Grassroots Psychosocial Factors Affecting Diagnosis and Management of Neurodevelopmental Disorders: A Case of Ward 13 Seke Rural District Zimbabwe

Regina Banda

Department of Applied Psychology, University of Zimbabwe

Abstract

Various factors related to context appear to influence effective management of mental illnesses. With this in mind, this paper sought to investigate how a rural context in a low income country likely influences the diagnosis and effective management of mental disorders known as neurodevelopmental disorders (NDDs). The article investigated the factors influencing identification and effective management of neurodevelopmental disorders (NDDs) in Ward 13 in Seke Rural District in Chikomba West. The paper uses a phenomenological qualitative research design. Purposive and convenience sampling were utilised to identify participants. Data from key informant in-depth interviews was triangulated with data from caregivers of children aged 10 years and below in Ward 13 Chikomba West Seke rural district. Themes identified using Braun and Clarke thematic analysis framework include vague knowledge and awareness, limited access to specialised care resources and various worldviews influenced by culture including attitudes and beliefs. Enablers included presence of psychosocial support in the community. It was concluded that various factors interact at personal, institutional and national levels, among others, to give rise to barriers and enablers of early diagnosis of NDDs. Knowledge and culture were overarching factors that are amenable to change. It is recommended that organisations and policy makers create programmes and policies that target amendable factors that deter timely diagnosis including attitudes, self-efficacy, beliefs and knowledge.

Keywords: neurodevelopmental disorders, help-seeking, comorbidity, management of symptoms, debilitating, supernatural,

Introduction

Many people needing psychological services fail to get them with 15% in the low and middle-income countries (LMICs) accessing such help (Skylstad et al., 2019). The World Health Organization (WHO) (2021) indicates limited access to mental health services for children, though no statistics are available for sub-Saharan Africa (SSA). This paucity of statistics is worse in rural settings (Nsereko et al., 2011). Although some countries including Nigeria, Ethiopia and Ghana have made strides to improve access to mental healthcare by integrating

mental health into their healthcare policies, shortages of facilities and manpower specialised in mental healthcare remains a challenge, with main psychiatric units being found in urban centres (Atewologun, et al., 2025). Mental health services are therefore highly centralised (Mlambo et al., 2014; Wainberg et al., 2017). Chibanda and Mangezi (2010) lamented the same scenario regarding mental health services in Zimbabwe, yet 61.4% of Zimbabweans live I rural areas (Zimbabwe National Statistics Agency (ZIMSTAT), 2024). Prevalence of mental conditions in children globally is alarming with 20% of children and adolescents suffering from debilitating mental illnesses (Skylstad et al., 2019). Although prevalence of NDDs in sub-Saharan Africa is not known, global trends in increases of incidence are also expected (Ruparelia et al., 2016). The Diagnostic and Statistical Manual for Mental Disorders Edition 5 (DSM 5) identifies these NDDs to include attention deficit hyperactivity disorders (ADHDs), autism spectrum disorders (ASDs), intellectual disability (ID) and communication disorders (CDs), among others (American Psychiatric Association (APA), 2013).

NDDs are highly comorbid, having an onset in infancy (APA, 2013). A disruption occurs in the development of the brain that affects social, intellectual, personal and occupational functioning (Thapar et al., 2016). NDDs vary in causes, management and responsiveness to treatment (Banda, 2021; Thapar et al., 2016). Thorough assessment by different specialists is necessary due to NDDs' complex nature (Ruparelia et al., 2016; Thapar et al., 2016).

Early and correct diagnosis that is provided for by professional medical practitioners is imperative and possible from as early as 14 months (Rosenberg et al., 2011). Early screening and assessment averts worsening of NDDs by providing a chance for early interventions (Manolova, 2017). This early diagnosis is necessary for effective management of (NDDs) (Sicherman et al., 2018). In Africa, however, there is generally a trend of delayed diagnosis (Anwar et al., 2018; Franz et al., 2017). This study thus targeted investigations of factors that affect diagnosis at grassroots in a rural community since these populations are found to be worse off in terms of access to health care.

A multi-disciplinary approach is necessary for effective NDD management (Ruparelia et al., 2016). Childhood mental illnesses require multiple informants such as teachers, parents and other individuals that spend time with the children. This is because heavy reliance is placed on recognition of behavioural signs (Franz et al., 2017). This study chose to identify key informants that can elucidate how, at rural community level, the inputs and actions of these potential multiple informants can affect early diagnosis of NDDs.

Research objectives

The study sought to determine:

- 1) The knowledge of NDDs found in a rural community members
- 2) The general perceptions and beliefs inherent in rural community dwellers about the causes and effective management of NDDs
- 3) Socio-economic and structural barriers and enablers of identification and management of NDDs in a rural community setting.

Research questions

The research questions that the study sought to answer were:

- i) Do rural community members possess knowledge of NDDs?
- ii) What are the community members' prevalent perceptions of and beliefs on the causes of NDDs and their effective management methods?
- iii) What socio-economic and structural barriers and enablers towards identification and effective management of NDDs are found in a rural community?

Literature review

There is a knowledge gap in populations and practitioners alike about the identification and management that is effective for NDDs. A study in Nigeria indicated a general trend of poor knowledge of identification and management of NDDs among healthcare providers in primary healthcare (Agbo et al., 2024). This finding is consistent with earlier studies in Zimbabwe where there is little knowledge of NDDs, including ASD in Zimbabwe (Banda, 2021; Chitiyo & Chitiyo, 2019).

Ratombo (2020) found that an interaction of culture, the economy and religion impacts interpretation of signs observed in the children. Similar observations can be deduced from a Nairobi study where stigma, lack of knowledge and lack of affordability to services were found as factors that hinder identification, diagnosis and management of NDDs in informal settlements (Segre, et al., 2023). Other influential factors that impact diagnosis include lack of resources (Alonso & Little, 2019), no trust in professionals (Tirintica et al., 2018), negative attitudes and a low knowledge (Wainberg et al., 2017) and community influences including stigma (Skylstad et al., 2019).

Culture influences interpretation of symptoms (Nsereko et al., 2011). Culture shapes caregivers' behaviours through creation of certain beliefs and attitudes (Skylstad et al., 2019).

These result in multiple help-seeking pathways that are rampant in Africa. However, help-seeking also depends on income levels, physical barriers, and beliefs among others (Radez et al., 2019). These multiple pathways lead to delayed or no diagnosis of NDDs (Anwar et al., 2018). Beliefs also breed perceptions of symptom severity and burden of care in the caregivers that serve as motivators or deterrents in seeking help for suspected mental illness (Skylstad et al., 2019).

Skylstad et al. (2019) identified an information gap on mental illnesses that exists among service providers and stakeholders involved in the management and identification of NDDs. Traditional healing has been found to be the most accessible and most utilised practice in SSA due to the fact that it is more readily available than medical service providers and that it caters for cultural perspectives and concerns of its users (Berhe et al., 2024). In this systematic review, Berhe et al. (2024) found varied studies including those that showed improved care in collaboration between mainstream medical practitioners and traditional healers; continued complementary use of both without collaboration of practitioners and some studies that provided evidence of human rights violations in the use of traditional methods to care. Zimbabwe, however, medical professionals and traditional healers do not consult each other (Mangezi & Chibanda, 2010) thus depriving service providers of key information necessary to improve their services. Caregivers are unable to notice odd behaviours in the children at times, making friends and family crucial in pointing out behavioural disparities (Sicherman et al., 2018). Schools thus become vital in noting odd behaviour because of the presence of trained teachers and provision of a norm group where the child can be compared to (Godoy et al., 2014).

Stigma is ranked as the most influential factor preventing access to mental health services (Coombs et al., 2021). Stigma shapes individual perceptions of illnesses and causes isolation of the family and the sick individual (Wannenburg et al., 2018). Stigma also leads to feelings of shame and misunderstanding and neglect of the mentally ill (Gabra et al., 2020).

Research methodology

A qualitative exploratory approach to research was adapted to answer the three research questions.

The research questions sought to illuminate the research objectives of identifying whether or not rural community members possessed knowledge of NDDs. The study also sought to clarify the perceptions and beliefs that the rural community had on effective management and the causes of NDDs. Last but not least, the study also needed to determine the existing socioeconomic and structural barriers and enablers of identification and effective management of NDDs that were in existence in the rural community.

Resultantly, the population of interest included caregivers of children aged 10 and below staying in Ward 13 Seke Rural District. This is because the age 10 is the transition point for family versus peer influences (Skylstad et al., 2019). A key informants approach to research was also utilised targeting various individuals believed to be knowledgeable of NDDs in the community including primary school teachers, nurses, community health workers and spiritual leaders (Mumtaz et al., 2013). Religious leaders from the apostolic sect churches and their followers view their churches as practical alternatives to medical health service providers (January & Chimbari, 2018).

The study included caregivers of children aged 10 and less because primary caregivers of such children are the ones that have the sole responsibility of seeking medical care interventions on behalf of their children. Skylstad et al. (2019) clarify 10 as a transition period for peer vs. family influence to support this inclusion criteria. Participants also had to be residents of Ward 13 Seke Rural District Council. Key informants included were teachers responsible for infants. This was important because early diagnosis has been found to be most favourable for effective management of NDDs (Ruparelia et al., 2016). Understanding their beliefs, perceptions, knowledge and attitudes would help in clarifying any reasons for delayed or early diagnosis as teachers are key stakeholders. Religious leaders from the apostolic sect were also included in the study. Mainstream and Pentecostal church leaders were excluded from the study because January and Chimbari (2018) informed this research by clarifying that Pentecostal churches are found to be practical alternatives and influencers in mental health service provision. Community health workers were included in the study as key stakeholders that influence utilisation of medical services in rural contexts in Zimbabwe. Childhood nurses were also included because of their early influence in identification and diagnosis of pathology in children. Understanding their knowledge, perceptions and beliefs may clarify the factors that affect early diagnosis and early management of NDDs.

A census of the nurses who deal with childhood issues (2) and community health workers (CHW) (1) was ideal to select participants for the study given their limited numbers. Early childhood development (ECD) teachers were purposively selected for the study since they facilitate education for the youngest infants in schools. This gives light to the factors that affects

identification of odd behaviours in the youngest children in schools. Convenience sampling was then employed to identify 3 ECD teachers to be interviewed (Bryman, 2012). Four spiritual healers and 10 caregivers were identified using simple random sampling. An additional 2 caregivers were purposively selected for interviews after the CHW identified these as caregivers with children under the age of 10 who were believed to have NDDs. Although the ideal sample sizes for phenomenological studies averages three to ten individuals, data saturation informed the sample size for 6 caregivers interviewed for this study (Creswell & Creswell, 2018).

Thematic analysis was used to analyse the data using the Braun and Clarke framework (2006) (Maguire & Delahunt, 2017). Using Microsoft word, data was analysed manually utilising text highlights, copy and paste functions and commenting tools, creating codes and eventually developing themes. An interactive approach to analysis and data collection were employed as data collection and data analysis were done simultaneously (Vaismoradi & Snelgrove, 2019).

Informed consent in writing was sought from the participants in Shona vernacular and English. Participants were informed that participation was voluntary and that they could withdraw at any moment they felt the need to. Pseudonyms were used to conceal identification of the participants. Confidentiality was also ensured by keeping the recorded material in a secure place and the soft copies were password protected (Creswell & Creswell, 2018). Authority to carry out the study was sought from the Department of Applied Psychology Department since the original study was done as a dissertation paper by the author.

Results

The following themes were revealed in the study.

Vague knowledge and awareness of NDDs

There was vague knowledge and awareness of NDDs, their symptoms, how NDDs could be managed and where to get assistance.

"Personally, on child mental health issues I am not fully aware". KI1

"A child may not want their feet to touch wet soil. They are slow in doing things. They may not speak properly. Some love to chew at anything. They also have specific preferences in their food." (P1)

"... they do not understand the instructions of the teacher. Some remove their clothes. (P2)

"Children cannot verbalise. They don't understand their age mates. Some can't control the flow of their saliva." (KI4).

"One cannot sit still in one place." (P5).

C1 testified to a lack of knowledge of where to get assistance when they realised they needed to get their child some help:

"I did not know where to get help. Harare Hospital is where I went since it is the biggest child hospital."

Negative labelling of parents resulted from this lack of knowledge of NDDs:

"Sometimes you try to explain and people just don't understand. They believe we spoiled the child that the illness is for white children who are not disciplined." C1

Limited knowledge and awareness coupled with a dearth of words in vernacular to describe the disorders led to difficulties in authenticating and differentiating the disorders in young children:

"In Shona we say anopenga [they are mad] but level of madness is not easy to delineate for a child aged 10 or less." (KI4)

Another participant found it hard to name the disorders in Shona using the word "dzenga" that they could not clarify its meaning when asked to explain the word. Instead, they testified it was like epilepsy:

"Their brain is incomplete. It is identical to epilepsy." (P5).

Perceived transiency of symptoms

Most participants were reluctant to commit to whether or not symptoms are permanent or temporary. C2 believed their child would outgrow the symptoms:

"I seriously thought he would outgrow it, that I was over reacting." (C2)

One participant however clarified that transiency of symptoms depended on the interventions employed:

"The symptoms are definitely permanent especially if there are no timely interventions employed to manage the symptoms." (KI3)

Varying perceptions on aetiology of NDDs

Some believed the aetiology of NDDs was biological, others blamed environmental factors yet some still believed it was spiritual:

"It is not easy to isolate mental illness from Godly matters and witchcraft. Doctors have their own opinions that vary from others and it doesn't work... A few are born ill. People want to get rich, so they do rituals to steal the gifts of a child". (KI4)

"Mostly genetic. They inherit it." (P4).

"Down-syndrome comes from an extra chromosome X" (KI3).

"The children envelope these problems prenatally and parents rarely notice it before age 3." (P1)

"After consulting spiritual healers, some find out the dead are causing the illness and so stop looking for other solutions... Some are avenging spirits that need appearement and the parents simply have no means to appeare them. They wait for God's will." (P2)

"Their brains are closed up in like containers. These are evil battles with darkness. The brains are stolen." (P5).

Clarity from P5 indicated the supernatural forces are from ancestral spirits.

"These are the ancestors. They are the source of the dark spirits." (P5)

Perceptions of causes of NDDs as parental negligence and harshness

Some participants blamed parental negligence and their harsh nature in raising children in a variety of ways:

"Some parents confuse kids. They are harsh and children simply become confused. When the child does not respond because of the confusion, they take a stick to heat the children." (P1).

"Parents can beat a child in extreme ways in the name of discipline [at times we the parents are at fault...we can beat the child to an extent that is not normal, beyond their age." (P6)

Beliefs on aetiology of NDDs influence helpseeking pathways

How individuals viewed the causes of the NDDs determined the preferred way to manage the NDDs:

"...Prophet knows whether someone is bound. This means they can solve that. So, it depends on the situation. Where one is born that way, there is nothing that can be done because God allowed it." (P6)

"Some are spiritual wars. Only prayers can calm the person down... Some spirits cannot be appeased though. They may require human sacrifice to compensate the avenging spirit of a murdered relative." (P5)

Financial constraints affect diagnosis of NDDs

Affordability of care was a key determinant of care given to the children.

"As long as parents believe in medical causes, financially most are disabled. ... Most in the community are farm labourers and the farms hire people depending on their seasonal needs, rarely on a permanent basis. People earn between 30 and 40 dollars a month. They cannot sustain their daily needs with it, let alone medical bills" (P3)

"The private sector is simply unaffordable. Consultation costs 50 USD. Medication is cheaper in South Africa" (C1)

"We cannot afford private care. Even private schools that give adequate specialised care are beyond our reach. (C2)

One participant blamed parents who diverted financial assistance they got from organisations on behalf of their children:

"Some take advantage of their children. When they get help, they use the assistance for other uses instead of to help their children." (P1).

Culture shapes worldviews

Culture shapes a way of life for people, informing their beliefs and attitudes. Communities serve to advise its members but some were found not to readily take the advice given:

"Even if you advise them, they are angry that you are interfering with their lives, meddling. (P1)

One participant clarified however, that the root belief of the caregivers determined acceptability of advice given:

"Some have faith in *masowe* [apostolic sect, some traditional healers or pastors. Find out first what they believe then advise them according to their beliefs." (P6).

Worldviews impact prejudice and stigma

Negative beliefs and attitudes were associated with prejudice and stigma:

"Some may be shy, or even fear being the laughing stock" (P1)

"Caregivers may attribute the illness to superstitious causes and so hide away from the community to avoid community judgement. (P4)

"We judge first who it is that has the problem, and that determines whether we step up to help or not" (P2)

Ward 13 participants mainly attributed mental illness to witchcraft activities:

"Most believe in the supernatural caused to mental illness. Even the nurses tell you need to pray for your child and bad spirits will go away." (C2)

"Stigma affects the parents also. So, they are embarrassed to look for help" (P1)

"At times the mother's wickedness is seen as the cause, the illness in the child is punishment for bad sins of the mother... or a curse for wrong doing of the parents." (P3).

Resilience was noted in one participant based on their individual perceptions and attitudes:

"Everyone has an opinion, if you are not strong, you go mad following all sorts of advice. I decided to trust myself more." (C1)

One caregiver that had a child with ASD showed resilience:

"I knew there was nothing fishy about my child's condition. So, I did not get pressured to go to the traditional or spiritual healers" (C2)

Previous experience with the health service providers also shaped help seeking behaviours:

"I lost all confidence in the hospital service. Mostly the queues were long, sometimes no doctors came, and when they did, different ones who did not know your case were available." (C1)

"After my initial visit, being placed on a waiting list or a follow-up visit, I decided not to go back, the practitioners seemed confused about my child's condition. They were not competent enough to help my child." (C2)

How caregivers perceive the symptoms determines their stance on seeking help to treat the symptoms. C2 was forced to seek help at the time their child was being aggressive and school pressure was mounting for them to seek psychological services:

"...we sought help from educational psychologists when he was violent at school. The school demanded it. ... Only after some intervention from his ECD B teacher, did he seem to stop the aggressive behaviour."

Inadequate service provision

Mental health service provision was found to be inadequate according to the participants for a myriad of reasons. The nearest hospitals that provide mental health care are in Harare, about 52Km away from Ward 13. NGOs like Hope Orphan Support Services and Seke Rural Home-Based catered for HIV and AIDS related cases.

"Our hospital doesn't have a mental health staff member."(KI)

"There are no mental health organisations in Beatrice" (P1).

"Our public hospitals do not give adequate care." (C1)

Some participants felt a need to improve routine checks for children to include checks for mental health issues rather than keeping focus on the physical aspects only.

"The centres and schools must do more." (P4)

"Government is letting us down. Schools and hospitals need these specialised services where we can take our children." (C1).

Community members may help identify odd behaviour

C1 and C2 also showed how other members of the community are important in identifying deviant behaviour in children:

"...elders spoke. They realised the delayed speech. They suggested something that held down the tongue that needed operating. That's when we went to the paediatrician." (C2)

"My friend encouraged me to get him checked out. That's when I started noticing the signs. Her son seemed to have the same issues too." C1

Education professionals were also important in noticing the problematic behaviours of children in schools.

"You will realise the teachers can be helpful. The one that taught my child knew much about psychology." C1

Perceptions on managing NDDs

Various beliefs were found among the participants on how best NDDs could be managed.

Some believed caregivers needed to manage their lifestyles and those of their children:

"Parents need to socialise their children more by allowing them to play with others. Parents tend to close their children up if they think something is wrong with them." (KI3).

"Illnesses can be managed by eating healthy diet." (KI2)

Some suggested consulting medical practitioners. Various forms of assistance were suggested including prevention of prolonged labour, counselling services and medication:

"They can prevent mental illnesses cause by prolonged labour. Counselling parents also helps because stress is bad. Medication can also assist in managing illness." (KI2)

"Early intervention is necessary. If parents accept their children's conditions early they can get help early enough." (KI3).

"Medical professionals are certified and knowledgeable. They will assist parents better to care for their children." (P3)

"Seeking medical attention will help the parents understand what is going on with the child. One must however commit and sacrifice." (P4).

"Counselling from psychologists helps. They can also be advised on the best places to get more help there." (KI2)

"In addition to seeking medical help, they need to enrol the child in school to learn daily living skills to care for themselves." (KI3)

Attitudes towards medical practitioners and their interventions

Negative attitudes towards medical practitioners and their interventions existed in some of the participants who believed the practitioners" solution were not permanent.

"I understand some of the injections just reduce symptom severity. Mental illness issues are complicated. Some are spiritual matters. It is therefore not easy to deal with." (KI4)

"Some go to traditional healers and prophets. Doctors just give you tablets to reduce the symptoms but not treat them. Tablets make the sick one sleep after taking them that's all. When they awaken, troubles begin once more." (P5)

C1 had trust in the medical professionals due to personal convictions and experience of successful management of their child's illness:

"I believe in my child's advocate. I have to stand by that. I know it is not spiritual. It is a manageable condition. So far we are managing just fine."

Multiple help seeking pathways

Participants preferred a variety of help seeking pathways. Some indicated a preference of multiple pathways so that all angles of sickness could get an opportunity to be addressed.

"You must come to church. A spiritual church for the illness to be healed" (P5)

"I would do both. Doctors can assess. Because sometimes the child appears normal yet they are not. Then I will ask the traditional healers to seek out an explanation on what is happening" (P1)

"We are Africans. Some people are evil and jealous. We also have ancestors that did bad things. No harm in making sure we address the spiritual issues first. Because without that, even the doctors cannot see. The spirit won't let them" (P2)

Discussion

Factors that affect timely diagnosis interact as various levels including personal, familial, institutional and national levels. This integration is complex and can be analysed using the Bronfenbrenner concepts of the micro, meso, exo and macro-systems (Eriksson et al., 2018). The complex relationships include individual, interpersonal, institutional and national factors.

At an individual level, some participants knew the symptoms and signs of NDDs although the majority was not familiar with them, including KIs who were assumed to be knowledgeable about the NDDs (Banda, 2021). Those that knew the illnesses had encountered someone with the illnesses. Some mistook various illnesses including epilepsy, cerebral palsy, depression and anxiety for NDDs.

Level of knowledge of NDDs affected timely diagnosis. C1 and C2 delayed seeking help because they were not aware of NDDs and their symptoms. This finding confirms concerns raised in previous studies (Ruparelia et al., 2016). Some KIs also showed limited knowledge of NDDs as found in Alharbi (2018). This presents as a barrier to diagnosis since KIs are influential in informing help seeking pathways of individuals.

This lack of knowledge in turn informed on the worldviews of the community and ultimately help seeking behaviours of caregivers. Knowledge informed attitudes, beliefs and behaviours of the communities towards individuals with NDDs, their caregivers and perceptions of effective management. Perceptions that the conditions were supernatural were likely perpetuated by the lack of knowledge which in turn gave rise to stigma, negative perceptions towards efficacy of medical interventions and the role that the caregivers of the children played in the aetiology of the condition. Derogatory terms were at times used in Shona terms like "dzakadambuka" (they are broken) or "kupenga" (they are mad). This may be an indicator of prevalent stigma and a lack of attention previously given to mental illnesses (Coombs et al., 2021).

Perceptions of C1 and C2 determined the pathways they utilised to get help, basing mainly on their personal beliefs and experience. C1 followed through with diagnosis because it was helpful while C2 decided to withdraw from the diagnosis process due to the belief that the medical practitioners were not knowledgeable enough. Perceptions were also informed by community norms and culture. Some participants believed mental illness was caused by supernatural causes and so could be healed using spiritual and traditional healers. These findings confirmed those of earlier studies (Liang et al., 2016; Tirintica et al., 2018).

Only one participant was aware some symptoms can be transient. This may mean if symptoms evolved or were no longer present, the communities would not know the diagnosis of NDDs was still possible. This is against the knowledge that the diagnostic process relies on noticing behavioural oddities, both present and past (Thapar et al., 2016). The danger is in failing to mention even past symptoms or overlooking any present ones in informing the clinicians.

Participants were unsure of the referral centres they could use and had no local access to institutions that could assist in this referral pathway. This finding was similar to other studies that confirmed lack of access to localised care negatively impacts diagnosis of NDDs (Nsereko et al., 2011; Wainberg et al., 2017). Special needs centres including Sharon Cohen and St Giles were mentioned although participants were unsure of the actual care provided there. Sally

Mugabe Hospital and Annex, as the nearest referral centres are found in Harare, about 52km from Ward 13 Seke Rural district. The community thus had limited access to care as a rural community.

This physical lack of access was worsened by the economic problems the community faces as one participant indicated the residents were mainly farm labourers that barely have enough to eat. C1 and C2, as caregivers of children with NDDS, confirmed this financial barrier as quality care was linked to access to private care. C1 complained of expensive medication. C2 gave up her job in the COVID era to care for their child giving them a new role of care. Purpura et al. (2021) also lamented the existence of financial barriers to care.

Stigma was a great barrier in seeking a diagnosis. Participants mentioned that caregivers may shy away from seeking advice or help because of the fear of being labelled. Some mentioned caregivers may protect their children from the public labelling. These findings were similar to previous studies that found how caregivers at times withdrew and shied away from seeking help due to the fear of prejudice or being blamed for their children's illnesses, especially women (Coombs et al., 2021; Wainberg et al., 2017). This stigma found in previous studies was a product of little knowledge (Gabra et al., 2020). The same sentiments can be derived from the current study where some participants automatically viewed familial trends of mental illness to mean that the family members had meddled with dark magic.

Schools remain central in providing insight on the caregivers of abnormal behaviours noted in the children. Both C1 and C2 actively sought assistance for their child when they had enrolled for primary school education. Although this confirms the possibilities of delayed diagnosis in Africa as suggested in previous literature, it also confirms the importance of having knowledgeable individuals in schools as a public sector institution (Godoy et al., 2014; Ruparelia et al., 2016). The role played by the school authorities of pointing out disparities in behaviour buttresses the importance of a multiple players in the diagnostic process (Wannenburg et al., 2018). The current study confirms these findings in the 2 caregivers who had children with NDDs. Being in a school set up for both children gave a norm referencing group in which they could be compared to. Multi-sectoral and multidisciplinary teams across institutions must be formed and adequately educated to be able to correctly identify signs and symptoms which are the basis of referral to the medical professionals.

Preferences for help-seeking pathways varied in this study and these were informed by beliefs individuals held over effectiveness of methods chosen. Participants believed the nature of the

illness determined who they could consult as found in earlier studies (Alonso & Little, 2019; Johnston & Burke, 2019). Multiple help seeking patterns were preferred in some participants, while other preferred to consult spiritual healers only and some preferred medical practitioners.

Lack of collaboration between stakeholders proved to give rise to a fragmented flow of information as confirmed by Mangezi and Chibanda (2010). Some participants knew of NDDs and their symptoms while others were ignorant of the same. Some believed in supernatural causes, while other attested scientific explanations to the illnesses. The KIs possessed varying options that at times opposed each other in terms of knowledge of NDDs and how they could be effectively managed yet these are the same people that caregivers need to get enlightenment from collaboration of key stakeholders was found necessary to iron out disparities in information (Ruparelia et al., 2016).

Self-efficacy in caregivers is instrumental in determining diagnosis. Self-efficacy was a product of many factors including cultural, economic and structural factors as insinuated in previous studies (Alonso & Little, 2019; Johnston & Burke, 2019). Caregivers that believe they are able to assist their children by seeking help from mainstream practitioners are likely to get earlier diagnosis. This is evident in C1 who was determined and able to go through the process. C2 on the other hand stopped seeking medical advice because they believed they were not able to access adequate care for their child since they could not afford private care that they thought was best. The rest of the caregivers postulated the general feeling that some caregivers do not seek help if they believe the spiritual causes are beyond what they can fight against.

Conclusions and recommendations

It can be concluded that individual factors like knowledge and attitudes have a bearing on timely diagnosis. Negative attitudes towards medical practitioners have an effect of delaying or totally denying diagnosis of NDDs. These negative attitudes are informed by knowledge of NDDs, previous experience with the medical practitioners, communities in terms of norms and cultural beliefs that inform on how individuals perceive symptoms of mental illness. Knowledge is a necessity across all systems levels. As individuals continue to interact with various subsystems, they develop help seeking behaviours that either aid or deter timely diagnosis of NDDs.

This paper recommends designing programmes and policy frameworks to increase early diagnosis of NDDs. Attitudes, beliefs and knowledge are three factors that are amenable to change. These three are instrumental in changing behaviours and thinking processes in

communities to foster increased efforts in obtaining early diagnosis. Early diagnosis is possible if symptoms of NDDs are identified early in childhood and there exists favourable conditions in the environment that promotes consultation with mainstream practitioners. This means communities must get rid of stigma and prejudice, knowledge of NDDs be increased across institutions since humans are social creatures. Norms in the community must favour consultation with mainstream medical practitioners. Furthermore, medical practitioners must share knowledge.

Limitations and delimitations of the study

The study was limited with participant apathy in the KI. The researcher however utilised data triangulation comparing information from the KIs with that of the caregivers interviewed. The exploratory study gave insight to idiographic information of the participants. Future studies could therefore utilise this information to carry out studies that evaluate whether factors raised in the study can be generalised to other rural settings in Zimbabwe.

Researchers could also investigate the effectiveness of utilising theory of change models to modify thoughts, behaviours and attitudes of individuals to foster change in communities and individuals.

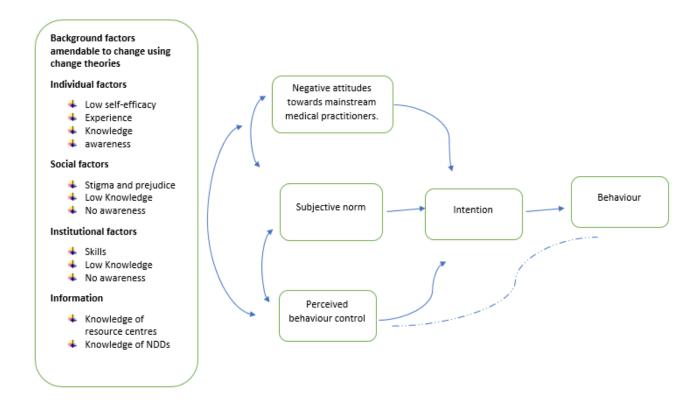


Figure 1: Pathway to behaviour modification using the theory of planned behaviour model (Source: Banda, 2022)

References

- Addo, R., Agyemang, S. A., Tozan, Y., & Nonvignon, J. (2018). Economic burden of caregiving for persons with severe mental illness in Sub-Saharan Africa: A systematic review. *Plos One*, *13*(8), 1–12.
- Agbo, N., Adeniyi, Y., Akpa, O. M., & Omigbodun, O. (2024). Neurodevelopmental disorders in sub-Saharan Africa: A survey on primary healthcare workers' knowledge. *Health Science Reports* 8:e70760, https://doi.org/10.1002/hrs2.70760.
- Alharbi, A. M. (2018). Knowledge and attitude of families and health care providers towards autism. *Journal of Public Health*, 2(2), 2–14
- Alonso, J., & Little, E. (2019). Parent help-seeking behaviour: Examining the impact of parent beliefs on professional help-seeking for child emotional and behavioural difficulties. *The Educational and Developmental Psychologist*. https://doi.org/10.1017/edp.2019.8
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Association.
- American Psychological Association (APA). (2020). *Publication manual of the American Psychological Association* (7th ed.). American Psychological Association.
- Anwar, M. S., Tahir, M., Nusrat, K., & Khan, M. R. (2018). Knowledge, awareness, and perceptions regarding autism among parents in Karachi, Pakistan. *Cereus* 10(9):e3299. https://doi.org/10.7759/cureus.3299
- Arnault, D. Saint. (2009). Cultural Determinants of Help seeking: A model for research and practice. *Research and Theory* 23(4), 259–278. doi:10.1891/1541-6577.23.4.259
- Atewologun, F., Adigun, O. A., Okesanya, O. J., Hassan, H. K., Olabode, O. N., Micheal, A. S., . . . Oso, T. A. (2025). A comprehensive review of mental health services across selected countries in sub Saharan Africa: Assessing progress, challenges, and future direction. *Discover Mental Health* 5(49), https://doi.org/10.1007/s44192-025-00177-7.
- Banda, R. (2022). Psychosocial factors in the community influencing help-seeking behaviours of caregivers for neurodevelopmental disorders in Ward 13 Seke Rural District: A pathway to behaviour modification. University of Zimbabwe
- Banda, R. (2021). Autism Spectrum Disorders: knowledge and attitudes of primary care givers. *International Journal of Psychological and Brain Sciences*, 6(6), 86–94. https://doi.org/10.11648/j.ijpbs.20210606.13
- Berhe, K. T., Gesesew, H. A., & Ward, P. R. (2024). Traditional healing practices, factors influencing to access the practices and its complementary effect on mental health in sub-Saharan systematic review. *BMJ Open 14*:e083004., https://doi:10.1136/bmjopen-2023-083004.
- Chitiyo, A., & Chitiyo, J. (2019). Autism spectrum disorder in Zimbabwe: A brief review of trends, conditions, challenges, and intervention practices. *International Journal of Educational Research*, 6(1), 50–59.

- Coombs, N. C., Meriwether, W. E., Caringi, J., & Newcomer, S. R. (2021). Barriers to healthcare access among US adults with mental health challenges: A population -based study. *SSM-Population Health*, 15;15:100847. doi:10.1016/jssmph.20210100847.
- Creswell, J. W., & Creswell, D. J. (2018). *Research design; qualitative, quantitative and mixed methods approaches* (H. Salmon, C. Neve, M. O'Heffernan, D. C. Felts, & A. Marks (eds.); 5th Edition). Sage Publications Inc.
- Eriksson, M., Ghazinour, M., & Hammarstrom, A. (2018). Different uses of the Bronfenbrenner's Ecological Theory in public mental health research: what is their value for guiding mental health policy and practice. *Soc Theory Health*, 16, 414–433.
- Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. J. (2017). Autism spectrum disorder in Sub-Saharan Africa: A comprehensive scoping Review. Autism Research10(5), 723–749. https://doi.org/10.1002/aur.1766
- Gabra, R. H., Ebrahim, O. S., Osman, D. M. M., & Al-attar, G. S. T. (2020). Knowledge, attitude and health-seeking behavior among family caregivers of mentally ill patients at assiut University Hospitals: A Cross-sectional study. *Middle East Current Psychiatry*, 27(10), 4–11. https://doi.org/10.1186/s43045-020-0015-6
- Godoy, L., Mian, N. D., Eisenhower, A. S., & Carter, A. S. (2014). Pathways to service receipt: Modelling help-seeking for childhood mental health problems. *Administration and Policy in Mental Health Service Research* 41(4), 469–479. https://doi.org/10.1007/s10488-013-0484-6.
- January, J., & Chimbari, M. J. (2018). Opportunities and obstacles to screening for perinatal depression among women in Zimbabwe: A narrative review of literature. *South African Journal of Psychiatry*, 24(0). doi:10.4102/sajpsychiatry.v24i0.1127
- Johnston, O. G., & Burke, J. D. (2019). Parental problem recognition and help-seeking for disruptive behavior disorders. *Journal of Behavioral Health Services and Research*, 47(1), 146–163. https://doi.org/10.1007/s11414-018-09648-y
- Liang, M., Machando, D., Mangezi, W., Hendler, R., Crooks, M., Katz, C., Abas, M., Thornicroft, G., Semrau, M., Jack, H., & Kidia, K. (2016). *Mental health in Zimbabwe*. https://www.kushinga.org
- Maguire, M., & Delahunt, B. (2017). Doing thematic analysis: a practical, step by step guide for learning and teaching scholars. *All Irelan Journal of Teaching and Learning in Higher Education* (AISHE-J), 3(335), 1–14.
- Mangezi, W., & Chibanda, D. (2010). Mental Health in Zimbabwe. *International Psychiatry*, *7*(*4*). 93–94. doi://10.1192/S1749367600006032
- Manolova, H. E. (2017). Editorial: neurodevelopmental disorders and importance of early assessment and early interventions. *Journal of Intellectual Disability*, 5(4), 100–101.https://www.lifescienceglobal.com/pms/index.php/jiddt/article/view/5164
- Mesidor, J. K., & Sly, K. F. (2014). Mental health help-seeking intentions among international and African American college students: an application of the theory of planned behavior. *Journal of International Students*, 4(2), 137–149.

- Ministry of Health and Child Care (MoHCC). (2019). Zimbabwe national mental health policy. Ministry of Health
- Mlambo, T., Munambah, N. D., & Nhunzvi, C. (2014). Mental health services in Zimbabwe A case of Zimbabwe *National Association of Mental Health*. accessed June 2020. https://doi.org/10.1179/otb.2014.70.1.006
- Mumtaz, A., Maya, K. D., & Lai, L. C. (2013). Using the key informants interviews (KIIs) Technique: a social sciences study with Malaysian and Pakistani respondents. *Man and Society*, 24, 131–148.
- Nsereko, J. R., Kizza, D., Kigozi, F., Ssebunnya, J., Ndyanabangi, S., Flisher, A. J., & Cooper, S. (2011). Stakeholder 's perceptions of help-seeking behaviour among people with mental health problems in Uganda. *International Journal of Mental Health Systems*, 5(5), 1–9.
- Purpura, G., Tagliabue, L., Petri, S., Cerroni, F., Mazzarini, A., & Nacinovich, R. (2021). Caregivers 'burden of school-aged children with neurodevelopmental disorders: Implications for family centred care. Brain Sciences, 11(875). doi:10.3390/brainsci11070875
- Radez, J., Reardon, T., Creswell, C., Lawrence, P. J., Evdoka, G., & Polly, B. (2019). Why do children and adolescents (not) seek and access professional help for their mental health problems? A systematic review of quantitative and qualitative studies. *European Child & Adolescent Psychiatry*. https://doi.org/10.1007/s00787-019-01469-4
- Ratombo, F. (2020). *Help-seeking pathways followed by caregivers of mentally ill persons in Sithumule-Kutama*, Limpopo Province. University of Limpopo.
- Rosenberg, R. E., Landa, R., Law, J. K., Stuart, E. A., & Law, P. A. (2011). Factors Affecting Age at Initial Autism Spectrum Disorder Diagnosis in a National Survey. *Autism Research and Treatment 1*. https://doi.org/10.1155/2011/874619
- Ruparelia, K., Abubakar, A., Badoe, E., Bakare, M., Visser, K., Chugani, D. C., Chugani, H. T., Donald, K. A., Wilmshurst, J. M., Shih, A., Skuse, D., & Newton, C. R. (2016). Autism Spectrum Disorders in Africa: Current Challenges in Identification, Assessment, and Treatment: A Report on the International Child Neurology Association Meeting on ASD. *Journal of Child neurology* 31(8) https://doi.org/10.1177/0883073816635748
- Sarafino, E. P., & Smith, T. W. (2011). *Health Psychology: Biopsychosocial interactions* (7th ed.). John Wiley & Sons Inc.
- Segre, G., Cargnelutti, G., Bersani, C., Njogu, W., Roberti, E., Campi, R., . . . Bonati, M. (2023). Early detection of neurodevelopmental disorders in African children living in informal settlements in Nairobi. *BMJ Paediatrics Open 7:e002117*., http://doi:10.1136/bmjpo-2023-002117.
- Sicherman, N., Loewenstein, G., Tavassoli, T., & Buxbaum, J. D. (2018). Grandma knows best: Family structure and age of diagnosis of autism spectrum disorder. *Autism* 22(3). https://doi.org/10.1177/1362361316679632

- Skylstad, V., Akol, A., Ndeezi, G., Nalugya, J., Moland, K. M., Tumwine, J. K., & Engebretsen, I. M. S. (2019). Child mental illness and the help seeking process: a qualitative study among parents in a Ugandan community. *Child and Adolescent Psychiatry and Mental Health*, 13(3), 1–13. https://doi.org/10.1186/s13034-019-0262-7
- Thapar, A., Cooper, M., & Rutter, M. (2016). Neurodevelopmental disorders. *The Lancet Psychiatry*, 0366(16), 1–8. https://doi.org/10.1016/S2215-0366(16)30376-5
- Tirintica, A. R., Andjelkovic, I., Sota, O., Pirlog, M. C., Stoyanova, M., Mihai, A., & Wallace, N. (2018). Factors that influence access to mental health services in South Eastern Europe. *International Journal of Mental Health Systems*, 12(75). https://doi.org/10.1186/s13033-018-0255-6
- Vaismoradi, M., & Snelgrove, S. (2019). Theme in Qualitative Content Analysis and Thematic Analysis. *Forum for Development Studies*, 20(3). https://doi.org/10.17169/fqs-20.3.3376
- Wainberg, M. L., Scorza, P., Schultz, J. M., Helpman, L., Mootz, J. J., Johnson, K. A., Yuvai, N., Bradford, J.-M., Oquendo, M. A., & Arbuckle, M. R. (2017). Challenges and opportunities in global mental health: A research to practice perspective. *Current Psychiatry Reports*, 19(5). doi:10.1007/s11920-017-0780-z
- Wannenburg, N., Niekerk, R. Van, & Wannenburg, N. (2018). Early diagnosis and intervention for autism spectrum disorder in Africa: Insights from a case study. *African Health Sciences* 18(1), 137–146. doi:10.4314/ahs.v18i1.18
- World Health Organization (WHO). (2021). Access to mental health and psychosocial support services remains unequal for children and adolescents in Africa. Alert UNICEF & WHO. http://www.afro.who.int/news/access-mental-health-and-psychosocial-support-services-remains-unequal-children-and-adolescents
- Zimbabwe National Statistics Agency (ZIMSTAT). (2024). 2022 Zimbabwe population and housing census gender thematic report. ZimStat.