

Original Research Article

Exploring the Lived Experiences of Mothers of Children with Intellectual Disabilities in Rural Kenya

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ABSTRACT

Approximately 20% of children and youths globally experience some form of intellectual disability rendering them dependent on parents and other caregivers for the performance of daily tasks of living. Looking after these children is very challenging for the caregivers. This mixed methods study sought to define the lived experiences of mothers of children with intellectual disabilities in their daily care of the children. Standard questionnaires and structured interviews were used to collect data from 94 mothers of children with intellectual disabilities living in Ongata Rongai, Kajiado County, Kenya. The study found that mothers experience strain of care, financial difficulties, stigma and discrimination and, lack of adequate specialized education, health and rehabilitation care. Mothers cope with these challenges through spirituality, resilience, hope, love and acceptance and utilizing the available rehabilitation and educational facilities. The study recommends increased provision and access to education and rehabilitation for the children and, psychosocial support for the mothers raising children with intellectual disabilities to lessen the burden of care.

Introduction

Intellectual disabilities are defined by lower average intellectual capability attended by discrepancies in communication and self-care needed for autonomous everyday living. These discrepancies usually appear at any stage in growth before the age of 18 and persist through the lifespan (AAIDD,2010). The most prevalent mental disabilities include Cerebral Palsy (CP), Spectrum Disorder (ASD), Down syndrome, and, Fragile X syndrome. Contingent up on the severity of the condition these present in varying forms of intellectual deficiencies. Cerebral palsy, one of the most prevalent hereditary childhood condition accounts for 1.5 to over 4 per 1000 live births worldwide (Centers for Disease Control and Prevention, 2018). Cerebral palsy ensues in infancy or early childhood and impairs a one's capability to move and maintain stability and bearing as a result of damage to the developing brain. Because the child's ability to move or control the muscles is adversely affected, most children often need constant support to perform tasks of daily living (Stavsky, Mor, Mastrolia, Greenbaum, Than, & Erez, 2017). Presence of Cerebral Palsy is characterized by seizures, language and communication problems, and mental disabilities (Abbaskhaan, Rashedi, Delpak, Vameg, & Gharib, 2015). Autism Spectrum Disorder (ASD) a compound developmental incapacity appears in early childhood and impairs communication and social relations of the child. Telltale behaviors include delayed language development, impaired social interactions and fixed repetitive actions such as bumping the head on walls or floor and screaming nonstop (Quinn, Strothkamp, & Seper-Roper, 2018). Distinguished by features such as a flat face, slanting eyes, short neck, small mouth and some degree of intellectual disability, Down syndrome is a genetic disorder (Asim, Kumar, Muthuswamy, Jain, & Agarwal, 2015). Fragile X syndrome is a genetic condition that has more severe signs in boys than in girls (Bagni, Tassone, Neri, & Hagerman, 2012) which include delayed speech, learning incapacities and mental disabilities. Fragile X syndrome is understood to be connected to the presence of Autism Spectrum Disorders (ASD), Attention Deficiency Hyperactive Disorder (ADHD), and Attention Deficiency Disorder (ADD) that contribute to pervasive behaviors in

the children. These disabilities are enduring and continue throughout the lifespan, making the children rely on their mothers and other caregivers to carry out for them tasks of daily living and self-care. The birth of a child with intellectual disabilities destroys the dreams and hopes of parents for the child's prospects and ushers them into changes that impact on all areas of their lives. Few people understand the physical and psychological difficulties that the mothers experience in their daily care of their children with intellectual disability (O'Connell, Halloran & Doody, 2013).

A systematic literature review by Corcoran, Berry and Hill (2015) on the experiences of mothers of children with Autism Spectrum Disorder in U.S.A. revealed that mothers experience the strain of care from having to assist with daily activities such as feeding, bathing, movement and others tasks of daily living. Due to the unpredictable behaviors of the children mothers find it difficult to get appropriate child care with most remaining at home to care for the child with ASD. A study done by WHO (UNCEF,2013) shows that children with intellectual challenges were 4.6 times more exposed to sexual violence than their peers without challenges especially when left unattended. In U.K. (Mount and Dillon, 2015), research show that mothers of children with Autism Spectrum Disorders (ASD) experienced challenges caused by the child's pervasive behaviors such as violence and verbal abuse and, strained family relationships. In Africa mothers were found to experience poverty, isolation and discrimination in their daily care of their children with intellectual disabilities. For example, in Ethiopia (Kerebih ,2017) mothers of children with multiple disabilities are unable to engage in formal employment due to caregiving responsibilities. Mothers are also isolated and discriminated against due to traditional beliefs concerning disabilities. In Malawi (Masulani-Mwale et al, 2016), mothers had to deal with pervasive and at times violent and self-injurious behaviors of their children by keeping constant watch over them, limiting the mother's chances of formal employment. To avoid embarrassment, mothers kept their children hidden from the public as there are no or few educational and rehabilitation services available for these children.

Gona (2016) states that in Kenya mothers of children with autism and other developmental disabilities experience the strain of care which negatively affects their physical and mental health. Mothers reported exhaustion and fatigue which result in physical illnesses, and stress, anxiety and depression. The need for constant care keeps the mothers away from interacting with the society. Extreme poverty levels, make it difficult for most mothers of children with mental disorders to access rehabilitation and treatment services.

In Kenya there is limited study on the experiences of mothers raising children with mental challenges. This research therefore sought to fill this gap by exploring the challenges of care giving and the coping strategies employed by the mothers of children with intellectual disabilities.

Methodology

In this study mixed research design was utilized to explore lived experiences of mothers raising children with intellectual disabilities. The use of mixed methods of data collection, analysis and interpretation, enhance validity of the results and accuracies for generalizations (Creswell ,2014). All the 94 mothers for the study were selected using the census technique as the targeted population was small in number. To get the nine (10%) of the mothers for guided interview schedule, simple random sampling was used. Therefore, data in this phenomenological study was obtained simultaneously, by way of questionnaires for the quantitative data and directed interviews to capture the life experiences of the mothers as they cared for their children. The target participants comprised of 94 mothers with children with intellectual disabilities that ranged between the ages 3-19yrs and were learners in schools with Special Needs Education (SNE) units in Ongata Rongai location.

The Caregiver Burden scale (Zarit, Reever & Bach, 1980), a 5-point Likert scale measuring in a continuum was used to measure the mothers' general health, financial status, social life and psychological wellbeing. The Caregiver Burden scale had an internal reliability of 0.898 at Cronbach alpha coefficient. To determine experience of seeming discrimination by the mothers, a general question with YES/NO options was asked. To test experience of definite stigma by mothers raising children with intellectual disabilities, a modified EMIC Stigma scale (Weiss, 1997), a 4- point Likert scale was used. This scale has been previously used in Kenya and developing countries to test stigma related to HIV/AIDS (Nyblade, et al, 2013) with good results. For this study, the scale showed a good internal reliability at Cronbach's alpha coefficient of 0.711

To explore the actual experiences of the mothers, an interview guide with open ended questions was applied. The quantitative data was analyzed using descriptive statistics using the Statistical Package for Social Sciences (SPSS) computer software and presented in tables. Qualitative information from the interviews was translated from Kiswahili to English, recorded, ordered and analyzed according to the themes emerging from the study questions and, the results presented in

narrative form. To conform to ethical standards, the participants were made aware of the nature of the study and signed consent forms to participate in the study. To protect confidentiality and privacy, the quantitative data was serialized and pseudonyms assigned for the interviews. The study was approved by Tangaza University College.

Findings of the Study

The study sought to explore the challenges faced by mothers of children with intellectual disabilities, in terms of strain of care and experience of perceived and actual stigma, as they raised their children. The findings were obtained from the administration of the Caregiver Burden scale and The EMIC Stigma scale questionnaires.

a) Strain of care for mothers of children with mental challenges

Results of the Caregiver Burden scale for mothers of children with intellectual disabilities are presented in Table 1.

Table 1 Strain of care scores for mothers of children with intellectual disabilities

Caregiver scale	Dimensions	Response of participants
	No or little burden	4(4.3%)
	Mild to moderate burden	12(12.7%)
	Moderate to severe burden	57(60.6%)
	Severe burden	21(22.4%)
		N94 (100%)

Table 1 shows that majority of the mothers ,57(60.6%) experience moderate to severe burden of care, while a minority 4(4.3%) experience no or little burden. A significant number,21(22.4%) experience severe burden and 12(12.7%) mild to moderate burden.

b) Perceived stigma and discrimination for mothers

Response to the question on perceived stigma for mothers of children with intellectual disabilities is shown in Table 2.

Table 2 perceived discrimination scores for mothers of children with mental challenges

	Frequency	Percent (%)
NO	21	22.3
YES	73	77.7
Total	94	100.0

Table 2 indicates that an overwhelming majority, 73(78.0%), felt discriminated against, while 21(22.0%) did not feel discriminated against.

c) Actual stigma and discrimination for mothers

The results for the EMIC Stigma scale are presented in Table 3.

	Negative talk from other people	Avoidance by family and friends	Avoidance by colleagues	Denial of service at Government or private facility
Most of the time	26(27.7%)	17(18.1%)	9(9.6%)	9(9.6%)
Several times	24(25.5%)	26(27.7%)	9(9.6%)	8(8.5%)
Once or twice	36(38.3%)	39(41.5%)	41.(43.6%)	5(5.3%)
Never	8(8.5%)	12(12.7%)	35(37.2%)	72(75.6%)

Table 3 indicates that, an overwhelming majority 72(75.6%) of mothers of children with intellectual disabilities have never been denied services, in either Government or private facility in the last 12 months, while 41(43.6%) have been avoided by colleagues, 39(41.5%) avoided by family and friends and,36(38.3%) experienced bad talk from other people, once or twice in the last 12 months.

d) Data from the Interview Schedule

The presence of strain of care and experience of stigma are strongly collaborated by the following themes emerging from the lived experiences of the mothers as captured in the interviews: (1) care giving challenges,(2) marital strain and family breakup, (3) financial strain, (4)stigma and discrimination and, (5)accessibility of rehabilitation and education services.

1) Care giving challenges

Mothers experience difficulties in caring for their children with mental disabilities as most of these children lack sufficient skills for daily living. Having to assist in everyday tasks of living such as dressing, bathing and movement, can be an exhausting and frustrating affair for the mother:

Even that is work, he does not walk and even bathing him is troublesome and even putting him clothes, before you finish...is hard work. I cannot leave here and go anywhere because you see he can't walk, or sit. This child you will leave him with who when he is like this? So you see you can't go anywhere you won't feel comfortable with him. Going with him anywhere is always hard work because he does not like being carried, he does not like being held, even in church when we go I don't have peace because he wants to be put down and he does not sit so you see it is stress?(Respondent 2)

Those people who have normal children, do they really know what people go through? Or do they just pretend they know? Because it needs a lot of grace for this, okay, because the community, what they rush to see is what we have not done for that child; they cannot see, they don't even want to know; because the normal child; to do their own things ,they just do it ,but this one ,I am telling you ,even to tie her own shoes can be a problem, even to put on the clothes, others even to feed. These children are different; that you try to put yourself in shoes of each going through different challenges. (Respondent 6)

Most mothers decried the lack support from family members and the neighbors in the daily care of the children with disabilities.

She was really affected but she has helped me; my mother has helped me a lot. The others , they don't even reach near ...even if they find she has soiled herself, they will look as she eats the feces , those days when she started. She will eat as they just watch as they watch, they will not do anything to help.(Respondent 1)

However a few indicated that they received help in daily care from spouse, in-laws or hired help as illustrated by these statements from mothers:-

My in-laws loved this child a lot. In fact they are the ones who stayed with him for many years, taking care of him till he was 5yrs. (Respondent 5)

When she is well I usually leave her with the helper at least to work but when she is unwell I have to be here myself. At other times I leave her with her Dad, but he has very few hours with her because he is out working. (Respondent 8)

For mothers of children with severe intellectual disability that limit or affect movement, such as cerebral palsy, lack of assistive devices such as wheelchairs and walking frames means that they have to assist in movement and transportation, which increases the demand of care. One mother who lives about 2 km from the child's school and carries the child to school on her back every morning and picks her every afternoon, expressed her frustration in seeking for a wheel chair for her child, as follows;

I do not have (wheelchair)....I have tried looking for where I can be helped but I have not found (Respondent 2).

Because of the demands of care, the mothers are unable to engage in full time employment or other income generating activities as they have to remain at home to care for the children with intellectual disabilities. Because of pervasive and difficult behaviors most mothers are unable to get help from neighbors or hired help for their children.

He is disturbing, meaning he does not rest, its moving about, busy. He sleeps at 12 midnight, touching everything. He feeds himself but the others I do for him; bathing, he soils himself where he is, I clean. Someone can get angry with him and even hit him, he wants to touch everything; one might hurt him. Even if I say work, there is no way I will leave him and go to work (Respondent 7)

Some mothers expressed the challenge of having to deal with the difficult and pervasive behaviors of their children with intellectual disabilities, which manifest as uncontrollable actions that can be risky for the child's safety as well as others.

Physically she is not challenged but mentally she is in a weird manner because she is wild. Sometimes she becomes wild, so it's hard to control. So she can even decide to go, she can just walk aimlessly once she is tempered. So because of her condition it makes me to just be at close quarters with her, because even to school I have to bring her in the morning and to come for her because she can't go alone; (Respondent 6)

Meeting the daily needs of a child with intellectual disabilities such as lifting and transportation, result in health issues such as exhaustion, chest pains and high blood pressure in the mothers.

I go with him to church but because he is heavy you get chest pains and also get tired. I feel I have no energy. If you have no strength even you can die before him. I usually feel my pressure (blood pressure) has gone up; I feel weak and I know it is pressure. Before I did not have high blood pressure but now I have known; I feel weak but what can you do and you have this child? (Respondent 4)

2) Marital strain and family breakup

The demands of raising children, with intellectual disabilities is a major contributor to marital strain, leading to family breakup, neglect or abandonment by the spouse, which left the mother as the sole care giver for the child.

I was the only person doing it because by that time the person I expected maybe to be close to me and help me those duties had rejected me. He (the husband) had rejected the child; not even the child, even me myself because I had gone through so much. He had even gone to the extent of saying he will marry somebody else (Respondent 9)

Mothers are often blamed by their spouse and extended family members, especially those from the fathers' side, for the condition of the children; for not doing some things right or by being associated to the mothers' family of origin.

They said maybe it's your family, back home, it's not them. Because they said their family line, they said they traced there are no children like those. It's your place. Then I could not understand my place how? Because even at our place, we don't even have such. So I said ,okay, since the child is mine then I should take care of her , and as much as they are talking ,then it's for me to give all the care and support for the child. It's something you don't understand; seriously, the way I gave birth to the others is the same way I did to this one. What effort was there for me to put, to get a better child than this one? So I said okay let me take it (Respondent 6).

Financial strain

Specialized medical care for children with intellectual disorders is expensive and can lead to severe financial strain at times making it hard for the mothers to meet the basic needs of the child and other family needs.

When you go to hospital it's expensive, at times his insurance is exhausted (sniffing) 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? (Respondent 4)

You see like now the child needs pampers (diaper) every day, milk, porridge, you see this flour half kilo? I buy, sometimes I get money for half kilo and it is not enough for three days because like when I have to go to work, I take him to daycare and there I must take food, that is pack for him some food and that is all money. (Respondent 2)

3) Stigma and discrimination

The mothers experienced stigma and discrimination in the way the public interacted with them and their children with some neighbors talking badly to the mothers on account of their children with intellectual disabilities.

Sometimes you can get some, you can meet with somebody and just hear, "look at her...you see they can tell you, why oh okay even where I stay, someone can just tell you, "I did not ask you to give birth to a disabled child" you see [sadly shakes head]. Now you feel hurt, it hurts. (Respondent 1)

So mothers also reported feeling uncomfortable in public when people stare at their children though they have managed to cope with this by developing residence and loving and accepting their children.

I go with him. He just moves about. As he moves about people passing near there look at him. I say let them look maybe it is the plan of God, he is the one who created him like that. (Respondent 5)

What I can say about it let me talk about my neighbors. My neighbors sometimes would look at the child with a way of maybe questions but maybe they would not, would not get the courage to ask me the question but maybe through what I showed them that I love the child they were able to receive the child positively. (Respondent 9)

Mothers also encountered rejection and maltreatment of their children with mental disabilities by members of the public, especially by the neighbors who show lack of understanding

But they do not understand because even when she does some small wrong they see as if, you hear them saying she knows when she is doing wrong, it's like she does it intentionally. Many do not understand, one who does not have a child with disability cannot understand. (Respondent 3)

Sometimes due to their unusual behaviors, children with intellectual disabilities are further rejected, with people at times turning violent or calling them abusive names. One mother shares:

My child greeted her and touched her. The lady called my child a demon spirit. This really hurt; it hurt, I told her my child is not a demon (Respondent 8)

4) Lack of rehabilitation and education facilities

Lack of awareness of available rehabilitation and education facilities, non-existence of vocational training for learners with intellectual disabilities in government schools, long distances to access schools and hospitals and, high cost of well-equipped private schools are some of the challenges that made it difficult for mothers to access quality education for their children with mental disorders.

I even did not know if there was special (special unit in public primary schools), now I asked myself who will help me, it's Mama M. (mother with child with C.P.) Who told me M. has joined school, this school, where was it when we were suffering, because we have suffered a lot looking for a school, where was it? (Respondent 2)

Whereas children with mild to moderate intellectual disability could greatly benefit from vocational training, much of what is taught at the special units in public schools is mostly social skills and academic learning. One mother expressed her desire for the children to be empowered to be independent in all areas as follows:

What they do here is like socializing .once the child is here she is socialized with others so there are those behaviors she will come up to adopt which she didn't have , so it is better than being at home. There is room for more if I am asked because I would want this child to entirely independent. Like she can manage to wash herself, like she can find

some, to be taught something to do because, since her hands are okay it's only her brain, I don't know how she can be helped to coordinate to do something at least for herself (Respondent 6)

Schools and hospitals for specialized treatment are far requiring at times that mothers use public means of transport to access the services. This is both cumbersome and expensive for the mothers. Furthermore, the well-equipped private schools are few and very expensive.

I get my medical from Karen dispensary from Rongai to Karen is far [about 20km]. I use public means. (Respondent 1)

Challenge on treatment was not there because most of the places I took him, he was treated free of charge. I was taking him to Kijabe Hospital (about 75km away). Now the challenge was looking for fare to take him (Respondent 8)

Yeah, but then the school, getting the right school for her it was a challenge. Okay I went to (a private school) when we were looking around for the schools but that time, they were a bit high so would not afford. It took me sometime before I settled at (a public primary school) for her. (Respondent 8)

All the participants, however, were appreciative of the positive changes their children with intellectual disabilities manifest after joining the special units in public schools despite the limited resources available. One mother said;

Even here (special school) she has improved yeah, because there before, she would soil herself and pee while seated and she cannot show you a sign that I want to do this. But now since she came here (school) at least she is improving (Respondent 3)

e) Coping strategies used by mothers of children with intellectual disabilities

Mothers coped with the challenges encountered in their daily care of their children in various ways including; (1) Love and acceptance (2) spirituality (3) resilience (4) celebrate achievements (5) support groups (6) family support (7) utilizing rehabilitation and education services ((8) Psychological counseling.

5) Love and acceptance

Mothers mainly coped with the challenges of daily demands for care by loving and accepting their child with intellectual disabilities.

I just accept her, though it is a bit strenuous taking care of her with the other kids, I have no helper. It is a bit strenuous but then I accept her, I love her. (Respondent 8)

You as a parent you are the one to love your child. Nobody can love your child for you; it's you to show them (community) how to love him or her. (Respondent 9)

Mothers also coped with blame and rejection through self-acceptance and affirmation.

I did not (blame myself) because as far as I am concerned, I deep inside me I know there is no part I played for the child to come the way she is, because the same, same woman, me, have given birth to other children being normal and being okay. (Respondent 6)

I am okay with my children. I cannot demean myself because other people demean me. I know in the eyes of God we are all equal. I am happy even though others talk badly about me: with God all things are possible. (Respondent 4)

6) Spirituality

Having hope that one day God will help their children to get better and live a normal life help the mothers cope with the difficulties of daily care for their children with mental disorders.

I usually say, if it is that one(cousin's child) who took a bag and went to school, even this one of mine ,I pray, I know, I believe one day he will take the bag, carry it and though he will be late education does not end. I tell them it is not that I have no stress, I encourage myself, it's to have hope in God (Respondent 2)

I think about this a lot but I put God ahead. His (child) life I leave to God, he will do according to his power I have no power. Even if we say what, if God has not said it, is it not God who will do everything? (Respondent 7)

Finding meaning in the condition of her child and helped one mother extend her care and concern to other children with intellectual disabilities similar to her daughter's.

I would say that God chose me in some way because that child He wanted her to be, He wanted that child to be on this world. So He chose me to be the mother. So I appreciate I am special to God because He trusted me with that kid; there were so many mothers but He chose me to be the mother of that kid. So me I try my best to give this child care. And now it's not only my child; this has extended to those children with the same problem., I have a special touch for children with those like this child. There is a door inside me which was opened that was not there, to me now I have attention for them all of them. (Respondent 6)

Resilience

Through resilience most mothers cope with stigma and discrimination by exposing their children to the public

I said whether people talk or not I will not hide my child. I even tell other mothers there is no need to hide, let people talk. I have never hidden my child, let people talk. For me I am used to this. I even walk with him everywhere; I am past that. I am used to my child. Even if they talk I do not notice I am not afraid. (Respondent 2)

I have never (hidden the child). I brought her to school when she was about 5 or 4yrs. She is now approaching 10yrs. It has helped her a lot and also me because I had a lot of problems (Respondent 3)

Some other mothers show their resilience by reaching out to other mothers with children with intellectual disabilities to encourage them to stop hiding their children with intellectual disabilities and creating public awareness on issues of intellectual disabilities in children.

I said, the one I know is hiding, I will go talk to them, even now I keep asking if there is a person with a child like mine, I go and give them courage. I give courage because even though they hide, these who hide, they go like that, you hear the child has died because they have not believed (Respondent 2)

As we walk he likes greeting people. There are some who refuse his greetings. It makes me stop and explain to them that my child cannot talk and likes greeting people, not all people but those he likes. So I encourage them to just greet him we move on. (Respondent 7)

Mothers also shield their children with intellectual disability from stigma by confronting the public, or do extra work to protect their children from unfair treatment by neighbors:

I tell them: can you mind your own business? I tell them, mind your own business leave mine alone. I tell them; you look ahead stop looking at my child and I move on.(Respondent 4)

I do extra, just for that blame not to be, to prevent them from harassing my child(Respondent 6)

7) Celebrate achievements

Mothers celebrate small achievements by their children with mental disorders as exemplified by the these statements:

When she comes at home (from school) you can see her really trying to sing or you can see her really trying. I am usually happy (laughing) and just listen to how she is struggling to say the sounds (Respondent 8)

I love my child a lot; he makes us laugh when he sings. He sings very well. If he sings for you church songs the voice is soft. He sings even better than a child who is normal. When he sings you enjoy a lot (Respondent 4)

I continue seeing changes each day. You know before this child could not talk, only drooling saliva the whole day. My joy is that these days he can wear one outfit the whole day without soiling it (Respondent 7)

8) Support groups

Most of mothers cope with social and emotional challenges by joining support groups where they share experiences and encourage one another.

I have joined a support group organized by the school. When we meet we talk, we share, same parents with children with disabilities, mothers sharing same situations. It helps a lot not only through verbal talking even seeing other types of disability; that would really maybe touch you and you feel that you are not in the world alone or maybe see that your child is not that severe. There are other severe cases and get encouraged. (Respondent 1)

9) Family support

Support from relatives and own children in caring for the children with mental limitations help some mothers cope with the difficulties experienced in caring for these children.

My people encouraged me, my family. And her brother and sister really like her. They really like her and understand her and when she is annoyed they know how to handle her (Respondent 8)

10) Utilize rehabilitation and education services

To cope with the financial challenges some mothers take advantage of the time their children are at school and engage in small scale businesses or do short duration casual work

That time, you know you can even go to the market and buy vegetables and do 1-2-3 things before the child comes from school (Grace, 31, married, unemployed)

Now at least I can, even if I get casual work for washing clothes I can do for a short duration, a few hours (Respondent 4)

11) Psychological Counseling

A very small number of mothers sought psychological counseling as a way of coping with the negative emotional and social effects of the challenges of raising children with intellectual disabilities due to lack of awareness and the cost involved.

I think even counseling is what help somebody to be out of her own box because if you only believe you are the only parent with disability, you will remain in your own box. But when somebody else comes in and tries to maybe advise you, counsel you, you feel that you are not alone; there is somebody who understands you. (Respondent 9)

Discussion of Findings

Caregiving challenges

The objective of this study was to explore the lived experiences of mothers of children with intellectual disabilities. The findings revealed that mothers of children with intellectual disabilities experienced increased care giving difficulties. Because of lack of daily living skills mothers have to assist in tasks such as feeding, bathing, dressing and movement of the children, which result in exhaustion and health issues such as chest pains, backache arthritis and high blood pressure in the mothers. This finding corresponds with the finding by Gona (2016), and Corcolan, Berry and Hill (2015), which found that mothers of children with intellectual challenges experience fatigue and health complications due to increased burden of care for their children.

Fear for the daily safety and security of their children increased the burden of care for the mother as lack of social and life skills made the children vulnerable to sexual and other forms of violence. According to UNICEF (2013) report, children with intellectual disabilities are 4.6 times more exposed to sexual violence than their peers because of being left alone as parents engaged in employment or other activities outside the home. Moreover, some mothers had to deal with pervasive and difficult, sometimes violent and self-injurious behaviors, which required constant care, leaving them with little or no time to engage in gainful employment. This is consistent with studies by Corcolan, Berry and Hill (2015), Masulani-Mwale et al (2016), and Kerebih,(2017) that reported that mothers of children with mental challenges had no time for other activities or for self, due to the increased care burden.

The strain and responsibilities of caring for children with mental disorders cause marital strain and family breakups such as separation, abandonment or, neglect of the mother and the children by the fathers. This agrees with the Families SIRG Position Paper, (2012) which reports that divorce and separation were experienced more in families with children with intellectual disabilities as opposed to families with normally developing children. Moreover, extended family members also rejected and stigmatized the mothers and their children and, offered little or no support to the mothers in daily care of the children which contributed to strained family relationships. This is consistent with studies in Kenya, (Gona ,2016) and in Ethiopia (Kerebih (2017), which found that due to cultural beliefs and superstitions, mothers of children with mental disabilities are blamed, rejected, and labeled, not only by the society but also by the family.

Mothers experienced financial strain when accessing quality medical care and rehabilitation for their children because of the costs involved. They also had difficulties meeting other financial obligations of their families because of high levels of poverty. These findings correspond to studies by Corcolan, Berry and Hill (2015), Masulani-Mwale et al (2016), Kerebih (2017) and Gona (2016), which indicate that due to extreme poverty most mothers are unable to access quality health care and rehabilitation for their children with intellectual incapacities.

Stigma and discrimination in form of bad talk by friends and neighbors, being labeled as bad mothers, staring by the public and, rejection and hostility towards the children, was another challenge that mothers grappled with in their daily care of the children with intellectual disabilities. Because of this mothers avoided taking their children to social gathering, for fear of being judged negatively (Masulani-Mwale et al, 2016), and Gona, (2016).

Interestingly, mothers were found not to experience stigma or discrimination when accessing rehabilitation and medical care for their children with intellectual disabilities from government or private facilities, unlike in the studies by Cantwell and Muldoon 2015, Masulani-Mwale et al,2016) which found that experience of stigma made the mothers of children with intellectual disabilities not seek health or education services for their children for fear of discrimination. This may be due to the government's effort to give social support in form of free medical and educational services, to vulnerable populations such as orphans and vulnerable children (OVC), which includes children living with disabilities and, the private sector's corporate social responsibility (CSR) policies that aim at giving back to the society by offering free social services to vulnerable populations.

However, mothers experienced challenges in getting rehabilitation and education for their children with intellectual disabilities. Lack of information on available facilities with services for the children, few schools and institutions with special-needs units specifically for children with intellectual disabilities and, the cost of medical and rehabilitation services from private institutions, made it difficult for mothers to provide quality care for their children, leading to frustrations, guilt and feelings of inadequacy as parents. This corresponds to the UNICEF (2013) report which shows that most countries of the world have done very little in terms of provision of well-equipped facilities to ensure that children with all forms of disabilities access education on the same level with their peers who are developing normally. Mount and Dillon(2015), Corcolan, Berry and Hill(2015),Masulani-Mwale et al (2016), and Gona (2016)found that mothers in developing countries have difficulties accessing affordable quality medical and rehabilitation services for children with intellectual disabilities due to the scarcity, cost and, vast distances involved.

B. Coping strategies

Despite the difficulties involved in attending to their children's daily care needs, mothers they reported effective coping mechanisms that helped ease the challenges. They all loved and accepted and, felt that nobody else could take care of their children as well as they did. This agrees with studies done in other parts of the world (Beighton & Wills, 2016, Yang, 2015, Thwala, Ntinda & Hlanze, 2015) that show that accepting and loving the children with intellectual disabilities, self-acceptance and affirmation helped mothers bear the challenges of care for their children. A strong faith in God and, hope helped the mothers cope with fear, worry and feelings of hopelessness and despair. The mothers believed that if it was the will of God, their children will get better and achieve independence as other 'normal' children and celebrated the small achievements their children made as signs that the children will get better, therefore keeping their hopes high. This corresponds with literature (Thwala, Ntinda & Hlanze,2015, Gona, Mung'ala-Odera, Newton & Hartley,2011, Gona et al,2016) that shows that spiritual coping and meaning making as a major coping strategy used by mothers raising children with intellectual disabilities. Mothers also coped by accepting the child and their condition as the will of God for them as mothers. This helped some mothers reach out to other mothers with children with similar situation therefore finding meaning and purpose in their

situation. Other mothers developed resilience and were able, through their personal strength and character to cope with negative societal response to their child with intellectual disabilities (Beighton & Wills, 2016, Yang, 2015, Thwala, Ntinda & Hlanze, 2015, McNally and Mannan, 2013) by exposing their children to the public despite the negative society response. All the participants in this study had enrolled their children with intellectual disabilities in non-residential schools and rehabilitation centers and, were not keen on taking their children to the few available boarding schools. This allowed the mothers to do short duration casual jobs or engage in small scale business ventures. This contradicts findings from a study done in Kilifi and Mombasa counties, Kenya by Gona, et al (2016), which indicated that mothers of children with intellectual disabilities took their children to boarding schools to allow them have time to engage in employment and other income generating activities. This can be explained by the government's effort to ensure inclusive education for all children, by ensuring that more public schools have a unit to specifically meet the needs of children with intellectual disabilities. Previously, children with intellectual disabilities were not considered in provision of education as it was not acknowledged that they had capacity to learn (Chomba, Mukuria, Kariuki, Tumuti, & Bunyasi, 2014) which meant that most such children were institutionalized.

To cope with the demands of care mothers relied on family support, especially from their relatives and their other children. This support was in form of either financial or help in daily care of their children with disabilities. However very few mothers reported receiving any meaningful support from their spouses as many were separated because of the demands of care. This may be attributed partly to the marital strain experienced because of the burden of care, the cultural roles assigned to women as caregivers, or to the notion that the disability is inherited from the mother's side of the family. These results agree with findings by Ambakile and Outwater,(2013) in a research done in Muhimbili Hospital Tanzania, which found that mothers who had the support of their spouse, family and friends coped better with the difficulties of caring for a child with intellectual disabilities.

All the participants in this study had joined support groups organized by the schools and institutions where their children attended. They expressed getting relieve from emotional distress and, building hope and resilience from knowing that they are not alone as there are others going through the same experiences. They also gained new insights in ways in attending to the needs of their children as well as self-care skills that help them ease anxiety and depression. Studies on experiences of mothers of children with intellectual disabilities (Ambakile & Outwater, 2013, Gona, Mung'ala-Odera, Newton & Hartley, 2011, Gona et al, 2016) show that those mothers who belong to peer groups manage better the challenges of raising children with intellectual disabilities through the sharing of experiences bring affirmation and encouragement. Though all participants acknowledged the value of psychological counseling, only a few, the educated and employed had ever received professional counseling. Due to poverty, lack of awareness and the generally under-developed mental health care system in Kenya, in terms of infra-structure and qualified personnel (Bitta, Kariuki, Chengo, & Newton,2017) most mothers cannot access mental health care for themselves. Public demand for treatment of mental disorders is also hindered by the stigma attached to mental health issues such as being labeled as mad.

Implications and Further Research

Due to lack of awareness, most participants had difficulties accessing rehabilitation and education services. The public institutions that offer rehabilitation and education services are poorly equipped to adequately cater for the needs of the children with intellectual disabilities. This research recommends that the Government enhance the rehabilitation and education of children through the creation of awareness of available services and, improving service delivery by employing more professionals and providing the necessary equipment and materials in public schools and institutions. This will help the children with intellectual disabilities learn skills of independent living such as movement, feeding and personal care, therefore reducing the burden of care for the mothers.

To help ease the strain of care for the mothers, the study recommends creation of public awareness involving the community and the security and other government agencies, to enable them take an active role in the protection of these children from getting lost and potential risk of violence, including sexual violence.

To help the mothers cope with the negative emotional and social effects of caring for their children with intellectual disabilities, this study recommends that the Government avail psychological support services for mothers alongside medical and rehabilitation for the children, which will improve the overall health of the mothers thus enable them give the best care for their children with intellectual disability.

Recommendations for Future Research

The findings clearly show that mothers of children with intellectual disabilities experience serious challenges of strain if care, lack of rehabilitation and health care facilities and, stigma and discrimination in their daily care of the children. Mothers cope with these challenges largely through loving and accepting their children with intellectual disabilities, faith in God, hope and resilience. A qualitative study to find out how the positive attitudes of spirituality, hope and resilience correlate with loving and accepting their children with disabilities is recommended. The result of this study would help the people tasked with development of disability programs incorporate values that motivate positive coping.

Further, there is scarce data available on the situation of fathers of children with intellectual disabilities in Kenya. A qualitative study to explore experiences of the fathers is also recommended.

Conclusion and Recommendations

This mixed study method aimed at exploring the lived experiences of mothers of children with intellectual disabilities found that mothers undergo difficulties of demands of care, financial difficulties, stigma and discrimination and, lack of adequate specialized education, health and rehabilitation care. Mothers cope with these challenges through spirituality, resilience, hope, love and acceptance and utilizing the available rehabilitation and educational facilities. Increased access to education and rehabilitation and, psychosocial support from the government and other agencies together with, understanding and acceptance by the society are recommended to help ease the strain of care for the mothers.

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