

**Nurturing Care for Children with
Neurodevelopmental Disabilities (NDDs): A
Cross-sectional Study in a Rural Setting in Kenya**

Qualitative report, June 2024

Introduction

Most studies about young children in (Low and Middle-Income Countries) LMICs have generally excluded children with NDDs, and therefore, little is known about the importance of interventions such as nurturing care to support their growth and development (1). Moreover, children with NDDs are often neglected by the health systems and experience inequality in health, nutrition, and wellbeing outcomes (2). Nurturing care has been recommended by the World Health Organization (WHO) as a pathway for addressing developmental needs and unlocking the full potential of children, including those with NDDs (3). Nurturing care refers to a stable caregiving environment that provides good health, adequate nutrition, opportunities for early learning, responsive caregiving, and safety and security. All children need nurturing care to thrive; however, children with NDDs require more intensive nurturing care strategies to survive and thrive (4).

While significant efforts have been made to improve the condition of children with NDDs, there is limited data on the nurturing care practices critical for children with NDDs (5). Moreover, there is no substantive evidence of nurturing care for children with NDDs in high- and low-income countries (6). This situation implies that caregivers/parents of children with NDDs may have limited or no access to nurturing care information, which is a key driver for positive outcomes for their children (5). With nurturing care, known and modifiable risk factors for developmental disabilities, such as underdeveloped maternal health-seeking behavior and family violence, can be monitored and effectively mitigated. Children with NDDs are often at risk for maltreatment, violence, and neglect due to unfavorable cultural beliefs about disability, discrimination, and family and community stigma (7,8). In addition, the limited resources in most settings of sub-Saharan Africa (SSA), where a majority of these children live, further constrain their care as the demands for their needs are high. Further, persistent parental stress, depression or negative feelings associated with having a child with NDDs present a great challenge and demand on parental care (6).

For children to attain their full development potential, nurturing care calls for access to good health, nutrition, opportunities for early learning, responsive caregiving practices, and safety and security. The reviewed body of literature demonstrates limited data in terms of the provision of caregiving practices to children with NDDs anchored on these nurturing care framework pillars (9). Nurturing care implementation has been rolled out in Siaya County for all children. However, it is not clear how nurturing care is provided to children with NDDs. To promote holistic early childhood development for children with NDDs using the Nurturing Care Framework, we conducted a study to understand the nurturing care practices for children with NDDs and to identify the nurturing care gaps that exist for these children. In this study, we sought to establish, document, and recommend appropriate nurturing care practices that caregivers/parents could deploy to manage the needs associated with their children living with NDDs. The study aimed to inform the development of strategies to support the holistic development of young children with NDDs. The study also provided key recommendations on practical best practices and interventions for improving the quality of care and developmental outcomes for children with NDDs.

Overall Purpose

The overall purpose of the study was to establish the status of nurturing care for young children with NDDs against the components of the nurturing care framework.

Research questions

- What are the current nurturing care practices for children with NDDs?
- What are the needs of caregivers of children with NDDs?
- What are the drivers or determinants of the quality of nurturing care provided to children with NDDs?
- What are the perceptions of caregivers about the nurturing care provided to their children with NDDs?

2.0 Methodology

2.1 Study Design, Site and Sample

The cross-sectional study was conducted in Siaya County, where the African Population and Health Research Center (APHRC) has previously conducted early childhood development (ECD) studies and is familiar with the setting. Siaya has been at the forefront of implementing nurturing care programs for young children (10,11), making the county a strategic choice for research on nurturing care. All caregivers of children aged 0–5 years who had at least one of the five main NDDs were included in the study. Children aged 0–5 years were chosen as this is the critical age for rapid physical, social, and cognitive development (15).

2.2 Data Collection, Management, and Analysis

For the qualitative component, we held focus group discussions (FGDs) with secondary caregivers and Community Health Promoters (CHPs), in-depth interviews (IDIs) with primary caregivers, and key informant interviews (KIIs) with healthcare providers to obtain information on their understanding of and experiences with the types and quality of care for children with NDDs. Each FGD consisted of 6–10 participants per group. Qualitative interviews were used to triangulate the information obtained from the quantitative interviews to understand better the provision of nurturing care. Qualitative data from the interviews were transcribed and translated before importing into NVivo 10. The imported data were coded and sorted based on the key questions outlined in the interview guides and aligned with the study's objectives. The sorted data were then summarized thematically in line with the research questions.

2.4 Ethical Considerations

The study was conducted after an internal review by APHRC's scientific review committee had been completed and ethics approval from Amref Health Africa's Ethics and Scientific Review Committee (ESRC) was received. The research team was trained on the protection of human research participants. We sought informed consent from all study participants. For those who could not read, the information sheet was read to them in their local language, and they were asked to provide a thumbprint to signify their consent. All survey data were collected in privacy and treated with confidentiality. All the qualitative interviews were audio-recorded after the participants' consent.

3.0 Results

We present results from the qualitative data about the five components of nurturing care.

3.1 Good Health

We determined health provisions that included forms of treatment by capturing information on how the growth and development of children with disabilities are monitored through the health system and the challenges caregivers encounter while seeking health services. In addition, we sought to understand the referral system, perception of the services provided, information provided and the sources of such information.

3.1.1 General Growth and Development for Children with Developmental Disabilities

Care for children with disabilities is relatively similar to that of those without disabilities. Key participants agreed that monitoring children's development was standard, irrespective of the nature of the disabilities. The community health promoters mentioned that their training enables them to monitor children's developmental outcomes at every stage of development by identifying delays in milestones and referring them where appropriate.

We can monitor a child at every stage of development and identify any delayed milestones. This is after the training we received FGD CHPs

Monitoring children's health and developmental outcomes begins during pregnancy and continues up to the early years after delivery. The general status of the mother and the unborn child are checked to ensure that all is well, and if anything is detected, the mother is referred to higher-level health facilities. The interviewed CHPs mentioned educating mothers on the importance of attending clinics and seeking medication. They check clinic books and cards to verify this exercise. A healthcare provider indicated that they provide the necessary services to expectant mothers. Nurses usually deliver the nursing services while the healthcare provider handles the clinical services. These services include performing medical examinations and providing treatment to patients.

3.1.2 Health Service Provision for Children with Disabilities

Health service provision for children with disabilities included forms of treatment sought by parents, health information given to the caregivers by providers, health referrals, health management for children with disabilities, perception of the services provided, uptake of the health services offered, and challenges in health service provision for children with disabilities.

Forms of Treatments

Participants interviewed reported various forms of treatments that caregivers sought for their children with developmental disabilities. While the majority depended entirely on the available medical services, a few also relied on prayers or visited traditional herbalists.

*I have tried everything: the traditional herbs, taking him to the hospital, and even physiotherapy. I have also tried taking him for prayers at the church, but where I have not gone is to a witch doctor....***FGD with fathers**

The caregivers were driven by a desire to get their children to live normally like other children. In some cases, the caregivers were forced to seek alternative treatments, such as prayers rather than medical services due to dissatisfaction with the outcomes, the cost of such care, or the distance to the health facilities. Some sought alternative care because of the perceived causes of the disabilities.

The doctor prescribed medicines for us, but there was no change. We again took her to the hospital, but now things were worse. After trying all these ways as instructed by the hospital and without change, we decided to seek other earthly ways. But the more we visited different places to seek treatment for our child, the more the problem worsened..... **FGD with fathers**

3.1.3 Challenges with Health Service Provision

Challenges presented were related to the cost of transportation and medical services, quality of care, distance to health facilities, and cultural beliefs. Fathers and mothers decried the high cost of medical services and transportation as a major hindrance to achieving healthy outcomes for their children. They complained about the high cost and poor availability of the drugs that their children were required to use. Some caregivers indicated that they had given up on taking their children to the hospital because of the cost of hospitalization.

Medication nowadays is expensive and far beyond the reach of the 'common man.' The high cost of treatment makes our children suffer more since we cannot afford the medical interventions they need. These doctors, once you do not have money, do not bother whether your child dies or not. The major challenge we have encountered so far is a lack of funds. **FGD father**

The nurses shared similar sentiments that corresponded with parent's view of the cost of care being a hindrance to the provision of proper healthcare for children with developmental disabilities. The nurses shared that it was difficult for the caregivers to acquire the necessary equipment for their children.

*Caregivers cannot afford the cost of medication for their children, and for that period when they have no money, they will not receive the care. ...**KII Health care provider***

Another challenge presented by most participants relates to attitude and stigma towards the children, especially from the communities where they live. The caregivers mentioned that sometimes the stigma prevented them from taking their children out for medication as there were general misunderstandings on the causes. For example, some people believed that disability was contagious and that one must stay away from such children because they could get "infected." Others were convinced that disabilities originate from the sins of the parents and saw it as a punishment from God. These thoughts were demoralizing for the parents, who therefore opted to keep their children with them.

*Members of the community fear these children, and they do not want to associate with them. They believe that close interaction with these children is contagious- they fear they can be infected through close contact. Therefore, caring for the disabled child is the full and exclusive responsibility of the parents; otherwise, he can face rejection and oppression in the family and community **FGD fathers***

Distance to the health facility was presented as a challenge. Most of the primary health facilities do not have any of the required treatments for children with developmental disabilities, forcing the caregivers to look for such treatments elsewhere. Most of the services they require are available in Nairobi, Kijabe, or Eldoret, making it almost impossible for caregivers to access them. Besides, some children had become too heavy for the caregivers to carry to the next facility, even for other curative services.

*It is not easy to carry them from home to the facilities because the distance is long, and the child is fully grown but sometimes unable to walk...**FGD CHPs***

Participants interviewed decried poor or no services for children with developmental disabilities as the county has not employed different specialists to manage the disabilities. For instance, there could be an occupational therapist who may not be able to handle a child who is autistic. The lack of services also included a lack of drugs within the facilities. The community facilities cannot handle developmental disability cases, hence the need to refer them to higher-level facilities.

There are no specific facilities for these children, and they have different disabilities. In Siaya County, they are normally taken to physiotherapists, but you find that some

are mentally challenged. There are no specific hospitals and doctors who have specialized in these areas..... FGD CHPs

3.1.4 Health Information Provided

The caregivers get diverse health information (advice) before giving birth and/or after delivery on how to care for themselves and their children. Health providers reported that they advised caregivers of children with disabilities on issues such as taking them to the hospital for treatment, appropriate diet, and nutritional supplements.

“I tell them to adhere to the clinic attendance to receive treatments and also inform them the children are supposed to be given a balanced diet. Their meals should have proteins, carbohydrates, and fruits. We also provide them with peanuts as a nutritional supplement.... KII healthcare provider.

Their sentiments were also shared by theCHPs who confirmed that they advised the caregivers, especially mothers, to ensure that they attended clinics to monitor the growth and development of the children effectively. They also informed them of the types of food they should eat while pregnant and how to take care of their children. The caregivers also learn how to identify the danger signs during pregnancy.

I educate her on the benefits of attending early clinics. By attending clinics, she will be able to monitor the growth and development of her child and receive medication that and learn about the type of danger signs to look out for, the type of diet she should be taking and how she should exercise selfcare.....FGD CHPs

After delivery, the health system continues to provide useful advice to caregivers on how to monitor their children’s development. They are informed about exclusive breastfeeding, complementary feeding, monitoring milestones, and general hygiene of the children.

After delivery, we continue to educate them and tell them that a child should be exclusively breastfed for six months and later introduced to other foods appropriately. We educate them continuously from pregnancy until their children are fully grown and that the hygiene of the child is essential. A child that is young and able to stand is strong. We also tell them that they can massage them.....FGD CHPs

3.1.5 Health Management for Children with Developmental Disabilities

The management of children with disabilities at the community level or in community hospitals depends on the nature and type of disabilities. The children are treated for normal illnesses, just like other children at the community facilities. At the community level, the CHPs help identify children with disabilities through clinical examinations and refer them for

treatment. Despite the challenges of high cost and distance from the facilities, parents of children with disabilities were keen to ensure that their children received the best healthcare services.

*I have taken him to all the tests, eye scans, and gg. I have gone to Kijabe Hospital and Aga Khan Hospital. Currently, a doctor from Aga Khan is the one monitoring him.....***Fathers FGD**

3.1.6 Perception of the Services Offered

Most caregivers interviewed perceived that there is a need to improve the health service provision for their children with disabilities. They felt that service delivery would be different if doctors had better knowledge of how to handle children with disabilities. The general feeling was that the entire health system within the county was not adequately prepared to sufficiently handle these children.

*What we have experienced is that most of the doctors have no experience in dealing with the neurodevelopmental disorders that we are experiencing. Therefore, you will realize that you are spending a lot of money, but the doctor needs help understanding the problem, or it is a new thing to him. **FGD father.***

3.1.7 Health Complications During and After Birth

Health complications were reported during pregnancy, birth, and after delivery. Most caregivers noticed that their children did not cry at birth, which was a worrying sign; it later turned out that their children had disabilities. Some children were born preterm and were kept in incubators for some time, while others developed complications for reasons that could not be explained.

*Nevertheless, my son had complications after delivery because he did not cry after birth. I saw the healthcare workers try to prompt him to cry in futility. I stayed with him in the nursery for three weeks....***mother IDI**

Prolonged labor was reported as the main complication that was a suspected cause of most of the disabilities. Healthcare providers reported that they were not able to handle such complications, and in such cases, they often refer mothers with prolonged labor to other facilities.

*We do experience children with developmental disabilities caused by prolonged labor. But when we encounter such cases, we refer them to Siaya County Referral Hospital... **Healthcare provider KII***

Participants also mentioned issues such as swollen legs, stress, anemia and bleeding as other general complications that they experienced during pregnancy. Some women mentioned domestic disturbances led to stressful life conditions, which caused the prenatal complications.

*I was stressed during pregnancy because finding food to eat was hard. I was also abandoned by my husband who did not care about me during pregnancy. He was not bothered and it was like I was begging him for the marriage to work...mother **IDI***

3.1.8 Perception of the Causes of Disabilities

Participants interviewed had two thoughts on what may cause developmental disabilities. From the interviews, we grouped the perceived causes as medical and traditional/cultural related.

Medical Causes

Perceived medical causes included the use of family planning pills, accidents, missing important prenatal services, mishandling during the birth process, prolonged labor and genetics. The use of family planning pills as a cause of disability was mainly mentioned by men, with some CHPs also adding their thoughts on this. On the other hand, women did not think the use of family planning could be a cause factor.

*I think it is time for the government to investigate these family planning drugs to identify if they are the cause of disabilities so that we can find a good solution or get the best drugs for family planning. In the past, our grandmothers used herbs for family planning, and it never led to disabilities.....**FGD father***

Prolonged labor, which has been discussed as one of the major complications during the delivery, was also seen as a medical-related cause of disabilities. Though not mentioned by the participants, from the description, we considered this as one of the medical causes of disabilities.

Traditional Causes

Traditional beliefs included witchcraft, demon-possession, child sacrifice for wealth, the father's failure to fulfill some traditions, or curses, mother's encounter with a person with disabilities while going to deliver, and disability inherited from the mother's side, among other causes.

*Some men and their family members do believe their children's disability is inherited from the mother's family. This opinion is strongly held by the paternal family. It is this blame that makes women leave their disabled children and marriages.**KII Health care provider***

3.2 Adequate nutrition

Adequate nutrition is the second component of nurturing care for young children. We looked at adequate nutrition for children with developmental disabilities in terms of nutrition information provided to caregivers, nutritional support, dietary modifications, responsive feeding, special diet, challenges with obtaining food, and challenges with feeding the child.

3.2.1 Nutritional information

The CHPs provided the caregivers with information on how to use locally available foods to provide a balanced diet for their children, nutritional supplements and to monitor their feeding patterns.

“.....mostly we do advise the parents to feed them on a balanced diet, and just as the fellow CHP said before a balanced diet should include all kinds of food: fruits, vegetables, proteins and carbohydrates. The foodstuff in this context should be easily accessed within the community. For example, locally available fruits and vegetables.....” FGD CHPs

The sentiments of the CHPs were also shared by the healthcare providers who mentioned that they also advised the caregivers on how to obtain affordable and nutritious food locally. They added that they taught caregivers how to prepare food for their children with disabilities. When children were still young, the mothers were advised to ensure that they breastfed their children exclusively for six months and supplement further for at least two years.

We do encourage them to maintain a balanced diet and encourage them to give what is available in terms of carbohydrates or proteins. Another advice we give is that they can also produce food instead of buying..... KII healthcare provider

Additional information provided includes the benefits of sustaining periodic visits to the health facility to check on nutritional-related issues like weight, vitamin A, and deworming.

We also advise them to visit the clinics regularly after one month for weight checks. They are to visit after six months to get vitamin A for up to 5 years and deworming services after every three months. We also tell them about the importance of balanced diet importance and what's available as they ensure to give the children a balanced diet.... KII healthcare provider

3.2.2 Responsive feeding

The CHPs indicated that they taught the caregivers how to feed their children with disabilities responsively. If the children cannot feed by themselves, the caregivers were taught by the CHPs how to handle such situations.

*...we encourage them to treat these children just like other normal children. There are those children who cannot eat by themselves and have to be spoon-fed. So as a caregiver, you have to take time to spoon-feed your child until he/she is satisfied...**CHP FGD***

3.2.3 Nutritional challenges

Like transport and distance to the health facility, lack of funds was a hindrance to providing food to children with disabilities. Most children with developmental disabilities reportedly had a problem with feeding, forcing the caregiver to provide support. In addition, some of them could not consume hard food, so it had to be liquified or mashed.

Related to the lack of funds was the unavailability of important resources like electricity that support the preparation and processing of food to improve uptake. Most families are unable to blend the food for lack of electricity and so resort to asking for support from neighbors.

*Lack of funds is the main challenge. They don't have enough funds that will enable them to feed these children properly. Sometimes a caregiver cannot afford to provide a balanced diet so she just provides the available food.....**FGD with a CHP***

*“.....my child does not consume solid food. But when eating his liquified meal using a spoon, most of the food pours down or on the clothes. Therefore, taking care of him is not an easy task. With solid foods like bananas, you have to mash them to soften enough for him to manage. ...**father FGD***

3.3 Responsive Caregiving

Under the component of responsive caregiving, we focused on the general caregiving practices for children with developmental disabilities, responsive caregiving information provided to the caregivers, support from the community or family and the role of male caregivers in supporting their children with disabilities.

3.3.1 General Care for Children with Developmental Disabilities

Despite the challenges that come with disability, most parents enjoyed caring for their children and were positive about parenting. CHPs reported that they provided any necessary support to caregivers of children with disabilities. This, according to them, had improved the caregiving skills of these parents. Among the notable practices mentioned were providing medical attention to children when they were sick, ensuring that children had something to

eat, showing love and affection, ensuring hygienic conditions and protecting the children against any harm.

The caregivers treat these children the same way they care for other children. They care for them well only that they can't change the condition of these children. Some caregivers teach other normal children that children living with disabilities are human beings just like them and should never discriminate or isolate themselves. They love these children only that someone might be busy or have a low level of income....FGD CHPs

3.3.2 Responsive Caregiving Information

Healthcare providers and CHPs provided various types of information to caregivers on responsive care for their children with disabilities. The CHPs mentioned that they advised caregivers that children with disabilities should receive the same care and love as their peers without disabilities. Children with disabilities also have the same rights as other children and the caregivers should ensure that they eat well, are clean and get the right medication as other children.

We advise the caregivers to nurture and care for their children who are living with disabilities the same way they do for other normal children. They also have a right to provision of food, right to medication and right to play just like other children...CHPs FGD

Caregivers have been encouraged to ensure that their children are not hidden from the public since this may imply that they are deprived of the care needed, which may consequently hinder them from achieving proper growth and development.

We also encourage caregivers not to hide their children in the houses but rather allow them to play freely with other children to facilitate their growth and development...CHPs FGD

3.3.3 Support from the Community/Relatives

Caregivers acknowledged receiving help from different members of the community, including close relatives. The support included sitting with the children when their caregivers were not around, financial support, encouragement, and prayers.

My mother supports me financially whenever I am in need. At times, she offers encouragement when I am distraught because of my son's condition..... IDI caregiver

On the contrary, most of the caregivers mentioned that they had never received any support from the community. Instead, the community gossiped about the possible causes of disabilities.

3.4 Opportunities for Early Learning

Opportunities for early learning for children with developmental disabilities were determined through the availability of play items, the interaction between the caregivers and their children, and the information provided to caregivers concerning opportunities for early learning.

3.4.1 Availability of Play Items

At the health facilities, CHPs made play materials that were used to enhance opportunities for early learning for all children. These items were sometimes used by the same CHPs to monitor developmental outcomes and identify delays. Children with disabilities are assisted to play with the same materials whenever they visit the health facility.

*We make different play materials so that the caregivers select according to what their children like. We can use shakers to help in monitoring if a child is alert and can follow the source of the sound. Every child has what they are interested in even if he/she has a disability..... **CHP FGD***

Play items were therefore available both at home and in health facilities. The CHPs made efforts to ensure that all children and their caregivers had access to the facility's toys and other play items. Fathers also reported spending some time making play items for their children.

*Mine loves playing a lot, and I used to buy him small movable toy cars. I also brought someone who made him a car using wires, which keeps him busy....**FGD father***

*I bought shakers for him. I use it to check his hearing ability. Sometimes I put a bright cloth on his face and allow him to follow it to check for his vision... **Mother IDI***

3.4.4 Information Provided to Caregivers

Basic information on play and interaction with children was mainly provided by the CHPs in the communities where the children lived. The CHPs who had received training on nurturing care for young children taught caregivers how to make play items, play with their children, and monitor the developmental outcomes of their children. The teaching happened during the health talks at the facility or during the routine home visits by the CHPs. Caregivers were also taught how to care for children.

We educate both the parents and caregivers on the kind of play materials that parents should have for these children to facilitate their growth and development....FGD CHPs

We teach them how to play with the children, nurture them, talk to them and with them. They also ensure the hygiene of their children is good...KII Healthcare provider.

3.5 Safety and Security

We determined safety concerns about children with disabilities, safety measures to protect children with disabilities and safety information provided to caregivers of children with disabilities. We sought to understand safety measures in terms of where the caregivers left their children when they were not around, who else had care responsibility and any form of violence the child had experienced. Some mothers seem not to have alternative caregivers to leave their children with as they either live away from people who can support them or do not trust the people around them enough to leave their children with them. The only option at their disposal is locking them in the house as they went to work.

When their caregivers are away, they are normally locked in the houses because other siblings also go to school and they have no one to look after them. The caregivers have to search for income so they have no choice.....CHPs FGD

The mother risks locking the child in the house because she has no idea how the child will be treated if left with other children. She feels more insecure when she leaves the child with another person than when she locks the child in the house so she would rather risk locking the child.CHPs FGD

The caregivers interviewed presented key safety concerns for their children. This included fear of the children getting raped, and self-injuries and accidents. The CHPs also noted that children with disabilities especially girls were vulnerable to rape.. They feared that these children may also consume poisonous things or may be kidnapped.

The only fear we have as CHPs is that these children are vulnerable to rape, especially the ones that are left by themselves. The rape cases come as a result of their insecurities. Sometimes a child that has epilepsy might fall down and then end up dying. Such cases do occur....FGD CHPs

We also fear that those who are left by themselves can even touch and consume something poisonous and then get exposed to danger. There are also cases of those who kidnap children and take their body organs. Those are some of the risks that they are exposed to.FGD CHPs

4.0 Discussion

The purpose of the study was to establish the status of nurturing care for young children, particularly those with developmental disabilities. The study documented the current nurturing care practices regarding health, nutrition, opportunities for early learning, safety and security and responsive caregiving. The study also assessed the psychological wellbeing of the caregivers and explored their perceptions regarding the quality of care provided to their children with developmental disabilities. In addition, the study analyzed the caregivers' experiences with current best practices of nurturing care including access to and availability of the services.

On health, the findings of the study showed that caring for children with developmental disabilities was complex, demanding, and expensive to the primary caregivers, particularly the mother. Even though children with developmental disabilities received the same services as typically growing children, the specialized services were generally lacking in the county. The caregivers stated that the specialized services were expensive and far away from the caregivers' depriving children of the critical care they needed. Further, there was a lack of specialized healthcare professionals to handle children with NDDs. In their scoping review, Adugna and her colleagues noted limited access to healthcare services for children with NDDs was caused by barriers such as inadequate healthcare services and a lack of personnel handling children with NDDs (18). The caregivers were generally dissatisfied with the health service provision for their children in the county. The findings on dissatisfaction corroborate those from previous studies that demonstrated that most caregivers of children with NDDs were not happy with the health services for their children (19).

The findings also revealed the myths and negative perceptions of the causes of disabilities as a major hindrance to quality nurturing care for children with developmental disabilities. The assumed causes included the child being demon-possessed, the child being sacrificed for wealth, or the parents being punished by God for some sins. These allegations are stigmatizing and discriminating against the child and promote the culture of isolation. Hiding children from the public denies them the nurturing care they need. In previous studies, stigma and negative attitudes have forced some caregivers to interact less with other parents (20) and place the caregivers at risk of poor mental health (21)

On the nutrition component, we noted that caregivers were taught how to use locally available food to provide specialized diets for their children. The caregivers indicated that they faced challenges in the provision of adequate nutrition for their children due to a lack of resources. In terms of responsive feeding, we noted that children with disabilities had problems with feeding and their caregivers supported them by monitoring how they ate and ensuring that they ate appropriate foods. Our findings relate to previous studies that established that children with developmental disabilities often experience feeding problems that may lead to malnutrition if not handled responsively (22). In addition, studies have also established that the high cost of healthcare needs for these children, the weak support system, and the difficulty of obtaining appropriate food put children with developmental disabilities at risk of malnutrition (22,23).

On responsive care, we noted that most mothers indicated that they used positive discipline to correct their children while some still used harsh punishment and acceptance of the status of

their children. In addition, parents ensured that their children received medical services as required, ensuring that they had something to eat and showed them love and affection.

We also noted poor male involvement in care for their children was related to the provision of any necessary supplies such as food but not support in the direct care of the children, for example, washing clothes. Poor male involvement may result from their busy schedules in fending for their families (which is also a way of contributing to care). Suggestions have been given to ensure that male caregivers balance between work and care for their children. Re-adjusting their work schedules or reducing their working hours are key options (24). On a different note, male caregivers of children with NDDs also require an emotionally supportive environment as they experience daily stress from complex caregiving roles (25). The mental health of male caregivers has not been extensively established as the focus is always on their female counterparts.

Under opportunities for early learning, we noted the availability of play items for some children most of which were bought from the shop. The primary caregivers indicated that they played and interacted well with their children. Like the responsive care component, most male caregivers are not actively involved in providing opportunities for early learning such as involvement in any play activities. Even though play items may be available for the children, most caregivers did not have quality time with their children as most children also could not effectively play due to the nature of their disabilities. CHPs and healthcare providers noted they have play corners in their facilities where all children were provided with opportunities for early learning. Existing literature has documented less participation of fathers especially in symbolic play activities compared to mothers (26). In general, mothers are more involved in caring for their children with disabilities than fathers, especially on workdays (27).

Safety and security for children with developmental disabilities is a big concern for their children. The issues raised include fear of being raped, self-injuries and accidents. Caregivers feared letting their children out because some of them could get lost and others may consume poisonous things. Previous studies have indicated that children with developmental disabilities are 2-3 times more likely to experience injuries than their peers (28). Because most children depend on their caregivers for safety, most parents who cannot afford house help are forced to lock their children in the house. Keeping children locked in homes or institutions violates their rights to association and deprives them of the care that they need (29). We also noted that most primary caregivers leave their children's older siblings, their fathers, or sometimes their grandparents as alternative care when they are not around. Kin involvement in care for children with developmental disabilities has been found to represent a powerful psychological and emotional experience for the mother with a positive impact on the child (30).

On a separate note, we noticed that caregiver wellbeing is of great importance to the nurturing care of their children. Our findings revealed that though most caregivers are happy with their roles as parents, they stated that caring for children with NDD is quite time-consuming, stressful, and demanding, affecting their health and wellbeing. These findings on caregiver mental wellbeing relate to previous findings that found that mothers of young children with NDD have poorer health especially mental health compared to mothers of children without any disability.

5.0 Conclusion and Recommendations

5.1 Conclusion

With the many challenges presented, it is worth noting that nurturing care for children with developmental disabilities remains a big gap. If the challenges are not addressed, then supporting the health and development of children with NDD may not be effectively achieved. For effective and quality nurturing care, the health and wellbeing of the caregivers should be the focus. Programs aimed at improving the caregivers' health and wellbeing (including men) are highly recommended.

5.2 Recommendations

Caregivers, CHPs and healthcare providers mentioned that the distance to the health facility where they can receive disabilities-related services is far and transportation is a challenge to most low-income earners. Disability-related services should be introduced to lower-level hospitals to prevent further stress the caregiver may encounter.

Most caregivers, especially men and some CHPs, hold the opinion that the use of contraceptives is associated with developmental disabilities. This belief needs to be investigated further as the idea distorts the use of contraceptives highly regarded as a birth control strategy.

Traditional/cultural assumptions do not have a basis as they are just claims from the participants. However, there is a need to educate the public on the causes of disability as some of these claims and myths affect nurturing care for children with disabilities.

Opportunities for early learning are one of the fundamental components of nurturing care, children with developmental disabilities need early stimulation and exposure to such opportunities. The findings revealed poor male participation in providing their children with disabilities opportunities for early learning. There is therefore a need to develop strategies such as male-only programs to enhance male participation.

Nurturing care for young children depends on the wellbeing of the mothers. Mothers of children with developmental disabilities face different challenges that exhaust them and therefore may lose focus on their children. Programs that promote the wellbeing of these mothers will be a critical strategy to enhance quality nurturing care for children with developmental disabilities.

6.0 References

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