baby.... She just smiled... put on that very superior smile, and just walked away to her seat. She didn't answer me.... And I became very hysteric.

Challenges

The second theme focused on the difficulties mothers face in the course of parenting a child with intellectual disability in Nigeria.

'It's not an easy task at all' Uwa.

Mothers described the continuous health problems of their child(ren) as a major stressor in raising their child with Down syndrome. This could also exacerbate marital problems. Participants stated that the birth of the child with Down syndrome brought about problems with their spouse. Some husbands got frustrated with the endless medical challenges. 'Even my husband was fed up, started angry with me every damn thing, he was angry that I should take the child to the village that he's tired of it, I should go and stay in the village with my parents.... Everywhere will be quiet, you will hear the child's voice shouting... The father will get tired and left me alone with the child'. Ada: The extended time mothers had to spend on their child with Down syndrome was described by all participants. Added to this was the stigmatisation faced which seemed to have been as a result of the child's recognisable physical features of the anomaly or behavioural problems. Mothers who mostly reported stigma and harsh treatments from members of the society were those who had to rely on public buses as a means of transportation. Participants with privately owned cars reported lower levels of stigmatisation which could be as a result of fewer encounters with the public. Mothers also revealed how having a child with Down syndrome affected the lives of other members of their families causing crisis and tension in the family unit. One participant explained that her husband was 'fed-up' and this led to marital problems. Several other mothers recounted how the lives of their other children were affected by the presence of a child with Down syndrome in the family. This is better explained by the Family System Theory which suggests that crisis in any family sub-unit creates the potential for crisis in all other units (Whaley and Wong, 2005). Central to this theory is an assumption by Turnbull and Turnbull (1996)- the input and output configuration of the family system. This posits how the characteristics of the family (input) interplay with the system to produce outputs (family function). In other words, the birth of a child with Down syndrome (family characteristics) is a stressor for the family and functions to affect the way the family interact with each other within and outside the family structure (family function).

Ada described how the lack of money made her to withdraw her other children from private education to a public one and when it got worse, she resorted to hawking and even to selling her new clothes to care for the child. Dealing with the child's low cognitive functioning was challenging for mothers. The problem of getting a school to cater for the child's needs was a source of stress for mothers. Consequently, mothers had to settle initially for regular schools. Some mothers faced additional stress as a result of refusal of the head of such regular schools to accept the children. However, those whose children were accepted soon realised that other parents withdrew their 'normal' children from the school or their child(ren) were unable to meet up with the pace of learning and they were soon advised to withdraw their children. Mothers described the behavioural difficulties in their children with Down syndrome. Occasionally, their child got into fights with other children in school. Mothers felt this happened as a result of the inability of the other children to understand the condition of her child. Participants said these problematic behaviours grew worse as the child grew older.

Table 1. Participants' Characteristics

Participant's name	Sex	Age	Tribe	Marital Status	Level of educational attainment	Occupation	Number of children	Number of children with Down syndrome	Age of child with Down syndrome
Ada	F	38	Calabar	Married	Secondary school	Laundrywoman	3	1	2+
Ese	F	46	Ibo	Married	Nigeria Certificate in Education (NCE)	Teacher	5	1	10
Hauwa	F	44	Delta state	Married	Secondary school	Caterer	5	2	12
Ola	F	67	Efik	Married	Bachelors degree	CEO/Volunteer	4	1	26+
Uwa	F	36	Ibo	Married	Secondary school	Trader	6	1	8
Yemi	F	34	Ibo	Married	Bachelors degree	Business woman	4	1	12+
Ini	F	41	Edo state	Married	Bachelors degree	Accountant	5	1	17+

Table 2. The age of the children with Down syndrome compared to the age they were diagnosed

Participant's name	Age of child with Down syndrome	Age of diagnosis of Down syndrome
Ada	2+	Above 3 months old
Ese	10	6 months
Hauwa	12	Above 1 year old
Ola	26	3 days old
Uwa	8	5 months old
Yemi	12+	2 years plus
Ini	17+	2 weeks old

When done in the full glare of the public, mothers complained of a feeling of shame. Uwa described her son's behaviour in church, this causes her stress. 'He's stubborn...Before when he was small...when you carry him and sit him down, he will stay...When he reach like seven years, he can't sit down...he will be disturbing. ...Wandering...scattering everywhere..you will be pursuing him...around the church..he will start shouting...all eyes on you... If we want to enter the bus, he will not agree, he will be drawing himself back ..it's not too good for me'. Uwa:

Positive Attitudes

Although children with Down syndrome tend to have challenging behaviours, the third theme identified the positive attributes of these children. Mothers reported that these children are sources of joy and make them happy. Children with Down syndrome were described as being friendly, warm and honest which increases the possibility of being accepted by people in their environment. Most mothers commended their children with Down syndrome using phrases like '*he is very hardworking*', '*he always helps out with house chores*'. Participants compared their children with Down syndrome to their other 'normal' children and disclosed that their children with Down syndrome were very sensitive and tended to be attached to them that their other siblings. Findings from a recent literature by Coopman and Lull (2014) and Pillay et al. (2012) are consistent with these findings. There was a general

agreement that despite the negative challenges in rearing a child with a disability such as Down syndrome, these children actually came with qualities that made their mothers happy. Ola described her child as a unique child who is warm and friendly. 'She's quite a unique child...among my other children, she is very warm, she's very friendly... People accepted her and they made friends with her because she is err very assertive.... She sees you, she walks up to you, introduces herself and tells you she wants to... be your friend'. OlaAll mothers described their child with Down syndrome as always being happy, friendly and having a loving personality when compared to their other children without Down syndrome. 'In the morning when we wake up, they will come to our bed, 'mummy good morning, daddy good morning', they will hug you, kiss you, hug daddy, kiss daddy, but others will not do it'. Ada:

Worry

The fourth theme referred to what mothers worried about in the course of raising a child with Down syndrome. Although there was a slight variance in responses, all mothers worried about the future of their child with disability, especially with regards to marital life and being able to live independently. Hauwa disclosed that she worries that her female twins will not be able to live unassisted lives and fears for when she is no more.

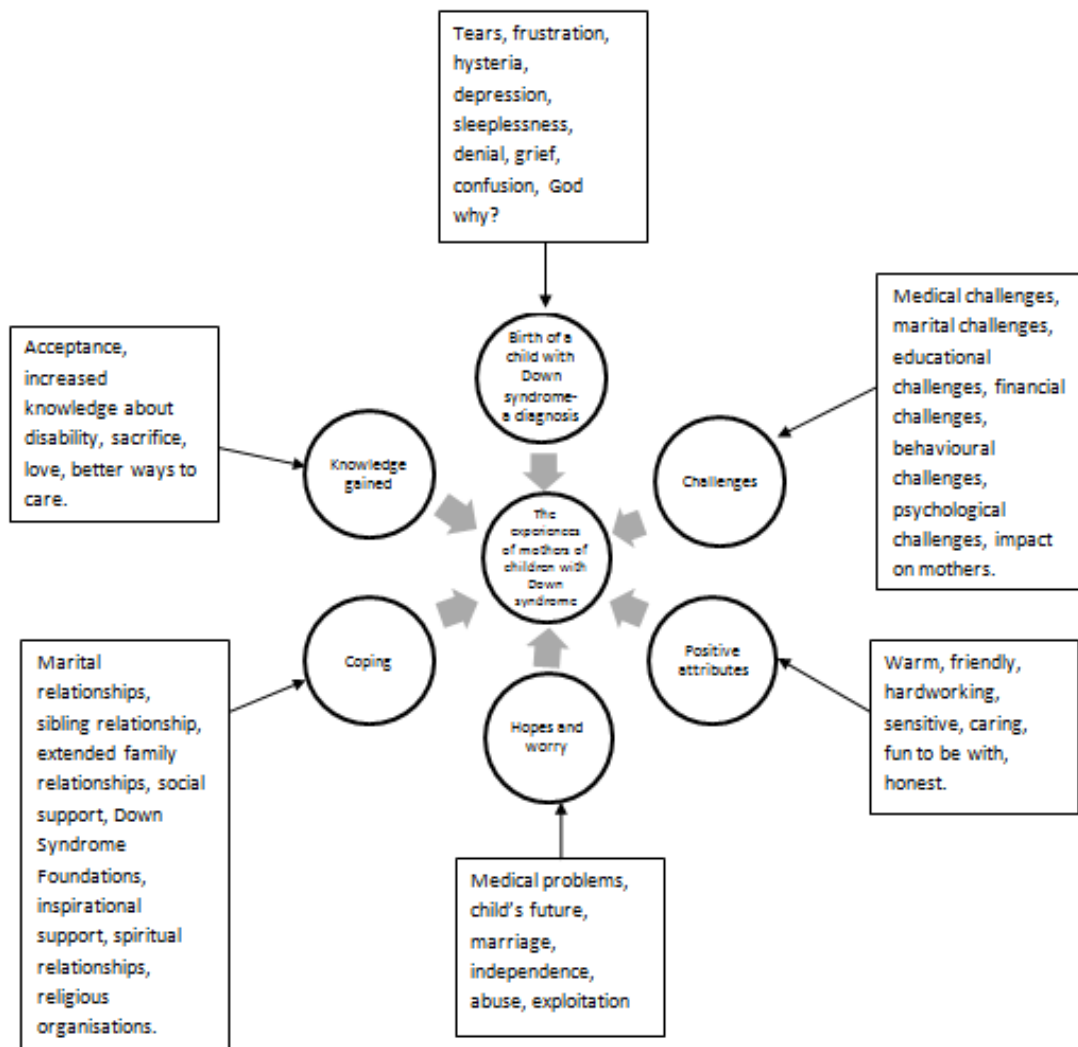


Figure 1. Identified themes and sub-themes of the research process

She narrated that it is a burden to her. '*starts talking slowly* when you have a child and you know that child cannot help herself, he cannot go to market for you, being a..a child with Down syndrome, you cannot just send her alone, they can't do something on their own without assisting them. They can't do anything,... so somebody has to follow them, be with them before they can do that thing. ...for how long?' so if I'm not there?... ,...you don't know if she can got married tomorrow. You have a child with Down syndrome that you feel that she can't do anything to say..to feed herself or to help herself if you are not there..... It's just like a burden, This fear has further led her to put the burden of caring for the twins on the older siblings as a means of securing their future when she eventually dies. This could be due to the unavailability of facilities to support the people living with disability in Nigeria apart from the privately owned Down Syndrome Foundation of Nigeria. Also, due to the societal beliefs associated with disability, these children may find it difficult to find a marriage partner in later life. In addition, several mothers mentioned that they worried as a result of their child's unending medical conditions and further stated that they believe it will be taken care of by God. The constant anxiety in mothers further cause more stress and sometimes led to depression. These findings are in line with studies by Burke et al. (2008) and Lee (2013) who report heightened anxiety levels in mothers of children with a disability.

Coping

The fifth theme describes ways mothers of children with Down syndrome coped with stressful situations arising from their child(ren)'s condition. Participants disclosed different support systems that helped them cope with challenges. This included support from extended and immediate family members, spiritual support, support from organisations, friends and neighbours. Patterns in the data reveal that mothers who started intervention early and who had more independent children had a more optimistic approach to coping with the stress of having a child with Down syndrome than those with highly dependent children. Acceptance for their child for mothers in the former group was also found to help mothers cope. Personal coping mechanisms: participants adopted various coping mechanisms which were influenced by their spirituality and support from their families. When confronted with the challenging experiences of raising a child with Down syndrome, mothers learnt to accept the situation and had hope in God who they feel has the power to change things. 'Nobody prays to have a child with... special needs... I did not pray for that but when it comes your way... you have to accept it... adapting to it... and asking God to give you the grace'. YemiMothers described their spiritual relationship with God as a strong coping strategy in the challenges associated with raising a child with Down syndrome than other measures.

Results of previous studies are consistent with findings of this research. Bingham et al. (2012) and Pillay et al. (2012) in their study found spirituality and religion to be sources of support to mothers of a child with disability. Malinowski posits that religion is used in coping, prediction and control. To Parsons (1957), it is the principal source which gives meaning and answers the utmost questions of all human circumstances, for instance, the reason God allows his human creations give birth to children with Down syndrome. Such life situations rebel against fairness and make living seem without worth, but religions offers solution to concerns of that nature, seen in instances when a mother expects that the challenges she faces as a consequence of having a child with Down syndrome will be rewarded in heaven. By so doing, mothers of children with Down syndrome are able to adjust and maintain stability during the challenges of rearing their child. Mothers who belonged to religious organisations such as churches relayed the emotional and spiritual support these organisations and the members provided to them through prayers and encouragement. Nonetheless, this support was only received by mothers if they were involved in such organisations. 'My spiritual faith have to really work in this aspect. So, I was moving close to God'. Ini: Commonly, mothers who took part in this study described the help of their spouses in coping with the difficulties in parenting a child with a disability. However, interviews with these mothers suggested that they are mostly the only ones involved in the care of such a child. This was evident in their use of words such as 'only me' and 'I', rather than the word 'we' which suggests a collective effort. Further, a participant who provided counselling for mothers of children with disabilities confirmed this by stating

'it's mainly the mothers that carry the burden and as we well know, in our society when a child is good, it belongs to the father, when a child goes wrong, it's the mother's child. So as far as they are concerned, this child is...has gone wrong, so that's the mother's child, you are on your own'

Even as post-colonial Nigeria confronts the conflicting legacies the influence of Western culture and pre-colonial traditions, its society is still patriarchal in nature- a main feature of a traditional society. Its system of social relations permits the dominance of men over women and as a result while men sit back, women are left to bear the burden of child rearing alone and worse still, if the child has a disability. This form of marginalisation of women is justified in a capitalist society, but in one such as Nigeria, women are doubly oppressed. First as a proletariat in the work place where the bourgeoisie makes profit by taking advantage of her labour power and then as a woman in a male-dominated society (Boserup, 1970; Hunter, 1973; Afisi, 2010; Umaru, 2013 and Dimka and Dein, 2013). De Beauvoir in *The Second Sex* (1949) gives a better analysis of this situation of the female folk and the social, cultural, historical and economic factors that accounts for their existence. According to Beauvoir, women's situation is dependent on the difference between the self-conscious subjectivity that has the ability to be free and superior and the non self-conscious things lacking ability to be free and buried in the immanent. Beauvoir asserts that women have been relegated to the immanent while men assume transcendence- 'He is the Subject, he is the Absolute- She is the 'Other' (Beauvoir, xxii). This contrast is vital in understanding male dominance in a society like Nigeria. Such position of women, if agreed to, is a moral fault, otherwise, it

denotes oppression. Beauvoir posits that women share in the blame for submitting to the role of the 'Other', she however maintained that women are oppressed because they are compelled to assume such a role. As individuals, Nigerian women have transcendent capabilities, but the culture and society denies this of them and forces them into immanence. Mothers who participated in the study described the support and care given by the Down Syndrome Association of Nigeria and the Down Syndrome Foundation of the United Kingdom. These organisations provided education for the mothers and their children and this played a vital role in helping them cope. This education was centred around better ways of caring for their child(ren) and further educated the children. 'I still belong there and a registered member of the Down Syndrome Association of United Kingdom erm and they had been the ones who supported me from the world go, not financially, but materially and otherwise, training and giving me resources'. Ola: In sharing their experiences, mothers referred to the poem titled 'Welcome to Holland' (Figure 2) as a poem that helps them cope with the challenges of raising their child(ren) with Down syndrome. Welcome to Holland is a poem of wide recognition, written by Emily Perl Kingsley who happens to have a child with Down syndrome and who is also a friend of the organisation where the research was carried out. The poem was described by mothers who participated in the research as a favourite which helps them. 'That poem called 'Welcome to Holland'... that's a very favourable poem of mine. You however planning to go to Italy but you ended up in Holland'. Ola

Knowledge gained

Mothers revealed that they have learnt from parenting a child with Down syndrome. This includes lessons of love, acceptance and appreciation for individual differences as well as for children with disability. Generally, mothers demonstrated knowledge of the cause of the disability and associated it with a defective chromosome; however, most of them had an *external locus of control* orientation (Rotter, 1966). These mothers believed that their child with Down syndrome came from God and that He created them the way they are. They did not believe that the abnormality could have resulted from having a child at an advanced age. Participants in this study all felt that through their experiences as mothers of children with Down syndrome, they had learnt their lessons. This ranged from having more knowing about disabilities and learning to accept the differences in others. 'Because I have erm really exposed myself to so much training, workshops, conferences and so on, I have learnt a lot... it made me a better person by been able to understand other people and to know that erm everybody can't be the same and therefore, we need to know how the other person feels and accept them also. We shouldn't expect them to be on the same level with you all the time'. Ola: All themes identified in this section were those directly experienced by mothers of children with Down syndrome. However, one theme surfaced that though was not directly experienced, seemed relevant to parenting a child with Down syndrome in Nigeria. This theme was repeated by 5 mothers in the course of interviews and these mothers reported that some children with Down syndrome are 'locked up' and 'hidden' by their parents in the homes due to the beliefs and stigma associated with having a child with disability in Nigeria. Mothers revealed that these parents who are either very highly placed in the society or belonging to the lower class are often ashamed to be associated with their child with

disability and as a result do not seek help for such a child. 'A lot of families now feel stigmatized and hide these children away and the people who are most guilty are our so called 'elites' because one, it's like the children don't sit well on their image. So, what they do is they would hide them and take them out of the country, dump them somewhere and then come and sit down as if nothing is happening. I have known quite a number, very highly placed Nigerians who have these children but you would never know they have them. No one knows except close family members...

When they have visitors, they would bring the other children out, that child would be left, that's the thing, we have so many'. Ola:

Conclusion

This study highlights the challenges that mothers face as a result of having a child with Down syndrome in a cultural setting such as Nigeria. Also emphasised are ways to improve current practice in order to provide support for mothers who care for children with disabilities in Lagos, Nigeria. Finally, this investigative study has accentuated areas for further research regarding experiences of families of a child with a disability. Such efforts are vital in enabling a better experience for mothers and other family members in the course of raising a child with Down syndrome and can aid children with disabilities look forward to living independent lives and making a meaningful contribution to the societies to which they belong.

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