

BACKGROUND

Mobile for community health worker project (mCHW) is a research project that was implemented by the Ministry of Health, Amref Health Africa, together with the UCL Institute of Education, Oxford University and supported by DfID. In collaboration with CHVs and CHEWs, it introduced in 2013 the assessment of developmental milestones of children under five in two communities in Kibera and in Makueni County. As a result, the CHWs and CHEWs identified a number of children with disabilities in both communities.

METHODS

Kibera slum and Kasikeu were purposively sampled because the mCHW project had identified child development milestones and as result children with disabilities were reported. Ethical approval was granted by the Amref Ethics and Scientific Committee (ESRC). The study used a mixed method design. Standardized qualitative techniques were used to assess stress levels and challenges to accessing health care. In depth interviews were carried out with thirty two (32) caregivers of children with disability in Kibera and Kasikeu, Makueni County. Caregiver strain questionnaire (CGSQ) and Parent Experience of Child Illness (PECI) scale were used to determine stress level. Data was analysed thematically and triangulated with quantitative data. Confidentiality was ensured during data collection and presentation whereby anonymous names were used for the qualitative results.

STUDY FINDINGS

A baseline survey revealed the following:

Structural barriers

Economic

"The thing started at 8 months. I took him to remove the baby teeth by a local person [local custom]. After two days, the child's mouth was swollen. So I went to the Dispensary, and was referred to the county hospital but I did not go because I did not have money..." (Connie, with Marco, 15yrs; Makueni)

"I: When your child gets sick, what do you do?"

"C: You know now I cannot carry him on my back we have to hire a motorbike and they are expensive. We cannot carry him in the Matatu [public transport]. So we are just there. The only one that can help us is private but they are very expensive." (Claudia, with Daniel, 16yrs; Makueni)

"One thing about the main hospital is that, unlike the more local hospital, you will be attended faster or at times you are in the line, you will be given first priority, but in the local hospital, you can stand and stand and no one cares about you." (Ruth with Nikki, 4yrs; Kibera)

Institutional, 3. Political, 3. Cultural

Stress Levels

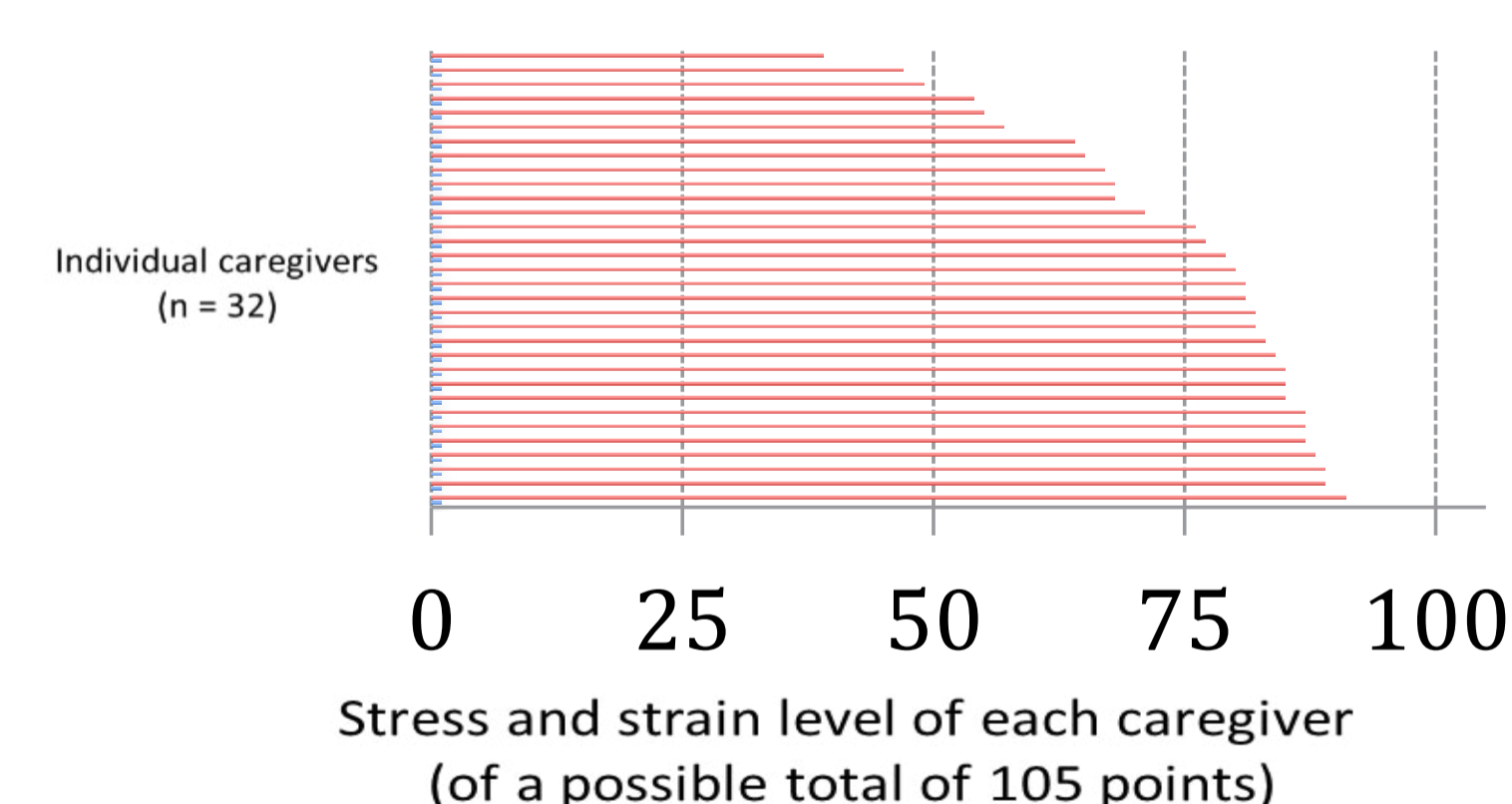


Figure 1: Stress level (0-100).

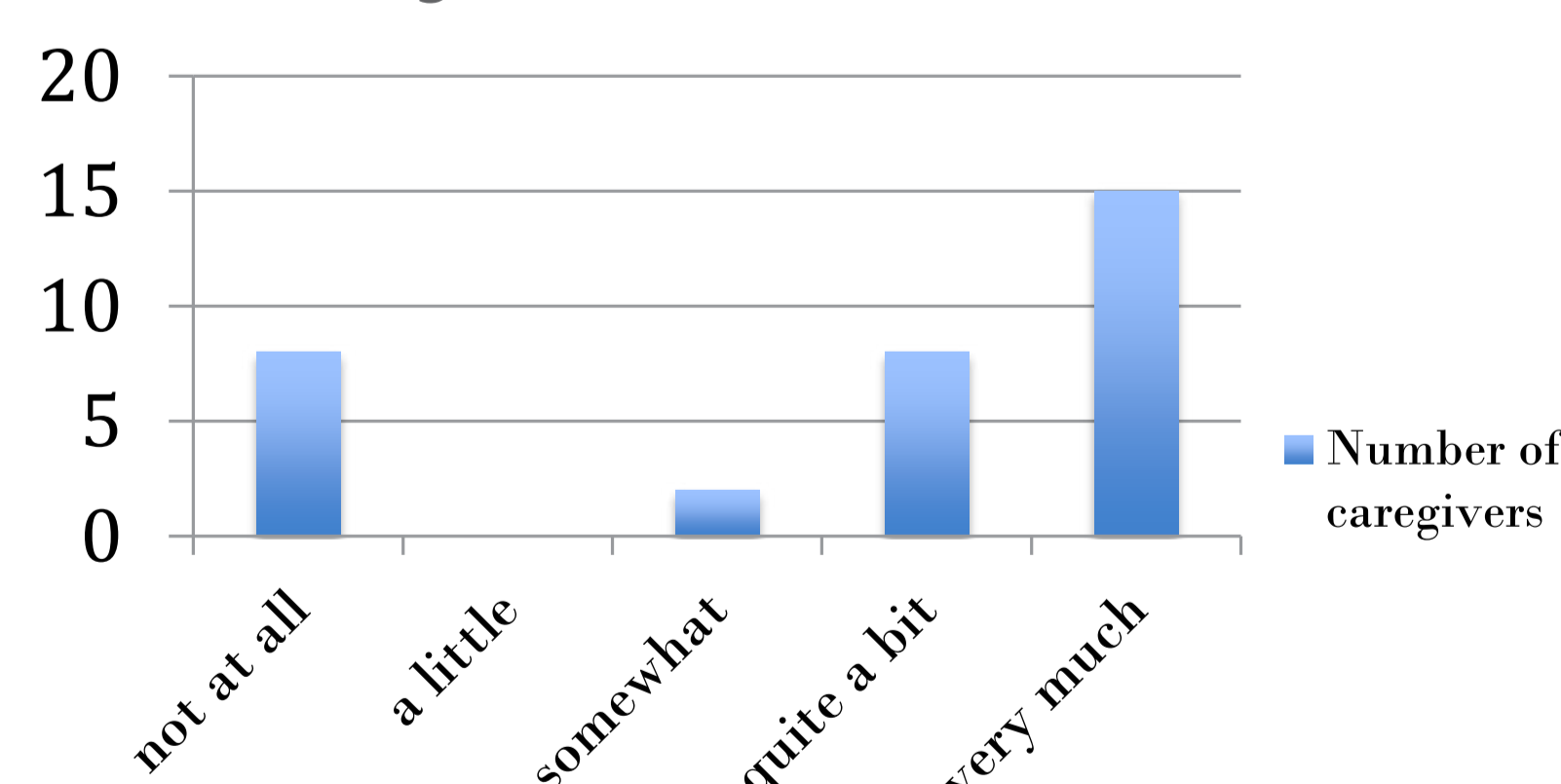


Figure 2: Feelings of Isolation by caregivers

Low follow up rates and no home visits by CHVs

"The problem is, that Kenyatta hospital charges for the services. The only thing that we can get is physiotherapy, but at this time, my child does not go for physiotherapy, as my husband does no longer provide [for the family]. I have not been to the clinic [with Tony] for three years. So I also cannot get medicine from the chemists, because they ask for the latest prescription. And the child now also has convulsions, and for me to know when to give the medicine - I don't know... I came long ago to Amref and I have never seen any health worker where I stay" (Carmen, 35 yrs, with Tom, 9 yrs; Kibera)

High Levels of Stigmatisation

"It was when Jenny was 10 months old that her condition changed, and when the condition changed, we were admitted for three months to the hospital. The family used to come and see us, but when they realized that the child's condition had changed, I did not see any of them

anymore after that and even my husband left me. I have no one that assists me at all... At this time I cannot do much, and because Jenny is also heavy, I mostly lock her up in the house so that at least I can do something. I have no one to look after the children and even if I tell the neighbors to look after the child, the neighbors laugh and say that they are not ready to touch the child. And because where I work, there is dust, I rarely go with her. The neighbors know the problem Jenny has, but they say that she has become disabled because she has been left by the father." (Ella, 43 years with Jenny, 8 years; Kibera)

SUMMARY OF FINDINGS

- Caregivers of children with disabilities in both communities suffer from high stress levels
- Most caregivers have feelings of guilt and a feeling that it is their fault that their child has a disability
- Many caregivers are too shy to ask the doctors question about their child's conditions
- Many caregivers reported a low awareness on disability issues in the community and on the medical origin of disabilities
- Many caregivers reported that other community members think disability is contagious
- Many of the children with disabilities are not in school
- Some, but not all of the caregivers received good social support from their families and from the communities

"There are so many people here with children with the same condition and this gives me the urge to still have my child since we share a lot with these parent. So what we did was to form a group and that is when I knew that I am not alone and I said to myself that I better stay with him because then God is with me." - **Mother of a child with a disability, Kibera**

"If the child can be in the same school as others, then that can be comfortable to the child. I can be comfortable if the child is in school." - **Mother of a child with a disability, Kasieku, Makueni**
"At first I withdrew myself from the community but later I accepted, and so nowadays I am with them. I received counselling whenever I took the child to physiotherapy." - **Mother of a child with a disability, Kibera**

"Some people in the community see disability as a communicable disease that can be caught by their children." - **Mother of a child with a disability, Kibera**

"The neighbors normally think that their children can also be disabled when their children join mine to play together." - **Mother of a child with a disability, Kibera**

TAKE AWAY POINTS

Disability is a medical condition

- Disabilities are medical conditions
- There are a large number of factors that contribute to disabilities, ranging from malnutrition, to birth complications, diseases and accidents that can cause disability
- Disability is NOT contagious
- Disability is NOT a course or divine punishment

Healthcare & Physiotherapy

- Each child is entitled to healthcare
- Encourage the caregivers to do regular physiotherapy exercises with the children at home can help improve or stabilize the child's condition
- Encourage caregivers to ask doctors and nurses questions until they fully understand their child's conditions and how they can support their child best.
- Empower caregivers to attend counseling and self-support groups to ease their stress and feelings of guilt

Education and School

- Encourage caregivers to send their child to school
- Encourage caregivers to let their children play with other children
- Encourage local teachers to accept children with disabilities in school

AWAY FORWARD

For CHEWs & CHVs

- Awareness raising in the community
- Child-centred healthcare delivery
- Talk to teachers

For Caregivers

- Ask all healthcare workers questions
- Create self-support groups
- Talk about stress

ACKNOWLEDGEMENT

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