Evaluation of Psychological Wellbeing of Mothers of Children with Intellectual Disabilities in Ongata Rongai, Kajiado County, Kenya

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Abstract

It is projected that up to 20% of children and adolescents globally experience some form of intellectual disability rendering them incapable of self-care and independent living. Parenting these children has adverse effect on the psychological and social wellbeing of the mothers due to the demands of care and other parental obligations. The objective of this mixed methods study was to evaluate the emotional health of mothers of children with intellectual disabilities. Questionnaires and interviews were used to collect data from 94 mothers of children with intellectual disabilities living in Ongata Rongai, Kajiado County, Kenya. Results indicated that anxiety, stress, depression, bitterness and low self-esteem were some of the negative emotional experience by mothers parenting children with intellectual disabilities. The study recommends availing of psychosocial support for mothers parenting children with intellectual disabilities to improve their psychological wellbeing.

Keywords: Psychological wellbeing, Mothers, Children and Intellectual disabilities

INTRODUCTION

Intellectual disabilities are characterized by below average intellectual ability accompanied by deficits in communication and self-care necessary for independent daily living. The deficits usually appear at any stage in development before the age of 18 and are experienced through the lifespan (WHO, 2010). Some of the most common mental disabilities include Cerebral Palsy (CP), Autism Spectrum Disorder (ASD), Down syndrome, and, Fragile X syndrome. Depending on the severity of the condition these manifest in varying forms of intellectual incapacities. Cerebral palsy is one of the most common congenital childhood disorders accounting to 1.5 to over 4 per 1000 live births worldwide (Centers for Disease Control and Prevention, 2018). Cerebral palsy occurs in infancy or early childhood and affects a person's ability to move and maintain balance and posture. This results from damage to the developing brain, which affects the child's ability to move or control the muscles meaning most children often require constant care to assist in tasks of daily living (Stavsky, Mor, Mastrolia,Greenbaum,Than, & Erezn (2017). Common indicators of Cerebral Palsy include seizures, language and communication problems, and mental disabilities (Abbaskhaan, Rashedi, Delpak, Vameg, & Gharib, 2015). Autism Spectrum Disorder (ASD) is a complex developmental disability that appears during early childhood and affects communication and social interactions of the child. Significant behaviors include delayed language, social interaction and restricted repetitive behaviors such as knocking head on walls or screaming incessantly (Quinn, Strothkamp, & Seper-Roper, 2018). Down syndrome is a genetic disorder that is distinguished by features such as a flat face, slanting eyes, short neck, small mouth and some degree of intellectual disability (Asim, Kumar, Muthuswamy, Jain, & Agarwal, 2015). Fragile X syndrome is a hereditary disorder that causes more severe symptoms in males than in females (Bagni, Tasssone,Neri, & Hagerman, 2012). Symptoms include delayed speech, learning disabilities and intellectual disabilities. Fragile X syndrome is believed to be associated with Autism Spectrum Disorders (ASD),

Attention Deficiency Hyperactive Disorder (ADHD), and Attention Deficiency Disorder (ADD) that cause pervasive behaviors in the children.

These disabilities are chronic and persist throughout the lifespan, rendering the children dependent on their parents and other caregivers to perform for them tasks of daily living and self-care. The birth of a child with intellectual disabilities shatters the dreams and expectations of parents for the child's future and plunges them into changes that affect all areas of their lives. Not many people, however, seem to understand the physical and psychological struggles that mothers, as primary caregivers, go through in their daily care of their children with intellectual disability (O'Connell, Halloran & Doody, 2013). Managing the child's lifelong health problems precipitated by their condition coupled with the demands of daily living, take a toll on the mothers leaving them with no enough time for self-care (Raina, O'Donnell, Rosenbaum, Brehaut, Walter, Russell, Zhu & Wood, 2005). The mothers have to assist with the daily tasks of the child such as feeding, cleaning, and movement, at times with no support from other family members which may lead to physical illnesses (Ha, Greenburg, & Seltzer, 2012) as well as psychological distress leading to anxiety and depression.

An examination of the situation of parents of children with ASD in the United Kingdom, revealed that parents experienced feelings of guilt, regret, frustration and uncertainty on how to best take care of the child which caused a lot of stress and anxiety on the mothers, who are mostly the caregivers (Mount & Dillon, 2015). In the Republic of Ireland research established that due to stigma, mothers of children with intellectual disabilities find it difficult to freely access services or look for the said services for their child, or even social support for themselves leading to feelings of frustrations and helplessness (Cantwell et al., (2015).

Research showed that parents experience challenges caused by the child's pervasive behavior. These pervasive behaviors are developmental disorders characterized by unusual, sometimes repetitive, actions such as flapping of the hands, body rocking, screaming incessantly or knocking the head on the wall or floor, as a result of communication and social difficulties(Mount & Dillon, 2015). Studies conducted in Australia by Eaton, Ohan, Stritzke and Corrigan (2016) and in China by Yang (2015) established that mothers fear being labelled as 'bad mothers' for failure to control the pervasive behaviors of their children with mental disorders. Fear of embarrassment and ridicule led the mothers to isolate themselves from the public resulting in increased incidents of anxiety and depression. The few studies done in Africa showed that mothers of children with intellectual disability experience higher incidents of anxiety and depression. For instance, in Ethiopia a study by Kerebih (2017) revealed that mothers feared for the future of their challenged children, especially in the event of the parent's death or incapacity, as most cannot take care of themselves, which leads to high levels of stress and depression. An exploratory research by Oti-Boadi (2017) which sought to determine the challenges and coping strategies of mothers of children with intellectual disabilities in Ghana found that mothers experienced feelings of sadness and grief at the awareness of the condition of their child. They were concerned with the future of their children who might never attain the expected developmental milestones for independent living. In addition the parents were apprehensive that their children, already discriminated against and rejected by the society, would have nobody to care for them in the event of their death or incapacitation. In Tanzania mothers of children with intellectual disabilities had disturbing thoughts concerning their children with mental illness especially on their future as most are incapable of sufficiently taking care of themselves (Ambakile & Outwater, 2013). Mothers experience feelings of sorrow, anger and bitterness, because of

the strain of care, stigma, discrimination and social exclusion by the society. Children with intellectual disabilities were more prone to physical abuse and defilement which contributed to the mothers' experience of sadness and bitterness. Mothers also expressed feelings of inadequacy and helplessness, especially when they failed to meet the needs of their families due to poverty attributed to strain of care for the child with disabilities (Ambakile & Outwater, 2013).

Research done in Kilifi County, Kenya revealed that mothers experienced feelings of frustration, shame, and guilt due to the problematic behaviors of their children with mental challenges and anxiety when they were not able to adequately provide the needed care to their children (Geere, Gona, Omondi, Kilafu, Newton & Hartley, 2012). An examination of the lives of caregivers of children with disabilities in Kilifi and Mombasa Counties indicated that mothers experienced feelings of loss and grief over the shattered dreams for their children. Due to societal stigma and blame as the cause of their child's disabilities, mothers of children with intellectual disabilities expressed feelings of guilt which contributed to the mothers' low-self-esteem, powerlessness and despair (Gona, 2016). Due to the constant care required by children with mental disabilities, most mothers are not able to engage in community activities or even in income generating activities, which results in withdrawal and social isolation, contributing to more experiences of stress, anxiety and depression by the mothers (Gona et al, 2016). In Kenya there are limited empirical studies pertaining the experiences of mothers with children with disabilities. Thus this study sought to address this gap by evaluating the psychological wellbeing as exemplified by depression and anxiety of mothers of children with intellectual disabilities in Ongata Rongai, Kajiado County, Kenya.

METHODOLOGY

A mixed research design was used to explore the psychological wellbeing of mothers raising children with intellectual disabilities. According to Creswell (2014) the use of mixed methods of data collection, analysis and interpretation, increases validity of the findings and enhances the accuracies of generalizations. Census technique was used to select all the 94 mothers and include them in the study because the target population was a manageable number. Additionally, simple random sampling was used to select nine (10%) of the mothers for guided interview schedule. Thus in this phenomenological study, information was collected concurrently, through structured questionnaires for the quantitative data and guided interviews to capture the lived experiences of the mothers as they cared for their children. The target population consisted of 94 mothers with children with intellectual disabilities that were aged between 3-19yrs and were enrolled in schools with Special Needs Education (SNE) units in Ongata Rongai location. To measure depression and anxiety the HADS depression scale (Zigmund & Snaith, 1983), a 4-point Likert scale measuring in a continuum was employed. Though the HADS depression scale was originally designed for use in a hospital set up, it has been applied in community surveys, with a strong internal reliability in general population in a community research (Djukanovic, Carlsson & Arestedt, 2017). The HADS scale has two sub-scales, namely the Depression subscale and the Anxiety subscale each comprising of seven items. The Anxiety subscale yielded an excellent internal reliability at Cronbach alpha coefficient of 0.924 while the Depression subscales a coefficient of 0.888. A prepared interview guide with open ended questions was used to explore the lived experiences of the mothers. The quantitative data was analyzed using descriptive statistics, namely, frequencies and means with the aid of the computer software Statistical Package for Social Sciences (SPSS) and presented in form of tables. Qualitative data from the interview schedule was translated from Kiswahili to English, transcribed, organized and analyzed based on the themes emerging from the research questions and the

findings were presented in form of narrations. To ensure that the study adhered to ethical standards when dealing with minors, the participants were informed of the nature of the study and requested to sign consent forms to participate in the study. To safeguard privacy and anonymity of the participants, serial numbers for both the quantitative data collection and interviews were assigned. The study was approved by Tangaza University College.

RESULTS

The study sought to find out the experience of mothers of children with intellectual disabilities, in terms of; anxiety and depression as they raised their children. The findings were obtained from the administration of the Hospital Anxiety and Depression Scale (HADS) questionnaire.

Anxiety for Mothers with Children with Mental Disorders

Responses of the anxiety sub-scale for mothers with children with mental disorders are presented in Table 1.

Table 1: Anxiety Scores for Mothers with Children with Mental Disorders

HADS Anxiety Scale: Dimensions	Participants' Responses
Normal	21(22.3%)
Borderline abnormal case	33(35.1%)
Abnormal case	40(42.6%)
Total	N 94 (100%)

Table 1 shows that 40(42.6%) of the mothers with children with intellectual disabilities had high scores for anxiety (abnormal case) indicating high chances of the mothers experiencing clinical anxiety , 33(35.1%) had borderline abnormal case and 21(22.3%) were within the normal range for anxiety, therefore are able to function normally.

Depression for Mothers with Children with Mental Disorders

Responses of the depression sub-scale for mothers with children with mental disorders are presented in Table 2.

Table 2: Depression Scores for Mothers with Children with Mental Disorders

HADS Depression sub scale Dimensions	Participants' responses
Normal	25(26.6%)
Borderline abnormal case	20(21.3%)
Abnormal case	49(52.1%)
Total	N 94 (100%)

Analyzed data presented in Table 2 indicates that majority, 49(52.1%) of the mothers with children with intellectual disabilities had high scores for depression (abnormal case) therefore highly likely to suffer clinical depression, 25(26.6%) were normal and 20(21.3%) had borderline abnormal case.

Data from the Interview Schedule

The presence of anxiety and depression as captured from the quantitative data was collaborated by the themes emerging from the interviews. The anxiety and depression were characterized by worry and anxiety, stress, sadness and bitterness and , low self-esteem. The theme of positive personal and family growth also emerged from the interviews.

Worry and anxiety

Mothers experience a lot of fear and anxiety in their daily care of their children. Fear for the survival of their children, especially when ill, and there is no money for medicine or the child cannot feed is a constant cause of anxiety for the mothers.

> *That is it! You see now this child, sometimes you see he is sick; you lose hope because that time he is sick, he does not feed. Now you see if he is unable to feed, this life, first if he does not take porridge and it's his main food, I ask myself how he will survive. This really gives me stress. If he does not drink this, now how will he be, how will he manage to survive? (Participant 1).*

All the participants expressed feelings of fear and worry over the day to day safety of their children as such children are prone to wandering and getting lost, putting them at risk of being sexually abused. Asked whether the child can go to school unaccompanied, a mother had this to say:

> *I once tried(allow the daughter to go to school alone) and people used to take advantage of her. Somebody with a motor bike had taken advantage over her on the way, he carried him and went on the way and the child cannot resist and say no. So that they made me to be insecure. Then I said no more other time will I allow that child to walk alone. It has given me challenge because now I cannot go and find work somewhere far from my kid, so now I decided to work where my child is. (Participant 6)*

Mothers also worry much over the future of their children as many fear what will happen to them if they are not there to take care of them. Their responses indicate a sense of desperation and sadness. They all relied on divine intervention for their children.

> *When I start thinking that way I just, I just shut my mind and say I leave it all to God, because I know it will be hectic, it will be bad because she requires my attention. I don't think anyone can really do for her what I do and I really try to avoid stressing my life; I dedicate her to God. (Participant 8)*

Stress

Most mothers expressed feeling stressed by the demands of care for their child with mental disabilities leading to feelings of hopelessness and despair aggravated by lack of social support and financial difficulties:

> *When you go to hospital it's expensive, at times his insurance is exhausted you have to pay cash and maybe the father does not have and is stressed. It gets to a point you ask God, why are you making me suffer like this? Until even me I ask God, why have you left me like this? (Participant 4)*

Sadness and bitterness

Some mothers expressed feelings of sadness and grief because of the state of their children and the demands of care. They questioned the meaning and purpose of existence especially when they could not meet the needs of their children with intellectual disabilities:

> *I started thinking, crying tears. The tears were flowing as I asked God, my first born child, why am going through this. It was very painful (Participant 5)*

Mothers described how their children with intellectual disabilities are treated unfairly or discriminated against by the society. The lack of empathy and acceptance made the mothers experience feelings of sadness and bitterness.

> *Sometimes when you are staying with people, maybe neighbors see your child is like that, if a mess is done in the compound, say toilets are not clean, you hear those mothers saying "this child's woman, she is the one who can do such". You know and sometimes you are very sure your child has not gone those sides. So you take it knowing that's part of discrimination and you don't feel good. You fail to*

understand why they are treating you like this, why they cannot put themselves in that condition. (Participant 6)

Low self-esteem

Due to perceived and actual stigma and discrimination towards them and their children with intellectual challenges, mothers suffer from low self-esteem that makes them isolate themselves from the community.

About me and the community, by then I was very withdrawn because by then had not trained as a special needs teacher. I was not emotionally fit so I could not interact with people and maybe share my problem. Okay, let me say I am the one(self-isolation) because at first I was emotionally depressed so I would not go out and start sharing and when I started to be open is when maybe I met other parents who have children with disability. That's the time that I saw that "oh my child is not that severe". I started now to share out my story. (Participant 9)

Personal and family growth

A few mothers expressed personal and family growth in terms of career growth and, family happiness and cohesion as expressed by two mothers:

In fact I was just a regular teacher. When I got the child, she is the one who motivated me and I saw that maybe this condition came as a bridge in my life so that I can cross on the other side and that is when I now I started to train as a special needs teacher. Even she has taught me so many things because she is a very social girl; even if you didn't have that good rapport with the maybe the father, definitely it will come. (Participant 9)

She gives me joy. She is usually jovial. I feel she has a space in the family that she occupies even though she can't talk or walk but we are just happy as a family being with her. (Participant 8)

DISCUSSIONS

The objective of this mixed methods study was to examine the emotional health of mothers of children with intellectual disabilities. The findings show that the daily care pressures experienced by mothers of children with intellectual disabilities have negative impact on their psychological wellbeing.

Mothers experienced a lot of worry and anxiety in their everyday care of their children, a major source of worry being the fear for the future of the children, as they were often the only guardians of these children. Due to rejection, stigma and discrimination of their children with intellectual disabilities, mothers worried about the lives of their children, if they died or were unable to take care of their children because of incapacity of whatever nature. Mothers felt that they were the only ones who could give their children with intellectual disabilities the best care and feared that their children would be neglected and suffer, and probably die, without them. A study in Ghana by Oti-Boadi (2017) and in Tanzania, Ambakile and Outwater (2012) concur with this finding. The results indicated that due to the stigma and rejection by society, of children with intellectual disabilities, mothers constantly worried over the future of their children in the event of their death. Mothers of children with Autism Spectrum Disorder (ASD) worry over the safety of their children, particularly because they are prone to wandering and getting lost, which expose them to increased risks of sexual violence. This is also consistent with the results of the report by UNICEF (2013) and a study at Muhimbili National Hospital, Tanzania (Ambikile &

Outwater, 2012), that showed that children with intellectual incapacities were more prone to violence, including sexual violence, as many have no ability to report such incidents. Mothers also worry and are anxious especially when the children are sick, fearing about the survival of the child.

Mothers experienced increased levels of stress from the demands for care. Having to assist in daily tasks or living such as bathing, feeding, dressing, and movement of their children, coupled with providing for the other needs of the child and the family, with no help from spouse, family or the community, made the mothers susceptible to fatigue, exhaustion and, stress leading to feelings of helplessness and despair. Anxiety over the general wellbeing of the children, especially in times of illness, was a source of stress and depression for mothers of children with intellectual disabilities. The finding concurs with the study in Ghana by Oti-Boadi (2017) which found that the strain of care coupled with poverty, elevated anxiety and depression levels in mothers of children with intellectual limitations.

The mothers experienced of rejection, labeling and isolation by the community. This led to self-stigma and withdrawal by the mothers resulting in increased incidents of stress and depression in the mothers. The results are supported by research done in China by Yang (2015) which showed that fear of public stigma and labeling on account of giving birth to children with intellectual disabilities made mothers isolate themselves and their children from the public through keeping the children at home. As a result, there are reported high levels of stress and depression among mothers of children with intellectual disabilities. Being labeled as bad mothers brought about feelings of self-doubt and inadequacy in the mothers giving rise to increased stress and anxiety as the mothers were not sure they were giving the right care for their children. This finding is confirmed by a study conducted in Australia (Eaton, Ohan & Stritzke, 2015) which found that bad- mother labels lead to low self-esteem characterized by self-stigma and self-isolation which increased cases of anxiety and depression among mothers of children with intellectual disabilities.

Financial difficulties due to poverty made it difficult for mothers of children with intellectual disabilities to obtain quality medical care and rehabilitation, which led to feelings of frustration, guilt, and stress in the mothers. These result are concurrent with studies done by Ambakile and Outwater (2012) in Tanzania and Gona, et al (2016) in Kilifi Kenya which found that the strain of meeting the education and medical needs of the children greatly contributed to the presence of stress, anxiety, despair and depression in mothers of children with mental disabilities.

Sadness and bitterness were expressed by mothers in form of anger and frustrations due the strain of care, rejection by spouse and family as well as unfair treatment and discrimination against their children with intellectual disabilities by neighbors. Mothers were also negatively judged for example, for perceived neglect or torture of their children with intellectual disabilities such as locking them in the house. The neighbors and the public report to the authorities without seeking to understand why such mothers lock up or tie their children with intellectual challenges in the house. They also offered no social or emotional support, which increased the feelings of sadness and grief in the mothers. This negative attitude may be attributed to low level of awareness and exposure to issues of intellectual disabilities among the population. The finding concurs with studies done in other parts of Africa Oti-Boadi (2017), Ambakile and Outwater (2013), McNally and Mannan (2013 and Masulani-Mwale et al, (2016) which indicate, that generally mothers of children with disabilities go through sadness and grief due to shattered dreams and expectations of having a ‘normal’ child, cultural beliefs about disabilities and the negative reactions of the society

towards them and their children with disabilities. On a positive note, some mothers reported personal growth in terms of self-acceptance and career development after making meaning of the condition of their children with intellectual disabilities. Some had trained in skills that they used to teach and work with children with special needs while others reached out to other mothers of children with similar conditions as their children. Mothers also expressed experience of happiness and joy when their children made progress in achieving small landmark in their growth. They reported family happiness and cohesion attributed to the child with intellectual disabilities in their midst. This is in tandem with the findings of research done in Moshi, Tanzania by McNally and Mannan (2013) which reported that guardians of children with disabilities experience positive affects characterized by celebration of child's small achievements, family happiness and cohesion and, personal growth through career development.

CONCLUSION

This mixed method study aimed at examining the psychological wellbeing of mothers of children with intellectual disabilities found that the pressures of caring for a child with intellectual disabilities had negative impact on the mothers' psychological wellbeing. Mothers experience fear and worry over the security and future of their children, anxiety and depression due to demands of care, guilt and frustration and, discrimination and isolation, which effects their functioning as productive members of the community. However, some have experienced positive growth such as career development and, family happiness and cohesion despite the challenges mainly because of their own resilience and the support from their spouses or other significant family members. Psychosocial support from the government and other agencies and, understanding and acceptance by the society are recommended to help improve the psychological health of the mothers.

Implications and Further Research

An overwhelming majority of the participants had never received any psychological counseling to help deal with the negative emotional and social effects of caring for their children because of lack of information on where to get the services and the cost involved. This study recommends that the government incorporate psychological support for mothers into the rehabilitation schedules such that mothers concurrently access counseling services as they get medical and rehabilitation for their children. Psychotherapy offered through the support groups, either on individual basis or as group therapy would help the mothers deal with emotional and psychological issues that hinder them from fully participating in the growth and development of their families and our country.

At the same time the findings indicate a need for creation of public awareness, involving not only the general public but also the security and administrative agencies, to demystify intellectual disability in general and in particular among children. This awareness would help the community take part in protecting and safeguarding children with intellectual disabilities from getting lost and possible violence, including sexual violence. Consequently, this would minimize incidents of stress, fear and, anxiety among the mothers of these children. Recommendation therefore, is made for government and community agencies to create awareness among the public, including the security agencies, to demystify issues of intellectual disabilities in general and, specifically in children and therefore promote inclusion and integration of the mothers as valuable members of society.

Further Research

Findings of this study clearly show that mothers caring for children with intellectual disabilities encounter challenges that negatively impact on their psychological wellbeing. Research to explore the challenges and the mothers' coping mechanisms can be carried out. This would help the government and other state agencies come up with policies that help ease the challenges and therefore improve the psychological wellbeing of the mothers. The results of such a study could also be used to sensitize the community on issues of intellectual disabilities which would lead to greater understanding, acceptance and inclusion of the mothers and their children into the mainstream society as equal members of our communities.

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