**EFFECTIVENESS OF A PSYCHOSOCIAL TRAINING INTERVENTION IN REDUCING PSYCHOLOGICAL DISTRESS AMONG PARENTS OF INTELLECTUALLY DISABLED CHILDREN IN MALAWI**

**Abstract**

**Background:***Rates of disability are high in resource poor settings with eighty five percent of children with disabilities living in these settings.* *Long-term caregiving for disabled children is associated with fatigue, financial difficulties, parenting distress and other psychological issues.* *While such parents of children have repeatedly highlighted their feelings of discrimination, stigma and exclusion, leading to mental health issues, there is little research from the developing world addressing these issues.*

**Research Objectives:***This study aims to explore psychological experiences of parents caring for children with intellectual disabilities; understand their mechanisms of coping: and their psychosocial needs in Malawi.*

**Methodology:***This study used a qualitative phenomenological* *design. We purposively sampled parents who had children diagnosed with intellectual disability from two clinics in two cities in Malawi. Between January 2015 and March 2015 we conducted 10 FGDs and four in-depth interviews. All ethical study procedures were carefully followed. All interviews were tape-recorded, transcribed, and translated from vernacular to English. Thematic approach of data analysis was adopted to understand the data.*

**Findings:** *Caring for intellectually disabled children comes with a number of challenges. Parents have limited access to services for their children let alone for their own psychological issues; they experience stigma and discrimination; have mental health issues resulting from the caring role; have suicidal ideas and in some cases have even been coerced by neighbors to kill their disabled child. To manage these issues, most parents cope through their spirituality.*

***Discussion and Recommendation:*** *Apart from suicide and filicide, the findings of this study are similar to those done in other countries. It is recommended that parents’ psychological issues be managed concurrently when providing services for their children. There is also a need to develop psychosocial training interventions to address the needs of the parents of these children.*

**Introduction**

It is asserted that eighty five percent of disabled children live in resource poor countries. Where available, disability services are often limited or not accessible to parents ([Helander, 1993](#_ENREF_16)). Studies from Uganda and Kenya report prevalence rates of neurological disability in children to be 9.3% and 13% respectively ([Mung'ala-Odera et al., 2006](#_ENREF_20); [Uganda Bureau of Statistics, 2002](#_ENREF_45)). In the recent Malawi Key Informant Child Disability study, 39% of children screened were identified as having at least one disability – some of these limited to mild hearing or visual problems but many with more severe cerebral palsy or intellectual disability ([Tataryn et al., 2015](#_ENREF_41)). Parents of children with disabilities have a crucial role to play in the lives of their children even after their child has made the transition to adulthood ([Shin et al., 2009](#_ENREF_34)). Parents and family members particularly need to support their children who are unable to communicate their own decisions and who require day to day support throughout their lifespan ([Roberts, Mazzucchelli, Studman, & Sanders, 2006](#_ENREF_26)).

The association between care-giving and negative health outcomes for parents of children with disabilities has been investigated in many studies ([Cadman, Rosenbaun, Boyle, & Offord, 1991](#_ENREF_4) ; [Dykens, Fisher, Taylor, Lambert, & Miodrag, 2014](#_ENREF_6) ; [Emerson, 2005](#_ENREF_7); [R. P. Hastings & A. Beck, 2004](#_ENREF_15)). Most studies suggest that long-term caregiving is associated with fatigue, financial difficulties, parenting distress and constricted social interaction ([Achenbach T, 2000](#_ENREF_1); [Achenbach T & Rescorla L, 2000](#_ENREF_2); [Samadi, McConkey. I, & Kelly, In press](#_ENREF_29)). While this has been the traditional belief, some studies have demonstrated that there are also positive and rewarding aspects of caring for these children with intellectual disabilities ([Russel, John, Lakshmanan, Russell, & Lakshmidevi, 2004](#_ENREF_27); [Schulz & Grimes, 2002](#_ENREF_30); [Seltzer, Greenberg, & Floyd, 2001](#_ENREF_33)).

While parents of children with disabilities, in the developed world, have repeatedly highlighted their feelings of discrimination, stigma and exclusion, there is little research from the developing world addressing these issues ([R. Stewart et al., 2009](#_ENREF_40); [Zoccolillo, Murphy, & D., 1986](#_ENREF_53)). Studies conducted in Canada and the US have established that parents of children with disabilities were more likely to experience depression and distress than parents of children without disabilities ([Cadman et al., 1991](#_ENREF_4) ) ([G. H. S. Singer, B. L. Ethridge, & S. I. Aldana, 2007](#_ENREF_38)). Studies from Uganda reveal that parents of children with disabilities, mainly mothers or grandmothers, are subjected to stress in the form of physical ailments, isolation and insufficient time for household chores ([Quine & Pahl, 1987](#_ENREF_23); [WHO, 1997](#_ENREF_51)).

Existing research demonstrates that the parents of disabled children undergo strain due to the disruption of family and social relationships, exhaustion, financial difficulties, guilt and parenting distress ([Seltzer et al., 2001](#_ENREF_33); [G. Singer, H., S. & Irvin, 1991](#_ENREF_35)). The inadequacy of social support systems and the economic challenges of poverty, combined with the extra expenses associated with meeting the child’s needs area further source of stress ([Achenbach, 2000](#_ENREF_3)). Studies in Uganda and Kenya have revealed that disability is still perceived as a curse, a punishment from God for wrong-doing, or work of evil spirits ([Gona., Mung'ala‐Odera, Newton, & Hartley, 2011](#_ENREF_12); [Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005](#_ENREF_13)). This can result in parents hiding their children with disabilities for fear of isolation, segregation or discrimination.

While researchers have traditionally believed that parenting disabled children has a negative impact on parents, other recent studies have demonstrated that there can be many positive and rewarding aspects of providing care for children with intellectual disabilities. This includes an increased sense of psychological wellbeing and positive family traits or characteristics ([Russel et al., 2004](#_ENREF_27); [Schulz & Grimes, 2002](#_ENREF_30); [Seltzer et al., 2001](#_ENREF_33)). Secondly, those families where there is hope demonstrate more psychological resilience and positive wellbeing for families of children with disabilities ([Schulz & Grimes, 2002](#_ENREF_30)). This resilience has also been attributed to parents who take comfort in their spirituality, which helps them view their child as a blessing or a test of their faith, rather than as a burden ([Schwartz & Tsumi, 2003a](#_ENREF_31)).

Researchers have studied how carers adapt to care-giving demands ([G. H. Singer, B. L. Ethridge, & S. I. Aldana, 2007](#_ENREF_36); [G. H. S. Singer, 2006](#_ENREF_37); [R. Stewart et al., 2009](#_ENREF_40)). A number of studies from western countries have shown that support from spouses or from extended family members, especially grandparents, has the potential of helping parents cope with a disability ([Todd, Blomley, & Loannon, 2010](#_ENREF_44); [Wallender et al., 1989](#_ENREF_46); [Wang et al., 2013](#_ENREF_47)) ([C. Webster-Stratton & Reid, 2003](#_ENREF_49))(45). In Africa, informal sources of support such as friends and religious groups and the use of respite care services have been associated with reduced stress in carers of children with disabilities ([R. Hastings & A. Beck, 2004](#_ENREF_14); [Teri, 1982](#_ENREF_42); [C Webster-Stratton & Hammond, 1998](#_ENREF_48); [Weiss et al., 2003](#_ENREF_50)). The strength of the African societies lies in their cohesiveness and supportive nature in all aspects of life. The high levels of family cohesion and togetherness can be an important coping mechanism ([G. H. S. Singer, 2006](#_ENREF_37)). However, more recently, emerging studies have demonstrated how some carers in African settings report reduced availability informal sources of support particularly when the child has a severe disability([Tindal, Steinlechener, Lavy, & Mkandawire, 2005](#_ENREF_43)). The extended family, a major support in caregiving in African settings, may be disintegrating with poverty and the HIV/AIDS pandemic ([WHO, 1997](#_ENREF_51)). Previous cohesiveness is also compromised with the collapse of traditional systems coupled with social inequality present in many new African communities ([A. Stewart, 2002](#_ENREF_39)).

There are a number of theoretical models that are influential in discussing the relationship between caregiving among parents of intellectually disabled children and their mental health outcomes. Researchers have become more interested in explaining why some families are resilient and better able to manage and endure stressful events rather than documenting the frequency and severity of such events ([Prince & Murphy, 2000](#_ENREF_22)). The Family Care Model is one model which provides an understanding of the interaction of parenting a disabled child and parental mental health ([McCubbin & McCubbin, 1980](#_ENREF_19)). This model uses the theory of stress and coping theory by McCubbin & McCubbin and identifies three major stages in stress and coping These include: antecedents, mediators, and outcomes ([McCubbin & McCubbin, 1980](#_ENREF_19)).

This model highlights the detailed mechanisms of action for the challenges of parenting and its effects on their mental health.

This study aims to explore through qualitative processes, the psychological experiences of parents caring for children with intellectual disabilities. We aim to understand their mechanisms of coping with these challenges and their psychosocial needs in both rural and urban settings of Lilongwe and Mzuzu, Malawi.

**METHODS**

This study was part of a larger mixed-methods study aimed at developing & trialing a contextualized psychosocial intervention for parents of intellectually disabled children in Malawi. A qualitative phenomenological design (psychological) was used to explore the lived experiences of parents of children with disabilities. Phenomenological psychological studies focus on people’s perceptions of the world in which they live and what this means to them: “the lived experience” ([Risdall & Singer, 2004](#_ENREF_25)).

We purposively sampled mothers and fathers of children with intellectual disabilities, aged from 18 and above, from two selected child disability clinics catchment areas in Mzuzu (mixed rural and urban) and Lilongwe (urban) respectively ([Wolfensberger, 1969](#_ENREF_52); [Zoccolillo et al., 1986](#_ENREF_53)). Parents of children with disabilities in these clinics were referred to the study team where they were screened for intellectual disability by a psychiatric clinical officer, using DSM V Criteria for intellectual disability. “We conducted ten focus group discussions (FGDs) between January 2015 and March 2015. There were two groups for men and three groups for women in each of the two locations - Mzuzu and Lilongwe respectively. Four groups were for young parents while six were for older parents. The FGDs were held at community based disability clinics which offer services to children with disabilities. These FGDs continued until saturation of data was reached. Some themes which emerged from the focus groups required more detailed information. We therefore chose to conduct four in depth interviews (IDIs). These were conducted with two participants who reported coping positively with their child with intellectual disability during the focus groups. They were also conducted with two parents also reported high levels of stress, anxiety and difficulties managing their children with intellectual disability.

Study procedures were carefully explained to the groups and individuals and it was clarified that their responses were only for research purposes and that they would not lead to detriment in the access to the clinic services. All participants gave informed consent before participating in the study and consent for audiotaping the groups was also obtained.

The FGDs and interviews were held in the private rooms for privacy and comfort of the participants. A topic guide was created by CM which was shared with the rest of the study team. This was pretested in an independent setting and adjusted according to feedback from the research team. Probes were added where necessary. Interviews were led by the first author (CMM) and conducted by CMM and DS (a trained psychologist, in Mzuzu; and AN (a Psychiatric nurse) in Lilongwe. CMM, DS and AN speak both the local language and are fluent in English. The research team had a combination of males and a female and were trained on the topic guide, consent procedures; confidentiality; best practices in qualitative research; research instruments; ethical protocols during and after fieldwork; how to conduct qualitative interviews with parents; and how to ensure that parents and their children are not stigmatized. Role-playing was used, during this training, to develop interviewers' understanding and familiarity with the study tools. After the training, the interviewers piloted the tool at an independent clinic. Experiences and issues emerging from the pilot were discussed and the research tools were revised prior to starting the main focus groups.

All interviews were tape-recorded, transcribed, and translated from Tumbuka or Chichewa to English by CMM and DS. Note-taking was performed and verbal and non-verbal cues were monitored during all interviews. For quality purposes, the transcripts were compared to the taped interviews by DS. After familiarization with the transcripts, a code book for the interview data was concurrently but independently developed by CMM and DS by hand ([Reid, Webster-stratton, & Beanchaine, 2002](#_ENREF_24)). We jointly reviewed the coding outcomes, to ensure inter-code agreement and developed a codebook which was then utilized within NVivo 10.0.138.0-164-bit ([Castleberry, 2014](#_ENREF_5)) for easy retrieval and management.

A thematic approach of data analysis was adopted to understand the interviews. We organized the data from the IDIs and FGDs and encoding it into themes. During coding, major nodes were first created through prominent emerging themes which were emerging from the data. Patterns were then identified and put together to form tree nodes each bearing a name of a sub theme. A framework was then utilized to understand how these themes related to one another.

Word-for-word quotes from these are used in the paper to show major responses and findings. The study’s ethical clearance, institutional authorization and consent were sought from College of Medicine Research and Ethics Committee (# P.06/14/1591), as well as medical directors of the two clinics and participants of the study respectively.

**Results**

Findings for this study are presented narratively in themes and supported by verbatim quotes. Four main study themes emerging from the analysis of the study data are presented and included: Challenges in care; service inaccessibility; Stigma and Discrimination; impacts on mental health; coping mechanisms and required supports.

1. **CHALENGES IN CARE**

Parents narrated how the challenges that they encountered when caring for the children. Many parents described how they were grappling with multiple challenging behaviors posed by their children including aggression and pinching others.

*“He displays some strange aggression when engaged in school activities etc… He beats friends including those that are asking him to read or write.. But what can I do?” (FGD1, Mz, YW)*

Other reported behaviors included inappropriate urinating and defecating, often very inconveniencing, problematic and embarrassing for parents.

*“The challenge that I face with my child is that am not able to do business freely as my child defecates and urinates anytime, anywhere including pots….without any reason or saying – now I ask myself, how am I going to take this child to the market? He becomes a burden and an inconvenience in the compound and public spaces.” (FGD11, LL, YW)*

Some parents explained that due to the destructive and aggressive behaviors of some children, parents are evicted from their houses by landlords who cannot tolerate such behaviors.

*“Because of the behavior of this child, I keep on shifting houses from one place to another because landlords would not tolerate the behavior of my child especially when he enters in their house”. (FGD13, LL, OM).*

**2. SERVICE INACCESSIBILITY**

Parents in the study indicated that they had problems to access helpful disability services for their children. In the FGDs, they explained how they tried to look for services for their child (including special schools) to no avail.

*“…when I was in Blantyre, I was having appointments with Dr. X then I visited Console Homes only to be told they have closed services because government has run out of money. Later I have consulted Chilimba and Namiwawa schools where they have teachers for children with special needs. Then got transferred from Blantyre to Mzuzu….I can’t find the proper service” (FGD1, MZ, YW)*

Some parents indicated that they had nowhere to seek help for for their own psychological problems.

*“I often I become worried and disappointed….. I don’t sleep well …. I am worried because of these types of children I am having. 3 of them have got this problems and I wonder why it happened. But I have nowhere to go to get help for my own problems” (FGD14, LL, YW).*

Several parents also described how they would try prayers, and when it does not work they are no longer prayed for, are isolated and considered to have little faith.

*“..even when I go to churches , they perceive me as a person without faith because they have prayed for my child and my child is not walking and they see me as a person without faith . Now they just pass by me and my* child” (FGD1, Mz, YW)

**3. STIGMA AND DISCRIMINATION**

Parents described how they often face discrimination as they struggle to get the services. In some communities, many parents describe that due to complex cultural beliefs, there was speculation about negative causes of disability. For example, some participants described how it is thought that parents do rituals on their children to become rich-because their children do not change. Some participants described how this leads to families being evicted from their own villages because of these superstitious beliefs related to the child disability.

*“We are told that we have done rituals on our children for wealth/riches….and now they isolate me.. These negative attitudes and evictions are hurtful and take peace away from within our hearts” (FGD11 LL YW).*

*“Those of us who give birth to such children are dehumanized (tikunyozeka). They would say, “look at that child who ever gave birth to this child, did not achieve anything.. did it in vain.” (FGD3, Mz, YW)*

Community attitudes towards them were highly stressful. Some parents described how their faith was challenged.

*“I complain why God has allowed this to me; I think too much and isolate myself; but also, the way neighbors react to my child for wrong causes me pain; …. When they accuse me as a careless parent, …… this breaks my heart; it makes me feel stressed and depressed”.(FGD12, LL, OW)*

In some instances the discrimination lead to divorces because the woman was accused of giving birth to a disabled child by some husbands. In one situation, a parent described how she was divorced,

*“……...when my husband left me citing the child as a cause of divorcing me. I really felt like just dying; …….*

Some mothers described the negative advice that they had got from neighbors and relatives which included advice to kill their child so they could get rid of the problem, (the disabled child)

*“ …. Then I heard her saying, why can’t you stop giving this child water. She said, “Had it been the child was mine, I could have stopped giving the child water or choke him with water for him to die …One day I felt she may be right…” (IDI 1, Mz, YL)*

4. **IMPACT ON MENTAL HEALTH**

One of the major outcomes and themes emerging from the transcripts were the impact of the burden of care on parents’ mental health which leads then to parental stress and depression. Many participants described high levels of stress and described how their sleep pattern was disturbed by this stress:

*“... thoughts become persistent throughout; and so when night time comes those events are replayed over and over again in your mind disturbing the process of sleep”(FGD3, MZ, YW)*

Many also described the worries and fears that they had regarding the future of their children, especially, if they die.

*“…..when you think of the child’s future and also when you think of death that you are the only one taking good care of the child what if you die today, it’s terrible...” (FGD13, LL, OW)*

One major mental health issue which was reported was suicide. This was the most severe emotional reaction reported by some parents, especially mothers.

*“…Sometimes you even get to ask…. maybe if I just died I would experience permanent relief/rest; yes,.. this happens” (FGD3, Mz, YW)*

Suicidal thoughts were sometimes attributed to divorces resulting from giving birth to a disabled child by some mothers. In one situation, a parent described how she was almost accusing her faith in allowing such suffering to happen

*“……...when my husband left me citing the child as a cause of divorcing me. …. I felt like I was the cause of the problem. I am a leader in church so I was asking myself: what is God trying to do with me in this situation? ….. I felt that God was not a Loving God; that God was not hearing my prayer. So I wished I just took rat poison and die and leave this burden.” (FGD9, LL, OW)*

1. COPING AND REQUIRED SUPPORTS

Data showed that parents cope by using different methods like accepting the situation and being resilient but with spirituality being the main one.

*“Yes, let me just add that one need to have resilience as a person; you have to accept the situation at hand as one that is not reversible and one we have to live with. Crying, sadness is not going to help, you just have to live like this child is like any other children that this is his nature. ”.(FGD12, LL, OW)*

*“Yes I just want to add by agreeing with my friends; for me I tell God that what I have, I received from you and I accept whatever is happening concerning my child whom you created.” (FGD7, LL, OM)*

Some parents indicated that they needed education, rehabilitation and relief (like respite) services, and other material support to help them in caring for their children.

*“I think it will be well for us all to know the cause of the problem (disability) …what exactly happens for the disability to set in. Much more emphasis on whether the problem will be cured or not. Then what can we do to manage this child and help where we cannot manage like rehabilitation … ….yes to be happy one may need to get support from a disability children's’ home when we take our children like a school we can experience relief from the burden; the school can work as another support system.” (FGD3, Mz, YW)*

*“ We can receive any help; we do not need to specify…..like a good house, food etc. .” (FGD7, LL, OM)*

Some parents indicated that they needed counselling and wanted to benefit from support groups.

*“Mine is a request that if possible visit us often call us for such group discussions are good. We need counselling from you (FGD5, MZ, CW)*

**DISCUSSION AND CONCLUSIONS**

This study provides extensive qualitative data from a large sample of parents of children with disabilities in urban and rural African settings where it is evident that Children with disabilities pose a lot of challenges to their parents including limited access to disability and psychological services. The study showed that parents of these children suffer great stigma and discrimination and get coerced to commit filicide. The parents have varied needs for their material and psychological issues; however, spirituality is their main coping mechanism for these parents.

The data indicated limited access to services for the children’s disabilities and parents own psychological issues leading to more stress. Taking into account, the underdevelopment of disability, mental health services and poverty in Malawi and sub region, this could possible explain why carers of children with disabilities are hard hit by this service inaccessibility ([Gona, Mung'ala‐Odera, Newton, & Hartley, 2011](#_ENREF_10); [Helander, 1993](#_ENREF_16)).

While parents play a crucial role in the lives of children who require varied supports throughout their lifespan, long-term caregiving is associated with divorces, financial difficulties, parenting distress and constricted social lives ([Achenbach T, 2000](#_ENREF_1); [Achenbach T & Rescorla L, 2000](#_ENREF_2); [Samadi et al., In press](#_ENREF_29); [Seltzer et al., 2001](#_ENREF_33)). The data from this study resonates with this. Our study demonstrated more emerging mental health issues in transcripts especially from the female focus groups in comparison to the male focus groups. This also resonates with previous work demonstrating that care of children with disabilities impacts most on the mother ([Gath, 1977](#_ENREF_8); [Schwartz & Tsumi, 2003b](#_ENREF_32)). Furthermore, depressive symptoms are also more common in women regardless of their children’s disability ([Glidden & Schoolcraft, 2003](#_ENREF_9); [Kessler, Zhao, & Blazer, 1997](#_ENREF_17)). This means that there should be more of a gender balance or more male involvement in caring for these children to avoid females shouldering the entire burden.

Rejection, stigma, discrimination, societal myths and negative community attitudes associated with disability contributed to the depressive symptoms described by some parents in our study. Previous studies have reported the association between stress and care-giving for children with disabilities. This seems to be particularly prominent during periods where there are other stressors within the family for example financial constraints limiting access to health services when the child is sick ([R. P. Hastings & A. Beck, 2004](#_ENREF_15); [Quine & Pahl, 1987](#_ENREF_23)). In our study, most parents did not have support for the psychological problems that they raised. Some parents even reported suicidal thoughts resulting from the increasing stressors from unmanaged problems. This highlights the need for service providers to diagnose and manage common mental health problems among these parents. Further, many of the participants in our study had material needs attributed to poverty, similar to those in Kenya ([J. Gona, R, S, & K, 2013](#_ENREF_11)).

Spirituality and its effect on coping was a major one within our study. Many parents explained how their spirituality supports them but some described how they had turned away from their faith because they were not coping with their children but also because of negative attitudes from others in the community. Some parents ascribe their child’s disability as part of Gods plan and accept it. On the other hand, when they are isolated in payers for lack of faith, they feel abandoned by the very spiritual leaders that they look up to for support. Studies from Kenya and Iran have similarly described the need for spirituality within the lives of these parents. ([J. Gona et al., 2013](#_ENREF_11); [Samadi, McConkey, & Kelly](#_ENREF_28)). This means that spiritual accompaniment for such parents can help to alleviate stress. In addition, spiritual leaders need to avoid being judgmental and isolating parents whose children make little progress but can instead continue to offer spiritual support.

Parents in our study also describe the difficulties maintaining family cohesiveness following the birth of the disabled children and how, in extreme cases this may result in divorce. Some parents’ question their own faith and do not perceive their child as a gift or source of pride, but instead, a curse or punishment. Parents used both positive and negative ways of coping including the use of faith and spirituality, but some used harmful strategies such as drinking alcohol. Our data shows poor informal supports available to parents especially when close friends and community members who may help in caring roles actually accuse parents of bringing the problem (disabled child) into the family. In one extreme case, instead of helping the mother care for the child, the relatives and neighbors were reported to be persuading the mother to kill the child. This emerging data describing parents’ ideations relating to suicide and coercion to commit filicide were extremely worrying. We attribute these to intense build-up of unmanaged stress among parents due to unavailability of services for their children with disability and their own associated emotional problems. This is not considered in the family care model but would need to be considered in any program that we undertake in the future.

The findings from our study indicates the need for intensified individual and group counseling services as well as the timely referral of parents presenting with these common mental health problems. It highlights the need for the initiation of routine screening programs to diagnose and manage issues early on to prevent severe unmanageable problems.

Our study also highlights the need for the creation of culturally appropriate and specific psychosocial interventions for parents of children with intellectual disability in African settings. Furthermore, our research has shown need for: parents of children with disabilities to be provided with education on disability, its causes and its management. This should include material to clear misconceptions and myths about child disability but also discuss fears of the unknown and promote inclusiveness. There is a dire need to collaborate further with groups who may support respite services, special needs education facilities and other disability related services.

This is one of the first studies which provides extensive qualitative data from a large sample of parents of children with disabilities in urban and rural African settings where we have clear emerging themes on experiences for parents of children with intellectual disabilities but also the mechanisms which may be leading to severe stress, marital breakdown and even suicidal thoughts among some parents.

The data in our study can be applied to the family care model ([McCubbin & McCubbin, 1980](#_ENREF_19)) however, in our study there were additional factors which should be considered. The family care model uses the theory of stress and coping and identifies three major stages in stress and coping ([McCubbin H, B, Comeau, & & Needle, 1980](#_ENREF_18); [McCubbin & McCubbin, 1980](#_ENREF_19)), These include: antecedents, mediators, and outcomes. Causality flows from antecedents to mediators to outcomes. The antecedents considered in some studies are child characteristics such as functional dependency of children or severity of disability of the child. These are linked with the family characteristics, the household income and family functioning ability of parents to cope with stress. The mediators are psychosocial interventions. Outcomes can include caregiver’s improved coping skills and reduced psychological distress, culminating into improved quality of life; child's living status and participation in age-appropriate community activities. Our data demonstrated that antecedents such as the characteristics of the child such as inappropriate and aggressive behaviors when paired with marital issues, societal stigma and isolation and a lack of mediators may lead to ultimate negative influences to commit filicide and suicidal thoughts by some parents.

This study has some limitations. The caregivers included in this study were all recruited from clinic sites rather than those in the community who might not have had any service and hence may be not entirely representative of parents who are without any services and disabilities may be different. Furthermore, the study provides evidence from two specific sites in this setting but may not reflect views of all caregivers of children with intellectual disability in Malawi. However, there is a possibility that these parents could have presented with more stress due to unmanaged problems for their children. In addition, the study comprised of parents of children with intellectual disability and therefore the views of these parents may differ from those of parents with children with other forms of disability. Although many children of caregivers in the study had mixed and complex disabilities, it may be that those which were excluded, for example those with pure visual or hearing impairment or those with physical disabilities, could wreak more stress among their parents. These children may cause less stress than those with intellectual disabilities but it is very difficult to know this without doing further quantitative research. Finally, on self-reflection, As a male senior member of the St John of God team, CMM has particularly reflected on his positionality and the power relationships during the research. This may have influenced the confidence of research staff and psychologists in conducting the focus groups but also may have influenced what parents discussed at focus groups. We discussed this as a team and utilized Reflexivity methods to try to prevent these influencing results too much. This was a learning experience for the team as a whole but particularly for the primary researcher, CMM. CMM has learned the importance of potential power relationships between the researcher and research participants that might shape the data being collected, particularly when the researcher is in a power position and the other gender.

**Key messages:**

1. Parents of children with disabilities have multiple challenges at household and primary health care level.
2. Parents of children with disabilities suffer great stigma and discrimination and may even consider committing filicide due to these pressures from the community and society in Malawian settings.
3. Inaccessibility of services for parents of children with disabilities both to support their child and their own psychological problems has serious impact on the parents’ mental health in African settings such as Malawi.
4. Parents of children with disabilities in Malawi have varied needs; however, spirituality is a major coping mechanism for many.

**APPENDIX 1: DISCUSSION GUIDE FOR THE QUALITATIVE PART OF THE STUDY**

**TOPIC 1 Experiences in parenting intellectually disabled children**

Can you describe your different challenges or experiences and whatever you go through in your day-to-day caring of these particular children?

***Probe****: Which are your positive challenges/experiences and which are negative ones? What do you like or do you least like about this parenting role?; Times/Situations that you feel to be Challenging?; What are the other things that stress you in these parenting roles?*

**TOPIC 2 Psychological experiences in parenting intellectually disabled children**

How do the above experiences affect you psychologically?

***Probe issues on issues of****:*

1. *Sadness or happiness and why; Depression and why; Anxiety and why; Being worrisome and why; Being frightened with what and why?; Loss of sleep and why; and Loss of interest in things previously enjoyed and why?*
2. *Their perspectives and their friends/neighbours/community perspective on them as well as feelings of stigma and discrimination; functional disruptions; effects of the parenting role on relationships and relaxation opportunities?*

**TOPIC 3 Coping mechanisms**

Can you explain how you cope with these experiences?

***Probe****:*

1. *On what people who cope well do and vice versa; how community help people to cope?*
2. *Coping strategies like recreational activities and excise; Religious or spiritual activities; Relaxation or humour; Seeking peer support; Venting; and Adjusting.*

**TOPIC 4 Required psychological support**

What long-term psychological supports or assistance may help to alleviate some of the psychological issues above?

***Probe****: Psychological supports like counselling; respite services; support groups; Psycho-education on child disability and its management; and spiritual accompaniment.*

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