



AFRICA NCDs NETWORK

FOCUS GROUP DISCUSSION MINUTES

CAMEROUN – LITTORAL REGION

By ONGLA DIANE PASCALINE

National coordinator Value HealthAfrica

ANN AdvisoryMember

25/10/2022

MINUTES OF THE FOCUS DISCUSSION GROUP ON NCDs on 25/10/22

ATTENDANCE LIST

Presentation of Focus Group The meeting started at 10:30am with an introduction from Ongla Diane Pascaline ANN Advisory member with 12 members in attendance.

Twelve (12) PLWNCDS attend to the group discussion manage by

| Name and Surname | NCDs | Contacts |
|-------------------------------------|---|-----------|
| Lissouk Francine | Eyes Cyst | 671522031 |
| Ongla Diane Pascaline | Diabetic | 651249158 |
| Kwedi Mulema | Hypertension | 690954365 |
| Ngoula Sorel | Neurofibromatosis | 695281164 |
| Ngoula Sorel (representing her kid) | Kid with Ontogenesis imperfect | 695281164 |
| Nkot Bossomo Sorelle Patricia | Lupus and Kidney | 698539933 |
| Akoh Bernice | Diabetic | 674880106 |
| Mokube Cecilia | Spasmophilia and Hypertension | 674950014 |
| Mireille Nyom | Care taker of diabetic patient | 691762240 |
| Nsoh Sebastien ade | Care taker of diabetic patient | 671023268 |
| Mokam FOKO (live with desability) | Care taker of diabetic patient | 674751860 |
| Mengue Pascale Audrey | Care taker of Hypertension patient | 690478161 |
| Ongla Fils regis | Car take or hypertention and diabetic patient | 655806785 |
| Angeline Evina Bella | Mental Health (depression) | 679395811 |



1. How do people living with your disease or condition define themselves?

❖ *How (if at all) is your illness or condition part of your identity?*

Cecilia: Yes, before it was a problem for me, now nothing scared me.

Sorel Nkot: The disease is leaving, and I don't even consider myself as such anymore because it becomes a routine.

The rest of the group goes in the same direction

❖ *How has your health changed you? What did you learn?*

Ngoula Sorel: Today I am more determined and nothing prevents me from reaching my goals. I always get to the end of things.

Sorel NKOT: I Dialogue, I talk about is more around me when I have the opportunity.

Cecilia: I am doing more research to better understand my condition. I support anyone who is in the same situation as me.

Mireille: This is my first time to be part of a discussion group where we talk about health. I never realized my summer. There I would be more careful while doing my screenings.

Audrey: Taking care of my mother is not easy. I would like to better understand this disease given that the rest of the group thinks she's learned to trust only herself,

❖ *Which words do you prefer to describe yourself and why? (i.e., patient/survivor/person living with your disease or condition/ other)*

Some members consider themselves survivors because they have survived a lot of drama in their lives and have come to terms with the disease.

Sorel Nkot suffering from lupus prefers to define herself as an immortal because despite the multiple crises she is still alive and intends to remain so.

Kwedi Considers himself to be in a rather low spirit and tries to overcome his illness every day.

❖ *Would you describe yourself as a "patient"?*

Answer to this question is **NO** for everyone.

❖ *Are there any words that you object to being used and if so, why?*

- Sick because it makes us weak
- Disabled because we believe in our ability to overcome our situation
- Depressive because our state is not inevitable, we have to live with it.

What recommendations for improvement would you give to those planning environments that promote and protect health and trying to reduce people's exposure to risk factors?

Policy makers should create laws that better protect PLWNCDS in the workplace

Organize listening cells to better understand their disease or the disease of their loved ones.

Organize more free awareness campaigns for rare diseases, the costs of which are very expensive.

Train hospital staff to better support care givers.

2. What are the main challenges you and others living with your disease or condition, experience with regards to treatment, care and support?

Audrey: My mother's condition is complicated and today if she has a crisis I cannot apply first aid and at the hospital I received no support or awareness. Dieting is a problem and treatment is expensive

Cecilia: Rejection from the family; for them I became unbearable having fits of spasmodophilia every time. And for that I became a burden because I had lost my job. Some considered that I was possessed and I was having fits of madness.

Ngoula: My instructor felt that I did not have the ability to work because I was both disabled and sick. For my son it was also very complicated because the treatment was very expensive, we had to get together with other parents with children in the same situation to contribute in order to reduce costs.

Christine: I was completely chased out of a big local hospital because the caregivers felt that because I was in a wheelchair I couldn't take care of my mother who was in the midst of a diabetes crisis. We were sent home.

Sorelle Nkot and kwedi: Financial problems; and also the none availability of drugs

❖ *Do you feel respected by your healthcare service providers: doctors, nurses, community health workers, etc.?*

YES AND NO

YES: Majority feel respected by the doctors who welcome them very well and take time to listen to them and accompany them.

NO: The nurses are full of themselves and don't respect us. Sometimes some don't understand us

❖ *What kind of experiences have you had with care partners throughout the duration of your illness?*

For the sick: sometimes feel like a burden because it is not easy

For care takers: sometimes we want to give up but we hold on because going to the hospital every time is not easy and when we don't have financial support we also exhaust ourselves morally

- ❖ *Have you ever experienced challenges with the healthcare system in accessing affordable early diagnosis and treatment, in accessing psychosocial care, palliative care, or in accessing information and education about managing your disease or condition? If so, what was the challenge and how was it resolved?*

SorelleNkot: a great misunderstanding with caregivers, care and treatment are very expensive especially for us who do dialysis every week.

Kwedi: we don't often have the opportunity to be uplifted by community health workers. For us hypertensive people what are the first aid actions when we are in crisis?

Francine: I would have needed psychological support because after six eye operations it's not easy to have self-confidence.

Ngoula: my son does not follow the treatment regularly because it is extremely expensive. But today the solution found was proposed by the pediatrician who follows him. All the patients must meet on the same day for the treatment to be administered to the children, so we contribute so that the costs are divided by five.

According to the participants in the discussion there is nothing new. It should have more support and above all subsidies because some died because of lack of means.

- ❖ *What recommendations for improvement would you give to those planning treatment, care and support services?*

- Have a subsidized psychological support program for depressed patients
- Find a way to subsidize the most expensive treatments
- For people with diabetes, why not create a dietary monitoring solution?
- It takes sensitization on TV even for a minute during prime time programs
- The government must set up a listening cell for anonymous patients.

3. Prevention or reducing risk is an important area of addressing (insert disease or condition) other NCDs. How easy would you say it is for people in your local community to lead healthy lives?

- ❖ *Is it easy to exercise? Is it easy to have a healthy diet? Is it easy not to become a smoker? Is alcohol readily available?*

Cecilia: for acute spasmophilia. It take a complete Change of lifestyle. Healthy food and especially sport. For me it is thanks to sport that I was able to control my spasms. I make the effort to walk long distances. Avoid stress and get away from a toxic environment.

Ngoula: *I suffer from neurofibromatosis* and I advise to reduce stress and above all to let go. Today teasing no longer has an effect on me because the slightest stress is a source of crisis. So I enjoy every day.

Francine: The Dialogue. Avoid keeping everything for yourself because by repressing everything you get depressed without realizing it and you develop another illness. For people suffering from ocular cyst we need permanent control and above all experts.

Christelle: *My mother suffers from diabetes* and the main issues are feeding and processing. We should have a guide to know how, what, and when she should eat, especially how to administer her medication. I, a person with disability and alone, should have benefited from assistance.

To this question the most recurrent answers concern food. It is not easy to have access to healthy food because we take everything that passes through our mouths. Today food such as vegetables, fruits has seen a rise in prices so given the financial situation patients tend to go for what is cheaper and which is not always healthy.

With regard to the cigarette nobody smokes.

Alcohol it is easily accessible. Some drink but do so in moderation because sometimes they want to have fun.

❖ *What types of information and educational campaigns about healthy living are available in your community? About your disease or condition?*

The answer to this question for all is: **NO**. Not even on TV or in the hospital or in our neighborhood.

❖ *What role do you think people living with your disease or condition or other noncommunicable diseases can play to help ensure environments that promote and protect health?*

- Raising awareness in our various communities (neighborhood, associations and young women gathering)
- Invite doctors to create dialogue cells of PLWNCDs at least once a month
- Talk about it in schools, universities so that the sooner they know the sooner they are warned
- Get involved and also invite other patients to get involved in decision making in order to change things in their communities

❖ *What are the other social, economic or environmental challenges or risk factors in your community or environment that negatively influence people's health?*

Audrey: stigma and rejection

Cecilia: teasing, insults, abandonment by relatives

Francine and Kwedi: lack of means, no stable job.

Sebastian: too much noise due to the high number of snack bars where we live

Mireille: Today I filed a complaint against my neighbor for defamation. She spread false information about my health situation. Humiliation doesn't help.

❖ *What are the other social, economic, or environmental challenges or risk factors in your community or environment that negatively influence people's health?*

- Listening to sick people and supporting them in their care
- Create a law against companies that stigmatize and discriminate against people with NCDs
- The government should set up a toll-free number
- The government must require certain restaurant owners or open spaces to create non-smoking areas
- Raise taxes on cigarettes and alcohol

4. How (if at all) have you experienced discrimination or stigma in your community, workplace or health care system because of your disease or condition?

- ❖ *How has living with your disease or condition impacted on your employment/financial/insurance/social/relationships/ psychological status?*

Christine: nobody respects me because of my state of being handicap and they underestimate my ability to take care of my mother which in most cases I am sent back without being received

Cecilia: I was fired because my boss thought I had a lot of anxiety attacks; my family attributed my state of *spasmophilia* to witchcraft and turned their backs on me. I had to learn to fend for myself; at the hospital they took a long time to give me clear diagnosis.

Ngoula: my friends refused to go out with me I was a source of shame. As a nurse I had difficulties fitting in or obtaining an internship opportunities. I lost an educational year, I could not go to school because one of the side effects of my treatment was appearing during menstruation.

Mireille: I have not suffered particularly but in my community I have been a victim of defamation on my state of health.

Akko: I have never been a victim and hope never to be

- ❖ *Have you ever felt like you were not able to manage your condition or had access to care because of who you are, where you live, or how much money you have?*

YES AND NO

YES: Financial difficulties prevent us from managing the disease. Without money we cannot follow our treatment or go to the hospital to keep our appointments.

NO: access to the hospital is easy by means of transportation .we live at the heart of the city.

- ❖ *What would you say are the biggest challenges that people living with your disease or condition face in terms of stigma and discrimination?*

Cecilia: The employment problem. it is difficult to have a stable job or to keep the one we already have because of the crises we are facing.

Sorel: No friends, no serious relationship, everyone around us moves away from me. I'm lucky my mother supports me a lot.

Audrey: we face the situation alone since no one helps us.

Francine: I lost a lot of contracts because my eye was always swollen. Many people don't know about the eye cyst many think it's a witchcraft story.

- ❖ *What recommendations would you give to governments and society to address, confront and mitigate discrimination and stigma, and to protect the human rights of those living with the disease you have or condition?*

Enforce the laws already in place according to Kwedi. I am disabled and hypertensive I have my disability card I should benefit from a reduction rate at the hospital. But when I present my card no one takes my situation into account. I actually feel that, this should change.

The government must put in place texts that protect private and public employees against discrimination in the workplace or in schools. Same in healthcenters.

5. How would you like to be involved and play an active part in helping address your disease or condition and other Non Communicable Diseases?

- ❖ *Do you think that people living with different NCDs, e.g. cancer, diabetes, cancer, cardiovascular disease, chronic respiratory disease, etc. face similar challenges and should come together to improve their rights as a group?*

Sebastian: yes as everyone said before, we need to impact a lot of people and for that we will have to set up a group that can grow.

The rest of the group agreed with Sebastian and wanted more meetings at the community level.

- ❖ *What are some concrete and different ways people living with your disease or condition have been successfully empowered?*

Sorelle Nkot: I am part of a group of people with lupus

Cecilia: my phone is open to listen to people who have the same pathologies as me. Case of a depressed young woman who tried to commit suicide

Recommendations

What would you need in order to play a more active part to reduce the impact of your (condition/disease/other NCDs) in your community?

- stronger community organizations
- Networks of people with NCDs
- Opportunities to speak up and share experience (Social Media, Tv)
- Be educated and available and build our capacity to be able to face situations
- Break out of groups
- Talk in the media
- Discussion in our communities
- Be more include in such project
- Financial assistance

PICTURES OF THE FOCUS DISCUSSION GROUP





