

# Risk Factors of Depression Among Mothers of Children with Chronic Health Conditions and Disability in Central Malawi

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## Research Article

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# Abstract

The number of pediatric chronic health conditions and disabilities (PCHCD) in Malawi are rising. Caregivers of children with chronic health condition and disabilities (CHCD) experience elevated depression that undermine optimum childcare support. Currently, there is dearth of knowledge on the prevalence and underlying factors that predispose depression among mothers of children with CHCD in Malawi. The study aims to examine the perceived social environmental factors that triggers anxiety and depression among mothers of children with CHCD in rural Malawi.

## Methods

The study utilized a sequential mixed-method research design. A multistage cross-sectional study design was used to sample 198 mothers for the survey, and purposively recruited 27 mothers for the in-depth interviews. A descriptive analysis examined the prevalence of depression. A phenomenological approach was used to understand the drivers of depression. The qualitative interviews were transcribed and subsequently coded using thematic analysis.

## Results

The prevalence of depression among mothers of children under five years with CHCD was 47%. Notable perceived predisposing factors of depression were constant fear of their child's well-being and safety, lack of community and professional support, and inaccessibility of specialized healthcare services due to poverty.

## Conclusion

Depression among mothers of children with CHCD is a significant health problem in rural Malawi that warrant intervention. We suggest that programs that can enhance the wellbeing and safety of children and offer socioeconomic support to mothers can potentially mitigate depression.

# Background

Pediatric chronic health conditions and disabilities (PCHCD) are among the most pressing global public health concerns as they exert significant burden on children themselves, their caregivers, and the health and social care system more generally (Miller et al., 2016). Pediatric chronic health conditions and disabilities include any physical, emotional, or mental health condition that lasts for more than three months and is serious enough to cause limitations in the daily functioning of a child (Mokkink et al., 2008). Children with chronic health conditions and disabilities (CHCD) may experience daily life functioning limitations, dependance on medical technology or medication, require a high degree of medical care or other services and/or require special ongoing treatments which impact their development, activities, and experience of relationships on a regular basis (Miller et al., 2016).

Globally, more than 623 million children younger than 5 are living with significant chronic health problems and disabilities. It is also predicted that the prevalence of PCHCD will continue to rise due to major advances in the treatment and management of life-threatening health conditions such as chronic disease which have resulted in increased life span among children (Perrin et al., 2014; Van Cleave et al., 2010). However, the situation of PCHCD in the Global South is worsening due to hunger and malnutrition, unsanitary living conditions, inaccessible rehabilitation and healthcare services, and violence (Grech & Soldatic, 2016).

Studies have demonstrated that informal caregivers of children with CHCD are very important to the ongoing health and well-being of these children. In fact, most care provided in the context of PCHCD is done so by parents and other family members, particularly women (Cantero-Garlito et al., 2020). Family care to children with CHCD, while central, does result in significant risk of poor physical and mental health outcomes among caregivers when compared with their peers with children who do not have CHCD. Burnout and chronic sorrow have been identified as major psycho-emotional challenges among caregivers which can have physical and mental health consequences (Coughlin & Set hares, 2017). Caregiver burnout emanates from an ongoing childcare burden that triggers fear, anger, helplessness, and grief. Caregiver chronic sorrow refers to a profound trauma and unresolved grief that occurs periodically but persistently among parents that are caring for children with CHCD (Coughlin & Sethares, 2017). It is established that informal primary caregivers of children with chronic health conditions and disabilities experience an elevated stress and fatigue across the life course due to the children's failure to meet expected developmental milestones (Gérain & Zech, 2018).

In Sub Sahara Africa (SSA), mothers are the primary caregivers of children with CHCD. Several factors influence the primary role of mothers in the provision of care including, most notably, hegemonic masculinity as a discourse which results in the subjugation of women as power holders within society generally and within the family and community specifically (Hrženjak, 2020). The nature of gendered oppression exacerbates burnout which ultimately may negatively impact childcare practices. The pathways according to literature is that household gender inequality undermine mothers' autonomy in household decision making over access and control of economic resources (Akinyemi et al., 2019). Indeed, other studies affirm that gender imbalances within intra-household relationships and as well as strained and limited systems of support constrain mothers of children with health-related problems (Adugna et al., 2020).

In Malawi, epidemiological data indicate that epilepsy, physical, hearing, intellectual, undernutrition, and HIV/AIDS are amongst common forms of PCHCD (Lelijveld et al., 2020). It is documented that parents of children with CHCD struggle to balance their daily activities, experience emotional distress, and stigma (Barlindhaug et al., 2016). For instance, a study in urban Malawi found that 41% of mothers of children with intellectual disabilities in Lilongwe and Mzuzu cities were suffering from depression (Masulani-Mwale et al., 2018) and another study that was conducted at a major referral Queen Elizabeth central hospital in Blantyre city found that mothers of preterm infants had an elevated level of emotional distress when compared to mothers of full-term infants (Gondwe et al., 2020). However, there are limited empirical

studies that delve into the household and environmental factors that trigger depression and anxiety among mothers of children with CHCD. Therefore, the goal of this study was to examine the prevalence and underlying factors of depression among mothers of children with CHCD in rural central Malawi. It provides social workers and allied professionals with empirical data to inform evidence-based practice to address underlying triggers of depression and promote the wellbeing of mothers of CHCD effectively and efficiently.

### Theoretical perspective

The current study was guided by the biopsychosocial model of disability and health that posit that the nexus of biological, psychological, and social factors plays a significant role in human wellbeing and functioning (McDougall et al., 2010). The main tenet of the model is that disabilities arise from a combination of factors at the physical, emotional, and environmental levels. The approach was initially theorized by George Engel in 500 BC as a challenge to biomedical model of disabilities, and since then it has been widely used in the field of health, and disabilities (Lindau et al., 2003)]. The model takes the conceptualization of disability beyond the biomedical, and social models that focuses on an individual's level of functioning, and social constructs, respectively. It covers the full spectrum of disability and addresses issues that interact to affect the ability of the individual to maintain health and wellbeing for functioning in the society. The biopsychosocial approach to disability is consistent with the World Health Organization (WHO) International Classification of Functioning, disability, and health (ICF) model that recognizes that a person's level of functioning is a product of the dynamic interaction of health conditions, personal, and environmental factors (McDougall et al., 2010).

Drawn from the biopsychosocial model, the study aims to conceptualize the social environmental factors that impact the ability of mothers of children with CHCD to effectively perform child rearing responsibilities. These social environmental factors have been discussed in literature and may include social stigma, toxic relationships, lack of economic and social support, and unavailability of health services (Algood et al., 2013). Therefore, an understanding of underlying factors of poor mental health outcome of mothers can help to inform the designing of tailored interventional programs that can promote parenting success and eventually enhance proper development of children with CHCD in Malawi.

## Methods

### Research design

The current study utilized a sequential mixed method research design which included both quantitative and qualitative research approaches (Schoonenboom & Johnson, 2017). The aim was to enhance and broaden the current understanding of depression among mother caregivers in rural areas of central Malawi. Descriptive quantitative analysis was the primary method that was used to assess the prevalence of depression among mothers which was then followed by a descriptive phenomenological qualitative approach (QUAN→qual) (Creswell & Poth, 2016). A phenomenological approach was adopted

to deeply explore mother caregivers' perceptions, experiences, and meanings they attributed to mothering a child with CHCD with a specific emphasis on experiences of depression and its triggers.

### Study setting

The current study was conducted in six postnatal clinics in Dowa district of central Malawi in southern Africa (Figure 1). Malawi has a population of about 17,563,749 people of which 84% live in rural areas (NSO, 2018). In 2017, about 71% of the population was living in extreme poverty according to United Nations indicators (World Bank, 2016). Malawi has a high burden of childhood chronic illness and disability due high prevalence of chronic diseases such HIV/AIDS, malnutrition, malaria, pneumonia, and diarrhea (World Bank, 2016). Due to the prevalence of adherence to cultural traditions embedded within patriarchal norms, mothers assume the role of primary caregivers and spend most of their time taking care of the family members including CHCD. The study was conducted between the months of May and September in 2018 as part of an ongoing international project that focuses on understanding the underlying factors of child and maternal poor health outcomes in Malawi (Chilanga, 2013; Chilanga, Collin-Vezina, et al., 2020; Kerr et al., 2016; Riley & Chilanga, 2018).

### Study sample

#### Phase one: Quantitative data

The quantitative phase of the study used a multistage descriptive cross-sectional study design and thus employed a sampling strategy designed to select a representative sample of mothers and their children aged 2 to 59 months in Dowa district. Six out of eight outreach clinics were randomly selected in areas of Traditional Authority Chiwere in Dowa district. The selected clinics were Gogo, Ching'amba, Mkhalanjoka, Kalinyengo, Mvera and Mphande areas, within approximately five to ten kilometers of the Mvera mission hospital. During the study, Mvera mission hospital served a population of 27,719 people, of whom 4,527 were mothers with children between 2 and 59 months old (Chilanga, Collin-Vezina, et al., 2020). A total population of 407 (9%) of the 4,527 children were categorized as having at least one chronic health condition or disability by the hospital that included severe hearing or vision impairment, physical impairment, intellectual impairment, epilepsy, albinism, undernutrition, and chronic disease as operationalized by Tataryn et al., (2017). Therefore, the current study included mothers of 407 children with chronic health conditions and disabilities. To obtain a representative sample size, a Raosoft sample size calculator was used as recommended by McCrum-Gardner (McCrum-Gardner, 2010). A margin of error of 5% with a 95% confidence level and 50% response distribution was set providing a sample size of 198 mother-child dyad. A systematic sampling strategy was employed to select a sample of 198 ( $n = 198$ ) mother-child dyad from the 407 ( $N = 407$ ) sample frame. A name for the first child-mother dyad was randomly picked followed by picking every second child-mother dyad.

### Participant recruitment

The selected mothers and their children in the six postnatal clinics were contacted for informed consent to participate in the study during the regular monthly health screening for children. The screening program is an initiative of the Malawi government to promote maternal and under-five year child health through a framework of a continuum of care for mothers, newborns and children (Kerber et al., 2007). Community health workers who were assigned as research assistants sought informed consent from mothers to take part in the study. All interviews took place in the consultation room at each outreach postnatal clinic using a pre-tested questionnaire with various measuring instruments including maternal depression and child health status. The child's and the mother's anthropometric and health status data from their health passports was recorded in the questionnaire after their health screening program was completed based on the procedure by Tsega (Tsega et al., 2016).

## Measures

### Demographics

The study collected data relating to caregivers' demographic characteristics such as age, marital status, education attainment, and exposure to intimate partner violence. Data related to PCHCD was confirmed from the child health passport card along with age and gender.

### Depression

Depression symptoms were measured by a validated Malawi local language Chichewa version of the Self-reporting questionnaire (SRQ) that has been used in previous studies (Stewart et al., 2009). The Chichewa SRQ is a 20-item no/yes instrument adapted to screen anxiety and depressive symptoms in Malawi. The SRQ screening instrument has a cutoff point of 7/8 with greater scores signaling clinical? depression. The instrument has a high internal consistency of 0.85 on the Cronbach alpha and it was in the same range with the current study (Cronbach alpha of 0.83). The Survey was administered on Android tablets using an Open Data Kit (ODK).

The WHO protocol for conducting research on sensitive topics was adhered to because many questions focused on interpersonal violence (Ellsberg & Heise, 2002). Enumerator orientation and subsequent questionnaire pre-testing was conducted for five days. The primary author who was by then a PhD social work candidate, a clinical officer and an environmental health officer were responsible for training the enumerators. The research team, including the enumerators, were practicing professional community health, nutrition, and primary health care workers.

### Phase 2: Qualitative data

During phase 2 of the study, 27 mothers who were caregivers of children with CHCD and were diagnosed with depression were purposively selected using principles of maximum variation and saturation (Patton, 2005; Saunders et al., 2018). Factors used to categorize participants include, child age, gender, diverse forms of CHCD, mothers' education, household economic status, and geographical location. A semi-structured in-depth interview guide was used to initiate the discussions in the qualitative interviews. The

guide was pretested with 12 participants in the clinics that were not selected to participate in the study prior to actual data collection (Chilanga, Collin-Vézina, et al., 2020). The study drew upon multiple perspectives based on caregivers' age, education attainment, marital status, and level of socialization.

## Data analysis

Descriptive quantitative data was analyzed using an IBM Statistical Package of Social Sciences (SPSS) for Windows version 23.0 (IBM Corp., Armonk, NY, USA). The focus was to analyze the percentages of mother caregivers with and without symptoms of depression. Graphs was produced for visual presentation.

Qualitative data was audio recorded and transcribed verbatim into Chichewa language. The interview transcripts were subsequently translated into English by the authors. The transcripts were analyzed using hand coding in order to ensure deeper immersion into the data and understand meaning essence of the experience of the mothers (Patton, 2014). Relevant emic and etic codes were inductively derived to answer the research questions. Emergent codes were organized and linked to four broader themes. A number of strategies were used to ensure rigour and validity of the qualitative results that included member checking, triangulation and reflexivity (Birt et al., 2016). The preliminary results of the study were shared with participants in June 2019 at a feedback workshop that was conducted at Mvera mission hospital. Participants clarified and added various concepts that were later unified into the study results. To ensure face validity the respondents' conveying lived experiences has been presented in their own words.

## Research Ethics Review

Ethics approval to conduct this study was obtained from the Research Ethics Board of McGill University in Canada (protocol number: REB File #: 503-0518) and the University of Livingstonia research ethics committee in Malawi (protocol number: UNILIA-REC-4/18). Written permission was also sought from the public service offices at Dowa district commissioner's office, the Dowa district health office and the Mvera mission hospital management. Oral consent from local health leaders and research participants was obtained in all study areas. The rationale for obtaining oral consent was to protect mothers from potential IPV as it was agreed that partners could come across the written document. Further they were informed that they could withdraw at any time without consequence. Mothers were informed that participation to the study was voluntary, and they could withdraw at any time without consequence on their access to healthcare services.

# Results

## Quantitative Results

A total of 198 mothers of children with CHCD took part in the cross-sectional study and 27 of them took part in the qualitative study. The mean age of the mothers was 27 years, and more than half were

married. Majority of the mothers had a primary school education (68%). At the time of the participating mothers were caregivers of children with diverse forms of chronic health conditions and disabilities such as physical, chronic illness, epilepsy, albinism, and intellectual disability as shown in table 1.

Table 1: Demographic characteristics



	<b>Variable</b>	<b>N = 198</b>	<b>%</b>
<i>Mothers' characteristics</i>	<b>Age (years)</b>		
	15-19	13	6.6
	20-29	112	56.6
	30-39	58	29.3
	40-49	15	7.5
	<b>Education</b>		
	No education	29	15
	Primary	135	68
	Secondary	34	17
	<b>Received childcare education</b>		
	Yes	147	74
	No	51	26
	<b>Exposed to IPV</b>		
	Yes	134	68
	No	67	32
	<b>Marital status</b>		
	Married	123	62
	Single/divorced/separated	75	38
	<b>Has confidant</b>		
	Yes	95	48
No	103	52	
<b>Depression symptoms</b>			
Yes	93	47	
No	105	53	
<i>Children's characteristics</i>	<b>Sex</b>		
	Female	97	49
	Male	101	51
	<b>Age (months)</b>		

2-5	15	8
6-11	32	16
12-23	46	23
24-59	105	53
Physical impairment	17	9
Chronic illness	112	52
Albinism	14	7
Epilepsy	12	6
Intellectual disability	18	9

### Depression amongst mothers with children who have CHCD

As illustrated in figure 2, out of 198 mothers that were caring for children with CHCD, 93 (47%) were diagnosed with clinical depression.

The severity of the depression among the respondents were further assessed and the findings are presented in figure 3. The findings show that 69 (74%) had minimal to moderate while 24 (26%) had moderately severe to severe scores.

### Qualitative Results:

#### Perceived drivers of depression among caregivers

The results of the qualitative study are presented below, and exemplary quotations have been used to contextualize how participants attached meaning to the emergent themes. To ensure confidentiality, the respondents are only identified by pseudonyms.

#### (A). Consistent fear and hopelessness for the life and safety of a child

The results of the study revealed several psychosocial factors that were perceived to exacerbate depression among mothers who were caring for children with CHCD. Many of the underlying factors were linked to the persistent fear for the life and safety of their children. Four common underlying factors of constant fear among the mothers were identified from the data. The proceeding paragraphs explicate specific triggers of fear in accordance with the health condition of the child.

The study found that mothers of children with albinism were in constant fear that their children could be kidnapped and killed by albino hunters for their body parts. During the time of the study, Malawi was experiencing a surge in the number of albino abduction and mutilation cases that posed safety concerns

for children with albinism. Hence, all mothers of children with albinism expressed the view that they were always worried that their children could encounter a “gruesome murder”. The following excerpt exemplifies the opinion of a mother who had a four-year-old child with albinism and was identified to have a severe form of depression:

When the news broke in the past two years that people with albinism are being hunted like animals, I have been always worried for the safety of my child. I am having sleepless nights as the murders even broke into the house at night to grab the child. Consequently, I feel frightened when I hear any suspicious sound during the night, I wake up in the morning feeling tired, and headache... [Debora, 29 years].

The concerns of Debora were confirmed by Linda who had a three-year-old child with albinism. Linda shared insight on how her mental wellbeing was compromised due to mistrust of people around her child as she perceived that they could conspire with albino hunters:

The reports that I am hearing is that relatives of people with albinism such as fathers, and uncles are the one that are conniving with albino hunters. We are being warned that we should be vigilant of the relatives as they are potential threats. This makes me always to be worried whenever someone talk or carry my child even if this could not be the case if I had a black child [Linda, 33 Years].

Mothers of children with CHCD such severe undernutrition, and cerebral palsy stated that their mental wellbeing was deteriorating because they were always living in fear that their children could die any time. According to a mother with a three-year-old child who was suffering from cerebral palsy, she acknowledged that her mental wellbeing was negatively affected due to the poor health of her child:

When I was giving birth to this child, he did not cry, the nurse thought that he was dead but to our surprise he was breathing. Since then, the child does not respond to any stimuli such as verbal or facial cues. I technically support him in everything despite being three years. I do realize that this child will not survive up to teenage that makes me worry why this is happened to me [Rhoda, 24 years].

The sentiment of Rhoda was shared by another mother who had a two-year-old child who was diagnosed with HIV/AIDS and was suffering from undernutrition.

I lost hope if my child will grow like other children. I am always in and out of the hospital and I do not enjoy life... Unfortunately, there is nothing I can do to reverse this condition. The health condition of my child drives me crazy, and all our family resources are depleted [Chrissy, 41 years].

Childhood epilepsy was another health condition that respondents identified as a contributor of poor mental wellbeing among caregivers in the study communities. Mothers who were caring for children with epilepsy explained that they were anxious of the safety of their children as they are at risk of fainting over fire or in water. A mother of a child with epilepsy had this to say to express her worry:

My child is 5 years old, and she faints almost every week. When she was young, I was carrying her on my back whenever I was working on my domestic chores or when working in my garden. She has more

weight now and insist to play with her peers. This is where my worry comes as most of time young girls play with water or near the fire. I am always in fear that my child can faint on dangerous objects such as on stone, fire or fall in water bucket [Ellina. 31 years].

(B). Increased marital conflicts and limited social and psychological support

Marital conflicts and separation emerged as critical triggers of depression among caregiving mothers of children with CHCD. In Malawi, like in many countries in SSA, giving birth to a child with physical or mental disabilities is still considered a curse in which mothers are blamed for doing something wrong that angered the ancestors (Bunning et al., 2017). In the study areas, mothers spoke at length to explain their lived experiences regarding how giving birth to a child with disabilities resulted in or perpetuated spousal conflicts and separation that resulted in elevated depression among them. A respondent who was abandoned by her husband expressed her experience as follows:

When I gave birth to this child, I noticed that my sister-in-laws were not happy. When we went home, my husband was shocked. We started to have continuous arguments over the cause of the child's condition and after six months he abandoned me and the child. I am yet to get in terms with this abrupt breakup and most of time I spend sleepless nights thinking about it [Nasuluma, 32 years].

Nasuluma's narrative captured the view that giving birth to a child with physical disability was a potential trigger for her depression. She expressed that there was no social and psychological support despite seeking informal family counselling from her extended family network. Another respondent concurred with Nasuluma that lack of emotional support from extended family members contribute to depression when mothers have a child with CHCD. The proceeding excerpt underscores her view:

My child was born premature and HIV positive. He is now two years but looks as if he is six months old. His poor health has been a source of my depression as my husband and his family claim that I infected the child with the virus [Kanji, 24 years].

I asked Kanji to elaborate why they were accusing her of infecting the child with HIV. She stated that she was diagnosed HIV positive when she went for HIV testing and counselling (HTC) at the antenatal clinic. She believed she was infected by her husband who had multiple sex partners prior to her pregnancy but he has never gone for HTC session.

Another theme regarding marital conflict due to having a child CHCD was elaborated by Nasuluma who talked at length while emotionally charged. She had this to say:

My husband and all community members believe that I disobeyed cultural tradition and watched a sacred masked traditional dance (*gule wankulu*) while pregnant. They claim that this is the reason that I gave birth to a blind child because of my stubbornness. To be honest, I followed all cultural practices during my pregnancy, and it is heartbreaking that I am now being blamed [Nasumati, 39 years].

The preceding excerpt exemplifies cultural taboos and beliefs that focuses on causes of child CHCD among participants. Nyau cult was claimed to be a most feared tradition that that regulate behaviour of people in the study communities.

### (C). Reduced economic productivity and increased household financial burden

Finally, reduced economic productivity and increased household financial burden was acknowledged as one of the factors that exacerbate depression among mothers of children with CHCD. All respondents confirmed that they were experiencing constrained time to fully participate in economic activities due to increased childcare responsibilities. This financial precarity resulted in increased anxiety among those interviewed in the current study. One mother attributed her increased level of depression to her failure to perform concurrent multiple roles as follow:

In the past, I was patronizing all the market days in the week as a maize vendor. Nowadays, I cannot do that as my child was born with disability and she needs extra care that takes much of my business time. As a result, the business has dwindled which is affecting me psychologically [Rute, 32 years]

Household financial burden was another major factor that was cited to perpetuate depression among the respondents. The main concern was that children with CHCD need continuous medical attention that can deplete household resources otherwise intended for the entire family. One participant stated that:

My child was born with physical disability, and we were advised that month she have physiotherapy at Kamuzu central in Lilongwe or Salima district hospital. You know these hospitals are very far from here and we need a lot of money to attend these facilities. I only managed once when I sold my crops. Unfortunately, we do not have any more resources to take the child to the hospital. This makes me to feel sad as this child will not walk if she will not attend the needed healthcare services [Angera, 23 years].

Other caregivers talked extensively about how distance from the main hospital undermines access to specialized healthcare services. For instance, Maria, a mother with a boy child that needed constant brain tumor checkup had this to say:

My child needs monthly head scanning at central hospital but as you can see, we reside in remote areas. There is no tailored public transport system that target people with CHCD. I have given up as we cannot afford to travel to town every month. Seeing my child in pains and I cannot do anything to take him to hospital makes me feel bad and sleepless [Maria, 26years].

The excerpts illustrate the pathways in which raising a child with CHCD undermined maternal economic productivity that eventually affected access to specialized healthcare support. The identified precarious life negatively affects the mental wellbeing of caregivers.

## Discussion

Depression significantly undermines mother's capacity to care for children with CHCD. In developing countries such as Malawi, research is required to examine prevalence and predisposing factors of poor mental health of caregivers of children with CHCD (Cohn et al., 2020). This study confirms the findings from previous studies which have demonstrated that the burden of care among mothers of children with CHCD is high, leading to both depression and anxiety (32–89%) in Malawi (Masulani-Mwale et al., 2018b; Stewart et al., 2011). The current study focused on a population of mothers in rural central Malawi where prior research was not conducted. It was found that 47% of the caregivers were experiencing depression that was claimed to undermine childcare, relations with others in the family (including spouses) and community as well as women's capacity to earn a living.

Several factors were identified to exacerbate depression among caregivers of children with CHCD among women in the communities under study. Consistent fear for the life and safety of the children was one of the common themes among mothers of children mainly with albinism and disability. This finding could be attributed to the unprecedented surge in mutilation and killing of people with albinism and disability in Malawi for their body parts that are claimed to be used for charms (Cruz-Inigo et al., 2011; Mwiba, 2018). Consequently, many mothers were living in fear as albino hunters were reported to be breaking into the houses or snatching children from mothers that threatened their life and that of children. Unlike in Tanzania, the Government of Malawi does not provide temporary holding shelters in form of hostels that are used to house people with albinism. In recent years, Malawi is providing personal security alarms to people with albinism with an aim of alerting community members when they are under attack (Kajiru & Mubangizi, 2019; Tambala-Kaliati, 2020). Therefore, this study recommends policy makers in Malawi to tighten the security given to people with albinism and disability in the study communities. The amendment can potentially protect the fundamental human rights of children and mothers such as right to life and good health as enshrined in the disability and rehabilitation policy of Malawi (Mannan et al., 2012).

The study underscores that having a child with CHCD can trigger marital discord and intimate partner violence (IPV) that exacerbates poor mental health outcomes among women caregivers. Numerous socioeconomic factors were also attributed to the escalation of IPV. These include lack of support from extended families and communities, as well as stigma targeting both mothers and children. This finding supports and enriches the existing research on the additional risks related to IPV amongst mothers of children with CHCD in the study communities (Chilanga, 2013; Chilanga, Collin-Vezina, et al., 2020; Kerr et al., 2016; Riley & Chilanga, 2018). In the current study, mothers expressed that having a child with CHCD exerts an extra burden on their time that triggers anxiety and depression. Therefore, mental health promotion programs in the area should consider addressing IPV while promoting emotional support, financial compensation, and specialized services among mothers of CHCD. In particular, service providers of community police victim support unit programs (Mulambia et al., 2018) in the study areas should pay attention to the identified multiple stressors of depression that can be indirectly reported in a form of IPV or suicide ideation among mothers of children with CHCD.

Finally, the study supports the literature that misconception exist regarding PCHCD in SSA and the study areas that affect the mental wellbeing of caregivers (Masanja et al., 2020). First, the belief that the use of body parts of children with disabilities including albinism bring good economic fortune threatens the safety of mothers and their children. Second, it is believed that giving birth to a child with CHCD is because of punishment to a mother for wrongdoing. Therefore, the study advocate for transformative education curriculum, and community civic education that can empower community members to comprehend the causes of PCHCD. The government should focus on the development of culturally sensitive education programs demystifying the identified claims, while also promoting household gender equity that can eventually enhance the mental wellbeing of mother caregivers, their children, and future generations.

## Conclusion

The present study underscores a significant number of mothers who care for children with CHCD in rural central Malawi experience elevated anxiety and depression. The study contributes to literature on the underlying factors that contribute to stress and depression among the study population. The notable triggers include fear for the life of children and that of caregivers, IPV, precarious forms of livelihood, lack of social and emotional support, and limited access to specialized health services. The study has some social work policy and practice implication. These include but not limited to an advocacy to Malawi government to institute strong security measures to children and mothers of children with CHCD such as regular community police patrols. Development of social support networks and tailored mental health programs for mothers of children with CHCD that consider their social location. Finally, it is indispensable that programs that aim at building community social and economic capital such as village banks, food for work, social assistance, and community education should consider incorporating issues relating to awareness of CHCD. The initiative can enhance community social support towards mothers who are caring for children with CHCD that can eventually enhance their mental wellbeing.

## Abbreviations

IPV

Intimate partner violence

NSO

National Statistics office

CHCD

Chronic health condition and disabilities

PCHCD

Pediatric chronic health condition and disabilities

SSA

Sub Sahara Africa

US\$

## **Declarations**

### **Ethics approval and consent to participate**

The study received research ethics approval from the Non-Medical Research Ethics Board at McGill University, Canada (REB File #: 503-0518), and at University of Livingstonia in Malawi (UNILIA-REC-4/18). The study also received written consent from Dowa health office authorizing the authors to conduct research in the clinics under its jurisdiction. Informed oral consent was obtained from all participants before each interview. The authors obtained oral permission from the research participants based on the suggestion of the research stakeholders. The rationale was that a written consent paper could be easily seen by their partners that could potentially put the respondents at risk of IPV.

### **Consent for publication**

The authors informed the participants that the study will be published to partially fulfill the requirement for the PhD. With full understanding of the research and its intended purpose, all participants gave full consent for the researcher to publish the findings.

### **Availability of data and materials**

The study involved capturing of sensitive data according to WHO standards. I documented mothers' disclosure of violence by their current husbands. Due to the sensitivity of the study local Ethics Board and stakeholders did not recommend sharing the raw data publicly. In case some scholars may need the raw data for further analysis, they can contact the author for appropriate ethical steps before accessing the data.

### **Competing interests**

We declare no competing interests.

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The authors did not have any external funding for this research project.

### **Authors contribution**

E.C designed the study, collected, analyzed the data, and wrote the first and final draft of the manuscript. M.C supported in data collection, transcribing the data and revise the draft manuscript. The authors read and proved the final manuscript.

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## References

- Adugna, M. B., Nabbouh, F., Shehata, S., & Ghahari, S. (2020). Barriers and facilitators to healthcare access for children with disabilities in low and middle income sub-Saharan African countries: A scoping review. *BMC Health Services Research*, *20*(1), 15. <https://doi.org/10.1186/s12913-019-4822-6>
- Akinyemi, J. O., Banda, P., De Wet, N., Akosile, A. E., & Odimegwu, C. O. (2019). Household relationships and healthcare seeking behaviour for common childhood illnesses in sub-Saharan Africa: A cross-national mixed effects analysis. *BMC Health Services Research*, *19*(1), 308. <https://doi.org/10.1186/s12913-019-4142-x>
- Algood, C. L., Harris, C., & Hong, J. S. (2013). Parenting Success and Challenges for Families of Children with Disabilities: An Ecological Systems Analysis. *Journal of Human Behavior in the Social Environment*, *23*(2), 126–136. <https://doi.org/10.1080/10911359.2012.747408>
- Barlindhaug, G., Umar, E., Wazakili, M., & Emaus, N. (2016). Living with disabled children in Malawi: Challenges and rewards. *African Journal of Disability*, *5*(1). <https://doi.org/10.4102/ajod.v5i1.254>
- Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? *Qualitative Health Research*, *26*(13), 1802–1811. <https://doi.org/10.1177/1049732316654870>
- Bunning, K., Gona, J. K., Newton, C. R., & Hartley, S. (2017). The perception of disability by community groups: Stories of local understanding, beliefs and challenges in a rural part of Kenya. *PLOS ONE*, *12*(8), e0182214. <https://doi.org/10.1371/journal.pone.0182214>
- Burke, M. L., Eakes, G. G., & Hainsworth, M. A. (1999). Milestones of Chronic Sorrow: Perspectives of Chronically Ill and Bereaved Persons and Family Caregivers. *Journal of Family Nursing*, *5*(4), 374–387. <https://doi.org/10.1177/107484079900500402>
- Cantero-Garlito, P. A., Moruno-Miralles, P., & Flores-Martos, J. A. (2020). Mothers Who Take Care of Children with Disabilities in Rural Areas of a Spanish Region. *International Journal of Environmental Research and Public Health*, *17*(8), 2920. <https://doi.org/10.3390/ijerph17082920>
- Chilanga, E. (2013). Assessing the Impact of Nutritional Education on Gender Roles and Child Care in Northern Malawi. *Electronic Thesis and Dissertation Repository*. <https://ir.lib.uwo.ca/etd/1298>
- Chilanga, E., Collin-Vezina, D., Khan, M. N., & Riley, L. (2020). Prevalence and determinants of intimate partner violence against mothers of children under-five years in Central Malawi. *BMC Public Health*, *20*(1),

1848. <https://doi.org/10.1186/s12889-020-09910-z>

Chilanga, E., Collin-Vézina, D., MacIntosh, H., Mitchell, C., & Cherney, K. (2020). Prevalence and determinants of malaria infection among children of local farmers in Central Malawi. *Malaria Journal*, *19*(1), 308. <https://doi.org/10.1186/s12936-020-03382-7>

Cohn, L. N., Pechlivanoglou, P., Lee, Y., Mahant, S., Orkin, J., Marson, A., & Cohen, E. (2020). Health Outcomes of Parents of Children with Chronic Illness: A Systematic Review and Meta-Analysis. *The Journal of Pediatrics*, *218*, 166-177.e2. <https://doi.org/10.1016/j.jpeds.2019.10.068>

Coughlin, M. B., & Sethares, K. A. (2017). Chronic Sorrow in Parents of Children with a Chronic Illness or Disability: An Integrative Literature Review. *Journal of Pediatric Nursing*, *37*, 108–116. <https://doi.org/10.1016/j.pedn.2017.06.011>

Creswell, J. W., & Poth, C. N. (2016). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. SAGE Publications.

Cruz-Inigo, A. E., Ladizinski, B., & Sethi, A. (2011). Albinism in Africa: Stigma, Slaughter and Awareness Campaigns. *Dermatologic Clinics*, *29*(1), 79–87. <https://doi.org/10.1016/j.det.2010.08.015>

Ellsberg, M., & Heise, L. (2002). Bearing witness: Ethics in domestic violence research. *Lancet (London, England)*, *359*(9317), 1599–1604. [https://doi.org/10.1016/S0140-6736\(02\)08521-5](https://doi.org/10.1016/S0140-6736(02)08521-5)

Gérain, P., & Zech, E. (2018). Does Informal Caregiving Lead to Parental Burnout? Comparing Parents Having (or Not) Children With Mental and Physical Issues. *Frontiers in Psychology*, *9*. <https://doi.org/10.3389/fpsyg.2018.00884>

Gondwe, K. W., Brandon, D., Yang, Q., Malcom, W. F., Small, M. J., & Holditch-Davis, D. (2020). Emotional distress in mothers of early-preterm infants, late-preterm infants, and full-term infants in Malawi. *Nursing Outlook*, *68*(1), 94–103. <https://doi.org/10.1016/j.outlook.2019.05.013>

Grech, S., & Soldatic, K. (Eds.). (2016). *Disability in the Global South: The Critical Handbook*. Springer International Publishing. <https://doi.org/10.1007/978-3-319-42488-0>

Hrženjak, M. (2020). Multiple masculinities in primary caregiving situations: Degendering care and undoing masculinity. *Anthropological Notebooks*, *26*(2), 28–50.

Kajiru, I., & Mubangizi, J. C. (2019). Human rights violations of persons with albinism in Tanzania: The case of children in temporary holding shelters. *African Human Rights Law Journal*, *19*(1), 246–266. <https://doi.org/10.17159/1996-2096/2019/v19n1a12>

Kerber, K. J., de Graft-Johnson, J. E., Bhutta, Z. A., Okong, P., Starrs, A., & Lawn, J. E. (2007). Continuum of care for maternal, newborn, and child health: From slogan to service delivery. *The Lancet*, *370*(9595), 1358–1369. [https://doi.org/10.1016/S0140-6736\(07\)61578-5](https://doi.org/10.1016/S0140-6736(07)61578-5)

- Kerr, R. B., Chilanga, E., Nyantakyi-Frimpong, H., Luginaah, I., & Lupafya, E. (2016). Integrated agriculture programs to address malnutrition in northern Malawi. *BMC Public Health, 16*(1), 1197. <https://doi.org/10.1186/s12889-016-3840-0>
- Lee, M. H., Park, C., Matthews, A. K., & Hsieh, K. (2017). Differences in physical health, and health behaviors between family caregivers of children with and without disabilities. *Disability and Health Journal, 10*(4), 565–570. <https://doi.org/10.1016/j.dhjo.2017.03.007>
- Lelijveld, N., Groce, N., Patel, S., Nnensa, T., Chimwezi, E., Gladstone, M., Mallewa, M., Wells, J., Seal, A., & Kerac, M. (2020). Long-term outcomes for children with disability and severe acute malnutrition in Malawi. *BMJ Global Health, 5*(10), e002613. <https://doi.org/10.1136/bmjgh-2020-002613>
- Lindau, S. T., Laumann, E. O., Levinson, W., & Waite, L. J. (2003). Synthesis of Scientific Disciplines in Pursuit of Health. *Perspectives in Biology and Medicine, 46*(3 Suppl), S74–S86.
- Mannan, H., McVeigh, J., Amin, M., MacLachlan, M., Swartz, L., Munthali, A., & Van Rooy, G. (2012). Core Concepts of Human Rights and Inclusion of Vulnerable Groups in the Disability and Rehabilitation Policies of Malawi, Namibia, Sudan, and South Africa. *Journal of Disability Policy Studies, 23*(2), 67–81. <https://doi.org/10.1177/1044207312439103>
- Masanja, M. M., Imori, M. M., & Kaudunde, I. J. (2020). Factors Associated with Negative Attitudes towards Albinism and People with Albinism: A Case of Households Living with Persons with Albinism in Lake Zone, Tanzania. *Open Journal of Social Sciences, 8*(4), 523–537. <https://doi.org/10.4236/jss.2020.84038>
- Masulani-Mwale, C., Kauye, F., Gladstone, M., & Mathanga, D. (2018a). Prevalence of psychological distress among parents of children with intellectual disabilities in Malawi. *BMC Psychiatry, 18*(1), 146. <https://doi.org/10.1186/s12888-018-1731-x>
- Masulani-Mwale, C., Kauye, F., Gladstone, M., & Mathanga, D. (2018b). Prevalence of psychological distress among parents of children with intellectual disabilities in Malawi. *BMC Psychiatry, 18*(1), 146. <https://doi.org/10.1186/s12888-018-1731-x>
- McCrum-Gardner, E. (2010). Sample size and power calculations made simple. *International Journal of Therapy and Rehabilitation, 17*(1), 10–14. <https://doi.org/10.12968/ijtr.2010.17.1.45988>
- McDougall, J., Wright, V., & Rosenbaum, P. (2010). The ICF model of functioning and disability: Incorporating quality of life and human development. *Developmental Neurorehabilitation, 13*(3), 204–211. <https://doi.org/10.3109/17518421003620525>
- Miller, G. F., Coffield, E., Leroy, Z., & Wallin, R. (2016). Prevalence and Costs of Five Chronic Conditions in Children. *The Journal of School Nursing: The Official Publication of the National Association of School Nurses, 32*(5), 357–364. <https://doi.org/10.1177/1059840516641190>

- Mokkink, L. B., van der Lee, J. H., Grootenhuis, M. A., Offringa, M., Heymans, H. S. A., & Dutch National Consensus Committee Chronic Diseases and Health Conditions in Childhood. (2008). Defining chronic diseases and health conditions in childhood (0-18 years of age): National consensus in the Netherlands. *European Journal of Pediatrics*, *167*(12), 1441–1447. <https://doi.org/10.1007/s00431-008-0697-y>
- Mulambia, Y., Miller, A. J., MacDonald, G., & Kennedy, N. (2018). Are one-stop centres an appropriate model to deliver services to sexually abused children in urban Malawi? *BMC Pediatrics*, *18*(1), 145. <https://doi.org/10.1186/s12887-018-1121-z>
- Mwiba, D. M. (2018). Medicine Killings, Abduction of People with Albinism, Wealth and Prosperity in North Malawi: A Historical Assessment. *Proceedings of the African Futures Conference*, *2*(1), 30–49. <https://doi.org/10.1002/j.2573-508X.2018.tb00008.x>
- NSO. (2018). *2018 Malawi Population and Housing Census Preliminary Report*.
- Patton, M. Q. (2005). Qualitative Research. In *Encyclopedia of Statistics in Behavioral Science*. American Cancer Society. <https://doi.org/10.1002/0470013192.bsa514>
- Patton, M. Q. (2014). *Qualitative Research & Evaluation Methods: Integrating Theory and Practice*. SAGE Publications.
- Perrin, J. M., Anderson, L. E., & Van Cleave, J. (2014). The Rise In Chronic Conditions Among Infants, Children, And Youth Can Be Met With Continued Health System Innovations. *Health Affairs*, *33*(12), 2099–2105. <https://doi.org/10.1377/hlthaff.2014.0832>
- Riley, L., & Chilanga, E. (2018). ‘Things are not working now’: Poverty, food insecurity and perceptions of corruption in urban Malawi. *Journal of Contemporary African Studies*, *36*(4), 484–498. <https://doi.org/10.1080/02589001.2018.1547373>
- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity*, *52*(4), 1893–1907. <https://doi.org/10.1007/s11135-017-0574-8>
- Schoonenboom, J., & Johnson, R. B. (2017). How to Construct a Mixed Methods Research Design. *Kolner Zeitschrift Fur Soziologie Und Sozialpsychologie*, *69*(Suppl 2), 107–131. <https://doi.org/10.1007/s11577-017-0454-1>
- Stewart, R. C., Bunn, J., Vokhiwa, M., Umar, E., Kauye, F., Tomenson, B., Rahman, A., & Creed, F. (2011). A prospective study of psychological distress among mothers of children admitted to a nutritional rehabilitation unit in Malawi. *Child: Care, Health and Development*, *37*(1), 55–63. <https://doi.org/10.1111/j.1365-2214.2010.01111.x>
- Stewart, R. C., Kauye, F., Umar, E., Vokhiwa, M., Bunn, J., Fitzgerald, M., Tomenson, B., Rahman, A., & Creed, F. (2009). Validation of a Chichewa version of the self-reporting questionnaire (SRQ) as a brief screening

measure for maternal depressive disorder in Malawi, Africa. *Journal of Affective Disorders*, 112(1–3), 126–134. <https://doi.org/10.1016/j.jad.2008.04.001>

Tambala-Kaliati, T. (2020). *Lived Experiences of Persons with Albinism in Lilongwe District, Malawi* [Thesis, University Of Ghana]. <http://ugspace.ug.edu.gh/handle/123456789/35814>

Tataryn, M., Polack, S., Chokotho, L., Mulwafu, W., Kayange, P., Banks, L. M., Noe, C., Lavy, C., & Kuper, H. (2017a). Childhood disability in Malawi: A population-based assessment using the key informant method. *BMC Pediatrics*, 17. <https://doi.org/10.1186/s12887-017-0948-z>

Tataryn, M., Polack, S., Chokotho, L., Mulwafu, W., Kayange, P., Banks, L. M., Noe, C., Lavy, C., & Kuper, H. (2017b). Childhood disability in Malawi: A population-based assessment using the key informant method. *BMC Pediatrics*, 17. <https://doi.org/10.1186/s12887-017-0948-z>

Tsega, A., Hausi, H., Chriwa, G., Steinglass, R., Smith, D., & Valle, M. (2016). Vaccination coverage and timely vaccination with valid doses in Malawi. *Vaccine Reports*, 6, undefined-undefined. <https://doi.org/10.1016/j.vacrep.2016.06.001>

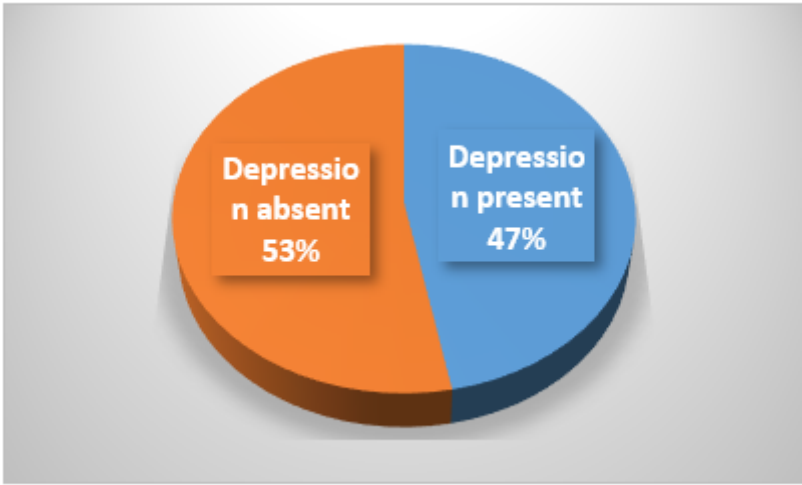
Van Cleave, J., Gortmaker, S. L., & Perrin, J. M. (2010). Dynamics of Obesity and Chronic Health Conditions Among Children and Youth. *JAMA*, 303(7), 623–630. <https://doi.org/10.1001/jama.2010.104>

World Bank. (2016). *Republic of Malawi: Poverty Assessment*. <https://www.tralac.org/images/docs/11708/republic-of-malawi-poverty-assessment-world-bank-may-2017.pdf>

## Figures

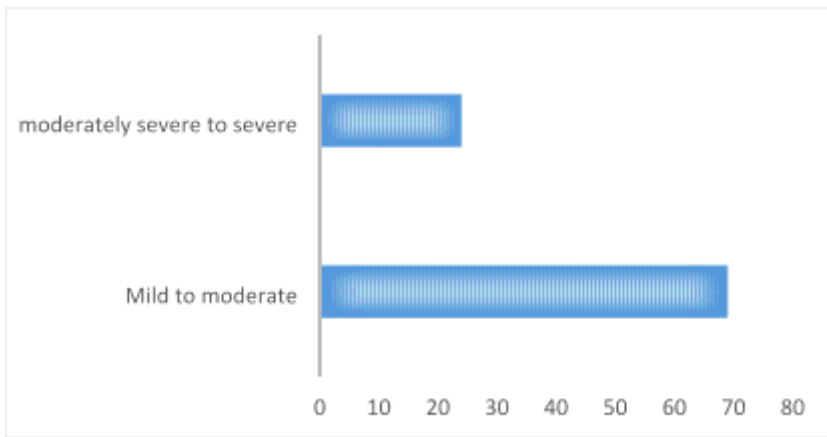
### Figure 1

The research setting



**Figure 2**

Prevalence of depression among caregivers



**Figure 3**

Depression severity