EVD SURVIVORS´ AND AFFECTED FAMILIES´REPORT
EXECUTIVE SUMMARY
KOINADUGU DISTRICT. SEPTEMBER 2015

Koinadugu DERC Psychosocial Pillar

Médicos del Mundo

DfiD – UK AID

Timeframe and location

The assessment has been launched on 23 of July with approval of the Psychosocial Pillar in Koinadugu. The interviews were carried out by the MDM team in the period of 27 July - 31 August 2015. Data entry began by 17 of August and followed by data analysis between 20 of August to 18 September 2015. Final reporting has been prepared from 14 to 24 of September 2015.

Due to the distribution of the survivors and affected families, the operation of the survey has been principally limited to the territory of Nieni Chiefdom.

Among the interviewed survivors the biggest number originates from Kumala (31% - 13 persons), Yoria (10% - 4 persons), Farekoro (10% - 4 persons), Bandakoro (10% - 4 persons), Kendaya (7% - 3 persons), and Sumbaria (5% - 2 persons).

Similarly the biggest percentage of caretakers interviewed comes from Kumala (43% - 45 persons), and Yoria (19% - 20 persons). There is also considerable concentration of the interviewed persons in Fankoya (10% - 10 persons), Funubakura (9% - 9 persons), Kendaya (6% - 6 persons) and Sumbaria (5% - 5 persons).

The objective of the EVD Survivors' and Families´ assessment:

- Assess in general the situation of the survivors few months after their discharge and the situation of the families after the passing away of their EVD-positive family member.
- Have a specific follow up on their psychosocial well-being
- Have a specific follow up on their medical condition
- Assess in general their living conditions in terms of community reintegration (including access to water and sanitation and livelihoods)
- Follow up and evaluation on activities they benefited from (ETC treatment, Disinfection of houses, PSS follow up, NFI kits)

MAIN CONCLUSIONS AND RECOMMENDATIONS

General situation of Survivors and the affected families

Numerous female-led households, significant number of widows and widowers among both survivors and caretakers. There are 46% of females heads of the households among survivors and 73% among caretakers. Not only widows of orphans are being affected by the impact of the outbreak: those that lost their siblings, children, co-wives, are often tremendously overburdened by responsibilities they have to face providing for basic needs of increased number of family members.

Psychosocial Wellbeing

Kessler scale shows that there is comparable percentage among survivors and caretakers who are seemingly coping with their stress, yet visible difference between the levels of high distress[1]: families are exposed to more critical amount of stress and the affected individuals are more at risk of developing psychological problems and should require more specialized attention from social and psychosocial workers.

Stress and struggle caused mainly by the burden of taking care of numerous family members, limited or inexistent resources to provide for their basic needs (food security scarce repeatedly in about 10-15%).

Coping

Positive thoughts, encouragement, hope, prayer and actions like listening to the music, gardening, interacting with friends and family, talking to the chief, were referred to as main coping strategies among the survivors.

Similarly caretakers indicated overwhelmingly encouragement, interactions with family and friends, faith. Among family members interactions with children were highly valued, mentioned by 23% of the respondents.

14% of affected families indicated thinking about having food to eat/food for my children as the most comforting thought.

The coincidence between the survivors and the affected families demonstrates that the type of assistance valued is often the social support: encouragement from family (33% survivors and 50% of affected families), practical help: looking after children, help in farm work, provision of shelter. Highly (but not the highest) note has been financial help (12% survivors and 2% of affected families) and supplies including food (35% of affected families). The category that appeared in both groups “eating together” 10% survivors and 4% affected families also indicates subtle yet strong relevance of social interactions at the family level.

[1] 2% for survivors and 10% for caretakers of affected families for overall Kessler scale score; 13% for survivors and 20% for caretakers in item “in last 30 days did you feel everything was an effort” with an answer “all of the time”

7% of the interviewed caretakers indicates receiving no support from either family or community.

Family losses

90% of survivors have also lost family members during the outbreak, on average with 4 family members perished, compared to 3 family members for the caretakers.
Loss felt more intensely as they families in 75% of the cases lost the breadwinner causing not only emotional pain but a serious immediate concern about their livelihoods situation.
Majority of patients died in Kumala Holding Center but 19% is accounted to have died at home with the family.

The mourning process has been interrupted by lack of possibility to perform the rituals, ceremonies as per customs due to safe burial measures, the families and communities were unable to participate, it was not considered respectful, family members couldn´t either see the body before the burial nor identified the grave, place where their loved one was rested.

Quarantine period posed a distress and concern for the affected families mainly due to food shortages - 42%. In majority of cases community reacted with encouragement and support 47%, distancing socially because of fear (11%) or imposed restrictions (17%), only in few cases affected perceived no help (4%) or rejections and stigma (4%) from their community.

Community Reintegration

71% of survivors and 81% of caretakers responded that they are allowed to participate in community activities. Those that responded negatively quoted mostly their age (too young or old, not strong enough to participate in work) or health status (not fully recovered). In majority of cases there was initial intense reaction form the community, sense of rejection due to fear of infection, that later subsided and permitted resuming normal social interactions.

29% of survivors felt stigmatized and rejected, 26% of caretakers felt stigmatized at least in the beginning, with 13% still feeling that they are being exposed to stigma.
The form of rejection for both groups – survivors that were EVD positive and caretakers that were never sick, only affected by the death of their loved ones, remains alike: people pointing fingers at them, rejecting them from participation in activities, unwilling to do business with them, excluding them from interactions, quoting as the main reason that they (survivors and caretakers or their family members) have “Ebola in their blood”, “can spread the virus”.

For 12% of the survivors (majority of those indicating being exposed to stigma) it affects their access to health because health workers are either afraid or unwilling to attend to them.

Situation of children

For 78% of children survivors loss of their family member has been the biggest impact of EVD. For the children from the affected families the lost sense of security is related to the death of their loved one, in most cases main caregiver.
There are 2 child-led households, looking after their siblings.

17% of the interviewed children were relocated after the death of their parents or caretakers, where over the half has been separated from their siblings because new caretaker was unable to take in all the children together due to the financial constraints.

Schooling

Education is the biggest worry and priority for parents and children. In the area where education is scares and illiteracy levels are extremely high (76% of survivors and 93% of caretakers declare having no education, in majority illiterate), remarkable 83% of children of survivors and 93% of children in affected families are going to school. For those that are not being schooled, the main reason quoted is the financial constraint. In some families not all the children are being educated or had to change the school given the lack of funds.

Reintegration at the school level progresses well both with peers and teachers, only with small amount of incidents related to stigma.

General living conditions, water and sanitation, livelihoods

Main livelihood activity for survivors and affected families is farming. Presently the number of professionally active adults is decreasing: among survivors due to deteriorated health status and inability to do hard work: from 67% before the outbreak to 49% presently dedicating themselves to farming.

Increased amount of survivors that have no income generating activity: from 9% before to 30% presently.

Among the caretakers, the impact was mainly the loss of their capital and forced to withdraw from their business and petty trade activities and revert to farming. There is also increase of percentage of caretakers that have no income generating activity: from 6% before to 13% now.

The main water source for majority of the interviewed is the stream (bigger number of interviewed survivors compared to the caretakers), the main towns affected being Kumala, Farekoro, Kaindaya, Bandakoro and Sumbaria.

Majority of survivors (88%) and the affected families (63%) do not treat their water.

The 79% of survivors and 86% of affected families use latrines yet highlight the need for their maintenance or repairs. Lack iof latrines was enlisted in Kumala (66%) and Sumbaria (33%).

Follow up and evaluation of the assistance interventions

The food has been undoubtedly cited as the most useful and praised assistance provided by both survivors (43%) and caretakers (49%), followed by NFIs (21% and 10% respectively).

The assistance indicated as still outstanding is money (47% of survivors and 27% of caretakers) to either cover the basic needs or education for their children. Microcredit, start up money to be able to launch the business was indicated by 21% of survivors and 10% of caretakers.

21% of survivors and caretakers have equally values pertinence of further food assistance, whereas clothing has been cited by 14% of survivors and 19% of affected families.

Housing was highlighted as urgent need for 21% of survivors.

Medical

Majority of the survivors still presents some physical ailments, mainly cited frequent headaches (55%), severe joint pain requiring painkillers (52%), joint discomfort (43%), and tiredness (36%). In overwhelming majority the identified symptoms remain without any treatment.
There are 3 pregnant survivors and 2 pregnant wives of the survivors.

Desinfection has been carried out in most of the cases, except 12% where the main reasons cited for lack of disinfection was because the infected survivors were living alone.

Access to health remains a challenge for survivors and to lesser extent for affected families. Survivors indicate there is still considerable level of hesitation or fear in attending to their health problems. Other reasons indicated were lack of money, distance and lack of trained staff. Interestingly, 17% of affected families didn't want to go to PHU indicating fear of infection with Ebola.
Majority of survivors (74%) declared they were not using the PHU in the months after the discharge compared to 45% of affected families that did not access the health facilities.

SENSITIZATION

In selected communities there will be need for **further sensitization** and work at the community level to facilitate reintegration and social inclusion of the survivors and EVD affected families.

In majority schools the reintegration is ongoing. Sensitization at the school level has a positive impact and reaching out and support offered from the teachers is highly appreciated by the pupils, especially those bereaved.

Psychoeducation at the school level should be encouraged to ensure good level of understanding of EVD risks and eliminate misunderstandings prejudices and misconceptions that are still present.
There is still a level of fear from and towards PHU staff that would require additional sensitization and training on specific needs (medical and psychosocial) in post Ebola context as well as community education to encourage patients to frequent the health posts.

EVD RESPONSE

Burial process: Attention to the burial issues should be reconsidered permitting more degree of observation for the traditions without infringing the necessary safe burial measures. Considerable potential role for the burial team.

Attempt to bring the closure for the bereaved: Symbolic ceremonies and rituals may be considered at the community level for the following few months during the 1 year anniversary of the outbreak, combined with the closure of the Kumala Holding Center in November 2015.

Loss of the loved ones: Emotional reactions (depression, sadness, hopelessness, anxiety, social withdrawal etc) are in line with the normal emotional response to the loss. It is important to mention that majority of cases what stands out that the grieving process tends to be overshadowed by the worries about covering the basic needs.

Supplies during the quarantine: More cited as the source of stress is the shortage of food or lack of security related to income, livelihood, education perspectives than the one directly linked to the loss of a parent or family member.

Loss of support and security, before connecting with the grief: the respondents, both adult caregivers and orphaned children overwhelmingly express concerns about how to get food, how to feed the family members, worrying about their future and survival.

The quarantine has been a challenging experience for most of the affected families, particularly difficult because of lack of adequate supplies. Shortage of food and water, apart from posing a threat to physical health, has a significant impact on the psychological wellbeing of the affected population, creating even more perception of despair and social abandonment compared to those that have their basic needs met.

Social distancing, lack of freedom of movement has a relevant impact on the affected persons and the measures should be taken to mitigate it (provision of supplies, medication, social contacts observing IPC measures). Expressions of support tend to have tremendous impact on the affected persons and are easily elicited if proper sensitisation is done

Distancing based on fear could be mitigated (hence import perception of the community inclusion by the affected) if proper education and sensitisation is carried out with consideration for local customs, language and context

Acts of stigma and rejection stem mainly from ignorance and misconceptions about Ebola (ie. hostility towards families of deceased patients because “they have virus in their blood”). The adequate work at the community level fostering interactions between EVD affected families and the rest of the community should assist in bridging the gaps.

In cases of blame and security, mediation should be introduced using the local community structures and engagement of relevant persons of influence.

Involvement of authority figures is essential because of their high influence and level of conformism in regard to their directives.

FOOD SECURITY AND LIVELIHOODS

74% of the caretakers of the affected families indicate that their households have **lost the breadwinner**. The disruption of the livelihoods, financial problems, disrupted farming during the outbreak were mostly cited by respondents as the main impact of the EVD on their lives, along with loss of lives of the loved ones.

Majority of the respondents **suffered multiple losses**, including 90% of survivors losing a family member during Ebola outbreak, making the adjustments in the communities much more difficult.

There is an urgent need to consider systemic addressing the basic needs at the community level, especially the food security and sustainability of the livelihoods, supporting the entrepreneurship of the individuals and facilitating becoming in charge of their economic situation.

Main type of assistance declared as needed by the respondents: financial assistance: microcredit, start-up capital for business, petty trading, seeds for farming, food items, shelter assistance, financial assistance or scholarships for children´s education.

Water treatment: the locations with limited access to water are **Kumala, Farekoro, Kaindaya, Bandakoro and Sumbaria where people use stream as the source of water.** The 88% of the interviewed do not treat the water. The rest of 12% treat water, more specifically by chlorine (75%), and the rest (25%) boils the water.

REINTEGRATION OF EBOLA SURVIVORS AND EVD AFFECTED FAMILIES

Majority of the interviewed individuals reported **encouraging reaction**s and support from the community, appreciated the support offered both in terms of addressing basic needs of those under quarantine, as well as social interactions. However, 29% of the survivors (12 responses) and 13% persons from the affected families were exposed to **stigma**, rejection of mistreatment from their community members, including 7% that faced security concerns. The hostility from members of community was mainly based on fear of infection and misconceptions on the risks. More sensitization and education, particularly in the communities where problem is more prevalent should be considered.

There is relevant problem related to **health access for the survivors** that have difficulty in being attended by medical staff that refuses to attend them, apparently due to continuous fear of infection.
In counterbalancing the effects of stigma, misinformation and concerns against the EVD affected persons, it is crucial to involve local authorities: town chiefs, mammy queens, youth leaders, as the most influential sources of information for the communities.19% of survivors suggests that

stigma they experience is related to their access to health.

More intentional effort to accompany the discharged person and assist them in their reintegration with his community after leaving ETC should be considered.

STRENGTHENING COPING AND RESILIENCE

The study shows that overall the survivors and caretakers are coping with the situation, though most of their **stress stems from concern about livelihoods** and catering to the basic needs of the persons they are responsible for. Majority of the interviewed persons demonstrated good capacity to face the challenges and they manage to cope with a impressive strength and resilience. The attention should be placed on the individuals that are more overburdened or perceive much less social support.

The **actions from the community** level (social interactions, attention, expression of sympathy and interest, practical neighborly help) should be strengthened to **optimize the sense of social support**.

It also highlights the **need for more attention for the individuals that sense lack of support** from their networks. The cordiality from community, sympathy shown, sign of interest, interaction no matter how limited, with family and community members, **sense of community protection** and care have been strongly appreciated and had important impact on the **perception of community support** and reintegration of the affected individuals and families.

The **sense of connectedness** as the protective factor while confronting adversities and difficult life situations converges as well with the feeling of gratitude. Interestingly in the survey 12% of the interviewed survivors and 10% of the affected families have expressed in the unsolicited manner the sense of gratefulness towards their community and family members for the assistance provided.

VULNERABLE CASES

Particular attention should be drawn to **vulnerable cases** and those **overwhelmed** with the burden of current responsibilities: single parents, child-headed households, widows, elderly, as well as those caring for children of late siblings or kids that are disproportionately overburdened due to multiple simultaneous losses within families.

Critical element to the addressing **needs of children in affected families** is ensuring the adequate means are available for the household: the overwhelmed caregivers often are not able to cater to most basic needs: i.e the number of persons to feed outnumbers the quantity of food available. It is important to note that children demonstrate high level of awareness of household problems and critical state of affairs, sharing the anxieties of the overstretched caregivers.

Special attention should be offered to the **child-led households** to facilitate identifying the most conducive solution and avoiding overburdening the minor with the responsibilities beyond their strength.

EDUCATION

More **support to access education for school-going age children** in the communities affected by Ebola, including the bereaved families and survivors. The additional assistance for schooling of the children is strongly advisable, taking into consideration its positive impact on their general wellbeing, stimulation of reestablishing the familiar routines and reconnection with the existing support network and peers.

In terms of addressing basic needs the **school feeding** plays a critical role and should be encouraged and if possible extended to community schools that till now are not covered. Its impact to the wellbeing of the children and alleviation to their families should not be overlooked.

Assistance needed in terms of **scholarships and financial assistance** that can be destined to support education should be encouraged.

Assistance with NFIs and school material strongly recommended as it is being cited as one of the immediate worries of the affected kids.

HEALTH SERVICES

Comments from the caretakers of affected families regarding fear of getting infected of Ebola at the PHU may possibly reflect overall reservation in the community towards usage of health facilities after Ebola outbreak. Need for further health promotion and encouragement for resuming access to health facilities in the communities.

Majority of **EVD survivors suffer from some post-Ebola complications** yet only small fraction of them is receiving treatment for their ailments (joint pains, eye problems, loss of strength, etc). There is a need for more **specialised medical assistance to EVD survivors** in Koinadugu, and establishing point of access closer to their communities would help them overcome the challenge of access to the Survivors Clinic in Makeni. Based on the recommendations provided by the survivors the location suggested by majority is Kumala.

Need to address the issue of **lack of adequate treatment for the survivors at the PHU level**. There is still relevant level of fear, bias, misconception and lack of knowledge on the part of PHU staff that can be overcome. The special medical needs of the Ebola survivors should be addressed and adequate information and training should be provided to PHU staff with the factual medical information and knowledge on how to assist

Need to adequately **diagnose and provide necessary treatment for the EVD survivors** in Koinadugu district, facilitating their access to the specialized health check overcoming transport challenge

Need **to reinforce capacities of Health services at Kumala level** to be able to serve to more complicated cases in view of inaccessibility of Kabala hospital for majority of population in Nieni due to the distance and unaffordable transport costs.

In regard to **pregnant wives of the EVD survivors** or pregnant female survivors, the adequate sensitisation and education regarding necessary safety measures (ie. delivery at ETC, when required) should be provided in adequate manner with proper accompaniment and support organised avoid stigma, anxiety and misunderstandings. The provisions should be put in place to ensure that the families do not have to cover the burden of travel costs by themselves, as it remains beyond their capacity and would be likely the principal reason for which they may ignore the recommendation.

Additional **training and sensitization should be provided to hospital and PHU staff** in the areas that offer health services to survivors to increase the awareness about the virus, what type of safety measures are necessary and types of risk, if any attention to survivors could pose.
Relevant trainings should be provided to the PHU teams, including midwives in regard to attendance to pregnant wives of survivors considering potential risks and precautions to be applied.