

Evaluation of Ebola response – Uganda

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Executive summary

In recent months Uganda has experienced three separate Viral Hemorrhagic Fever (VHF) outbreaks. Two Ebola outbreaks in the districts of Kibaale and Luwero and one Marburg event in Kabaale. URCS responded in all three cases with assistance from the IFRC Disaster Relief Emergency Fund (DREF) and aimed to support clinical interventions from the Ministry of Health (MoH) and Medicins Sans Frontiers (MSF). In order to fully explore the value added of Psychosocial Support (PSS) and community based volunteers in this type of epidemic response, the unique opportunity of these outbreaks was utilized to document and learn from.

Three independent evaluators representing Disaster Management, Health and Psychosocial support were sent to the affected areas in February of 2013 to gather lessons learned of the response. The main aim of this assessment was to evaluate the PSS response of URCS to these VHF, against the needs of beneficiaries and communities focused on the areas of most 'added value' of the URCS; community engagement mobilisation and support, documenting any unintended outcomes and best practice related to the operation. A field study was conducted by visiting two of the branches involved in the Ebola response, Kibaale and Luwero branch as well as various partners. Due to time constraints the assessment did not cover the Marburg response in Kabale. Qualitative interviews and focus group discussions (FGD) were used to gather the data with key stakeholders, volunteers and partners (see Appendix 1). Language of the interviews and FGD was English with no obvious problems. Half a day was spent with each branch.

To reach the overall aim of the evaluation the following questions were answered:

1. What is the value added of PSS in this type of epidemic response and what should be the RCRC role in providing this?

PSS programming aims to support interventions that facilitate support and enhance recovery from critical experiences such as emergencies and disasters. Psychosocial support does not pathologize people who are stressed by extraordinary events. Rather, it assumes that those who are stressed are competent and are able to determine whether or not they wish or need assistanceⁱ. There is plenty of evidence already that shows that psychosocial support programs increase the well-being and facilitate recovery from disasters^{ii iii}, however there is hardly any information about the role of PSS in epidemic response. The unique element of epidemics is the fear and stigma often associated with those that are infected. Because PSS is a key element in fear reduction and management of stigmatization, national societies or in this case URCS, should have a key role in training volunteers, staff and even partners in PSS and advocate the role of PSS in the design of Behavioural Change Communication - BCC. Ebola brings with it, significant amounts of fear and stigma driven by the communities' belief that the outbreaks are often due to witchcraft and wrongdoing by the victims and effected families. Fear reduction and minimizing stigma is important because stigma has a well-known negative effect on the mental health of beneficiaries as well as disease prevention and control^{iv v vi vii}. Thus, PSS can act as a crucial element into the health response by focusing on trust building, calming and motivational messaging.

Ebola viruses are highly infectious as well as contagious and can have a Case Fatality Rate (CFR) of up to 90%. The most straightforward prevention method during outbreaks is to avoid direct (skin-to-skin) contact with patients, their excretions and body fluids, or possibly contaminated materials and utensils.

The best models of pandemics highlight the powerful influence of fear and stigma in the management of infectious disease emergencies. Analogous models based on recent epidemics such as severe acute respiratory syndrome (SARS) illustrate the role of stigma in the delayed and disproportionate responses by affected populations and institutions. By extension of these lessons to infectious diseases in general, stigma can be seen as a biosocial phenomenon with 4 essential elements. First, stigma can present major barriers against health care seeking, thereby reducing early detection and treatment and furthering the spread of disease. Second, social marginalization often can lead to poverty and neglect, thereby increasing the susceptibility of populations to the entry and amplification of infectious diseases. Third, potentially stigmatized populations may distrust health authorities and resist cooperation during a public health emergency. Finally, social stigma may distort public perceptions of risk, resulting in mass panic among citizens and the disproportionate allocation of health care resources by politicians and health professionals^{viii ix x}. It is important for RCRC to look at how their current interventions in epidemic control are reflecting the above elements.

2. What were the relevance and effectiveness of key activities of RCRC supported by the DREF. Did they meet the needs of beneficiaries and add value to the overall response through all disease phases? As soon as the outbreaks were declared the MoH quickly encouraged the set up of a District Task Force (DTF) and the key activities of URCS volunteers in accordance with the DTF subcommittees included: 1. Community outreach for support of surveillance and case tracing activities; 2. Follow up of cases after discharge to continue surveillance and prevent social marginalization; 3. Advising on communication of disease prevention messages in close co-operation with local authorities using Information, Education and Communication (IEC) materials as well as using radio as media.

The main findings showed that according to all partners the role the URCS took on in community outreach activities played a vital role between authorities and remaining medical staff (as most of them left when the outbreak was declared) and the affected communities. Being apart of the community and having their trust, they were in a unique position to pass key messages. This was particularly important due to the fact that most of the health care staff left the hospital in Kibaale when the outbreak was declared and the humanitarian response was dragging behind 3-4 days. That highlights the need for support to medical staff themselves as fear drives them to leave their hospital duties. MoH set up a mental health counsellor at the hospital to work with the staff. However, this could have been done as a preparedness measure and staff resilience should have been built before hand. As a consequence of the community outreach (e.g. through an established hotline) many cases were being referred quickly to the hospital. The patients would be abruptly taken from their home, their possessions burnt, sprayed down at the hospital with disinfectant and stripped naked before being admitted to the isolation ward. Their communities would be alarmed by the sudden visit of the pick up teams, which would induce fear and hostility towards the suspected cases. The volunteers in co-operation with the mental health representative from the MoH would visit the community speak to the neighbours and community leaders in the effort of reducing stigma and increasing support for the people involved. According to the volunteers and the beneficiaries this had a certain effect but more effort needs to be put into these activities because although a change in attitude could be seen in the community it wasn't enough for the normal support mechanisms to function upon return of the person. Traditionally the community takes care of

each other e.g. provision of food and water (as there is no running water). The patients reported being unable to go to the market as they would be shunned away or threatened by community members (even after the 21 days had passed) and the normal social support structures in the community (where neighbours might bring food and water to the gate) did not function out of intense fear of Ebola and even beliefs about witchcraft. As the villages have no running water this, at times, caused a serious situation. Thus the 21 day follow up activities of suspected cases, the beneficiaries expressed that the volunteer was at times their only connection to the outside world during these days. The visits promoted hope, as they felt isolated, shunned and less valued as community members. They expressed the importance of community sensitisation with regards to reducing stigma and fear and how the simple visits of URCS volunteers had sent a message to the community about the household being safe to enter. Thus an increased visibility of URCS volunteers might have been likely to influence these negative elements further. They also referred to the volunteers as being points of safety for them as they could ask them to bring messages, get news or otherwise stay in contact when they had run out of airtime on their phone. The volunteers tasks on advising on materials will be covered in question 6.

3. How does PSS contribute to the overall objective of reducing morbidity and mortality of VHF? As has been established before, URCS community health volunteer's role in dissemination of information, handing out key messages and opening a forum of open discussion on the radio proved to be essential in creating public trust^{xi}. In co-operation with PSS program leaders the messages were evaluated and designed to have a calming effect. Open questions on the radio were suggested as a method to clarify any myths or misconceptions about the disease and enhance trust in health authorities. It was a general consensus between beneficiaries and partners that this had indeed a calming effect and motivated people to participate in the intervention and to report any symptoms sooner. It was perceived that this played a strong role in putting a halt to the spread of the disease as it minimized contact points by reducing the time from experiencing symptoms to reaching out to health facilities and as such reduced mortality. Thus it is important in deadly epidemics driven by fear, to design health promotion information not only with health behaviour change in mind but also with enhancing trust, reducing fear and stigmatization and promoting calming. Reducing fear and stigma also minimizes the likelihood of suspected cases being at risk for potential violence. There was one case in Luwero where the URCS lost contact with a suspected case that seemed to have disappeared.

4. Does PSS have any other impact in this type of response, and if so is it something that should or could be developed further?

Through supportive outreach activities in the 21 day follow up process other less visible consequences from stigmatization arose, namely the impact of VHF on livelihood. Since these areas mainly support themselves with agriculture, an Ebola affected community member (whether recovered or previously suspected) that mainly supports his/her family by crops might not be able to sell them for a certain period of time after being associated or diagnosed with Ebola. This had a great impact on these households that are 2-300 in these areas. It was clear that the community would avoid any possible products coming from Ebola infected household in the coming future. Patients that had recovered complained (still months later) about not being able to sell their products at the market and thus had little means of supporting themselves or their family. Further, efforts put into reducing stigma e.g. by integrating pss information more into the behavioural change interventions, might facilitate this and even resolve this in the future.

Another issue that may be important to address in a well designed PSS program is supporting family connections as some members would get marginalized from their own families as it was believed that they might have been bewitched.

5. What were the current training materials and were they effective and relevant. What are recommendations for improvement?

In spite of the URCS volunteers ability to take on different roles in the response, they felt strongly that lack of training was an issue that needed to be addressed for future response. Lack of training, especially in PPE made them at times feel unsafe. Such a training and pre-placement of even 20 kits of Personal Protective Equipment (PPE) would have helped to keep the volunteers objectively and subjectively safe. The current training of the local volunteers is not sufficient enough for them to function efficiently or safely in the role expected of them during an epidemic response. There is little preparedness training in PSS so most of the training was conducted after the outbreak was declared. Fear and stigma are not elements that are concurred in a matter of days and should therefore be a continuous work in progress for the branches. There is lack of training materials to use in the trainings and thus none to be handed out for the volunteers to refresh their knowledge at home. Ideally a short PSS field manual to use in epidemic response should be developed. The IFRC training material in PSS is also not designed for epidemic response but to disaster in general. Due to the nature of an infectious agent, the role of fear and stigma, it is important to have PSS material that has integrated this. This should be highlighted to the IFRC Reference Center for Psychosocial support. A training program that integrates important elements from various disciplines should be designed and implemented in these areas, preferably a combined training in community based health and first aid (CBHFA) integrating basic elements of health behaviour change, PSS, epidemic surveillance and control and the use of personal protective equipment (PPE)^{xii}. This effort is not likely to be wasted because it will also support the health of the community and the volunteers in normal times.^{xiii} It is clear that time is an important variable when responding to epidemics. A better training would enhance the community surveillance system, speed up the identification process and would minimize response time (which otherwise is delayed by training) and facilitate set up of necessary resources or at least contribute more efficiently to the patients well-being. Better preparedness training might have allowed for better care of the patients in the 3-4 day gap before MSF arrived. Furthermore, better training and preparedness would reduce stigma and fear before the outbreak, which should facilitate the work during the outbreak.

6. Where the IEC materials produced useful and effective?

The PSS focal points advised on designing the Information, Education and Communication (IEC) materials created for distribution to various target groups and locations. No specific measures were taken to measure the impact of the materials. Unfortunately none of these IEC materials were available anymore at the branches at the time of the evaluation and thus were hard to evaluate.

7. What was the role of PSS support to volunteers and staff? Why was this necessary and what impact did it have? What lessons learnt can we draw from this increased focus on support of RCRC volunteers and staff?

The findings reveal that the volunteers (and staff) should be provided with a formal support element as well. Stigmatization spilled over to the volunteers as they became known contact points of Ebola and thus a

potential risk to the community (in their eyes). They also reported having difficulties returning home at night as has been shown in other disasters^{xiv}, having conflicts with their families, having to change sleeping facilities (sleep outside or elsewhere), disinfecting everything they had in the evening with JIK, feeling psychosomatic and worried about their own health and about infecting the family as has been seen with SARS healthworkers^{xv}, getting attached to beneficiaries that were going through very difficult grieving process with no support network beside themselves and feeling worried about beneficiaries they knew were lacking food and water. They also mentioned not being able to go to the market unless they would remove any URCS identification prior to entering the market as they feared being assaulted by the crowd who would call out to them “Ebola” when able to recognize them. Although very little research is available on Ebola it has been shown that viral epidemics such as SARS are associated with significant long-term stress in healthcare workers and that reducing pandemic-related stress may best be accomplished through interventions designed to enhance resilience in psychologically healthy people^{xvi xvii xviii xix}. The role of health care workers may in this case be translated to the URCS volunteers as many of them are involved in social care of patients and communities although they might not be directly involved in their medical care. Due to the importance of these visits, the families or individuals in question, formulated a strong bond with the volunteer, which may be hard to break. Thus, an exit strategy or an official recognition of the work to be over is essential. The volunteers mentioned the need to have a counsellor at a branch level that they could ventilate their concerns with and seek support from. Especially support regarding difficulties at home and challenges working within the households. This can be set up through the Counselling society of Uganda that has a network of counsellors throughout Uganda.

8. Review the distribution of NFI goods. What role does the distribution of NFI’s play in the response. Is it a key role for the Red Cross and what other value besides replacement of material goods does this have?

Having all their possessions burnt, as part of the infection control and prevention activities, when brought to the hospital there is no doubt that provision of NFI’s and household visits and follow up of patients made all the difference to these people. Research has shown that loss of resources as a consequence of disasters has a large effect on mental health^{xx}. Thus this practical activity, to replace lost resources, had a large PSS effect as beneficiaries reported feeling respected and cared for by the authorities although at times what was replaced was not equal to what had been lost.

However, food items are also necessary for these households as they reported having gone without food and water for days. The volunteers mentioned the difficulties of arriving at a person’s household without any material support. The people might be lacking food and water and expect some form of material support from the URCS. Food and water distribution should be operationalized as soon as suspected cases start returning back to their households and such support should also be provided to the hospital in the emergency phase of the outbreak. URCS volunteers might act as wheels for this distribution to households or the distribution could be the logistical support needed for the volunteers in terms of follow up of patients.

9. Review current RCRC response and evaluate the potential for further academic research or documentation related to the impact of the activities in Ebola response. Outline possible research questions and next steps to implementation.

The first outbreak was in the district of Kibaale and on the 28th of July 2012 the MoH officially declared an Ebola outbreak in Kibaale district and in November 2012 about a month after the outbreak in Kibaale was declared over a new outbreak emerged in the district of Luwero. In both cases the MoH encouraged the setup of a District Task Force –DTF with all necessary subcommittees. The subcommittees that the URCS mainly played a role in were: Surveillance, case management and social mobilization and Psychosocial support (PSS). There are several research questions that could be answered to maximize the response to a VHF outbreak. They could be the following:

1. What elements in the community sensitisation process are the most effective to reduce stigma and fear?
2. What are the most effective health behaviour change tools used in VHF outbreaks and what makes them effective?
3. What are the psychosocial consequences of being a suspected case in VHF?
4. What are the psychosocial consequences for volunteers working in epidemic response?

Conclusion

The overall PSS response was perceived to be very effective. Response time is clearly a factor that can be influenced through better training and preparation. The nature of VHF being non-aerosol, contact based disease makes them ideal targets for prevention. Community health measures should thus be increased in high-risk areas in non-outbreak times as tools to sensitize and educate the community about the nature of VHF, preventive measure against VHF integrating education about psychosocial effects of stigma and the importance of community support. Such an approach has been shown to be effective to reduce fears and stigma in HIV related programming. In outbreak times PSS should continue to sensitize and educate but also work as a bridge between shunned and isolated individuals and their community. The way forward is to build an evidence based PSS program that includes elements that have been shown to be the most effective in PSS programs around the world. The currently best frame of reference towards scientifically sound programming is a set of five guiding principles of Hobfoll and colleagues' that recommend that post-disaster practices should promote 1) a sense of safety, 2) calming, 3) self- and community efficacy, 4) social connectedness, and 5) hope. These elements appear critical to the establishment of a recovery environment that fosters adaptation and resilience amongst individuals and larger populations. As a starting point for the RC Movement, in order to facilitate proper training for PSS volunteers in epidemics education material about PSS in epidemics needs to be developed. In spite of the IFRC responding to an average of 18 epidemics annually the IFRC training manual on psychosocial support does not address PSS in an epidemic response. Community health interventions would benefit from integrating PSS approaches into their work as tools to facilitate behaviour change building on the knowledge that fear causes resistance to change.

Background information

General introduction

With its 51 branches throughout the country, Uganda Red Cross Society (URCS), is highly active in disaster preparedness and response, including epidemic response and played a vital role in these outbreaks. Ebola is the human disease that may be caused by any of four of the five known ebola viruses. These four viruses are: Bundibugyo virus (BDBV), Ebola virus (EBOV), Sudan virus (SUDV), and Tai Forest virus (TAFV, formerly and more commonly Côte d'Ivoire Ebola virus (Ivory Coast Ebolavirus, CIEBOV)). It is clinically nearly indistinguishable from Marburg virus disease. There are no drugs or known vaccines against Ebola and its CFR can be as high as 90%. The largest outbreak recorded was in Uganda in 2000 and resulted in 425 cases and 224 deaths. This high number of fatalities had largely to do with delay in confirmation of the Ebola virus as all samples had to be shipped to Center for Disease Control (CDC) in South Africa or Atlanta, USA. This time the samples were tested in the Uganda Virus Research Institute (UVRI) in Entebbe bringing the confirmation time of diagnosis down from approx. 6 weeks to 4-7 days, which brought the death toll down to 17 in Kibaale and 4 in Luwero. It is thus clear that time is an important variable when responding to this epidemic.

The incubation time for Ebola is about 4-21 days with a sudden onset presenting itself in the early phase with fever, headache, muscle pain and chills. As it progresses patients develop diarrhoea and vomiting as well as sore throat and stomach pains and in about 50% of the cases the patient may start to bleed from various mucous membranes and openings of the body. In the early phase the general symptoms, that can apply to any number of diseases, can easily be overlooked as Ebola and may be the main reason for the delay in correct diagnosis and therefore response time. Due to lack of proper equipment and hygienic practices, large-scale epidemics occur mostly in poor, isolated areas without modern hospitals or well-educated medical staff. Since Ebola viruses do not spread via aerosol, the most straightforward prevention method during VHF outbreaks is to avoid direct (skin-to-skin) contact with patients, their excretions and body fluids, or possibly contaminated materials and utensils. Patients should be isolated and medical staff should be trained and apply strict barrier nursing techniques (disposable face mask, gloves, goggles, and a gown at all times). Traditional burial rituals, especially those requiring embalming of bodies, should be discouraged or modified. Outbreaks of VHF are different from pandemic influenza because of the inability to contain pandemic influenza through infection control procedures, the potential difference in scale and severity, and the opportunity to prepare for a pandemic. VHF is an infection with minimal community transmission and minimal infectious transmission prior to the onset of symptoms. Infection control procedures are therefore key aspects of containing the outbreak. Influenza, on the other hand, is readily transmitted before the onset of clinical illness and is prone to mutations that favour the virus's survival. Thus, pandemic influenza will be a community-acquired disease. The opportunity for intervention in VHF is thus one of the positive aspects of this otherwise deadly disease and also what makes it a great community health target point for interventions and an ideal venue for PSS programming to come in as an added benefit to address fear and stigma that are known obstacles to behaviour change. Ebola brings with it, significant amounts of fear and stigma driven by the communities' belief that the outbreaks are often due to witchcraft and wrongdoing by the victims and effected families. Fear

is further fuelled when infection control techniques and restrictive practices such as quarantine and isolation are employed to protect the public's health^{xxi xxii} Stigma has a well-known negative effect on the mental health of beneficiaries as well as disease prevention and control^{xxiii xxiv xxv xxvi}.

The best models of pandemics highlight the powerful influence of fear and stigma in the management of infectious disease emergencies. Public health strategies that deal with rapidly evolving disease outbreaks of new and emerging infectious diseases require a delicate balance between protecting the public's health and initiating exclusionary practices and treatments that can lead to fear and stigmatization of, and discrimination against, specific populations. Analogous models based on recent epidemics of plague and severe acute respiratory syndrome illustrate the role of stigma in the delayed and disproportionate responses by affected populations and institutions.

By extension of these lessons to infectious diseases in general, stigma can be seen as a biosocial phenomenon with 4 essential elements. First, stigma can present major barriers against health care seeking, thereby reducing early detection and treatment and furthering the spread of disease. Second, social marginalization often can lead to poverty and neglect, thereby increasing the susceptibility of populations to the entry and amplification of infectious diseases. Third, potentially stigmatized populations may distrust health authorities and resist cooperation during a public health emergency. Finally, social stigma may distort public perceptions of risk, resulting in mass panic among citizens and the disproportionate allocation of health care resources by politicians and health professionals^{xxvii xxviii xxix}. Chief among these lessons is the importance of building public trust. Factor such as government transparency must be established from the very beginning. Without clear and reliable information, the unknown risks of infection can exacerbate stigmatization and create undue alarm^{xxx} PSS in emergencies is more and more being integrated into a response either as a stand alone programme or integrated as a cross cutting theme into other sectors such as health, WatSan, gender issues, security and others. Not only is it important to built resilience in communities faced by adversity but also is it vital to recognize mental health components that could actually be obstacles to an otherwise well designed emergency health response. Volunteers can learn psychosocial support without any prior mental health education and according the IASC pyramid of need most community members solely need increased community support in times of adversity (see Appendix 2). Furthermore, learning to support others may also enhance the resilience of the provider. Psychosocial support does not pathologize people who are stressed by extraordinary events. Rather, it assumes that those who are stressed are competent and are able to determine whether or not they wish or need assistance. It teaches a respectful approach to reducing distress through enhancing safety and comfort, helping survivors of trauma to identify their needs, providing information and facilitating social connection and behaviour changeⁱ.

Every emergency has its characteristics and its risk factors for beneficiaries or volunteers, which^{xxxi} some have been studied and integrated into PSS programs or volunteer management programs worldwide^{xl}. However the psychosocial effects of living or responding to an epidemic are still underexplored except for the effects of fear and stigma on the individual^{lxxvii}. PSS program capacity to motivate and influence behaviours makes it an interesting add on for health behaviour change interventions, especially when time is of importance e.g. in

VHF outbreaks. Although risk communication activities are critical for keeping the general public informed during an outbreak, studies have shown that fear associated with stigmatization and discrimination has negatively affected public health efforts with chronic conditions and diseases such as mental illness and HIV/AIDS^{xxxii xxxiii}.

Work in previous epidemics has shown that working in epidemics has a stressful impact on the health care worker. Since the URCS are in a care taking role towards the beneficiaries those findings may be reflected in the URCS experiences. First, SARS experience contributed to social isolation in health care workers for several reasons: infection control procedures increased interpersonal distance; stigma and interpersonal avoidance diminished social and community interaction; and being assigned to unfamiliar work groups reduced collegial interaction^{xix}. Second, while family support usually buffers stress, healthcare workers with children experienced higher levels of distress during SARS^{xv}, presumably due to the perceived risk of infecting loved ones and concerns about caring for children if the parent is ill. Two years after the outbreak's resolution, healthcare workers in hospitals that treated SARS patients had significantly elevated rates of signs of chronic stress compared to workers in other similar hospitals. However, rates of depression, posttraumatic stress disorder or other mental illness were not elevated^{xxxiv}. Thus, long-term effects of SARS were common but were predominantly in the range of sub-syndromal stress response syndromes. Mediators of long-term stress should therefore become targets for interventions. Chronic stress was lower in workers who felt effectively trained and supported by their hospital. Organizational resilience depends on establishing reserves prior to crises. Epidemic or pandemic plans note the need for material reserves (e.g., stockpiles of supplies)^{xxxxxxvi}. Evidence from the SARS outbreak reinforces the importance of effective training^{xxxvii}, including training in skills that will be required when adaptation to the pandemic requires staff to work outside of their usual area of familiarity, and may also include training in psychosocial support and coping. In SARS, psychosocial support was far more effective when provided in the context of trusted pre-existing relationships^{xxxviii}.

The main purpose of this evaluation was to evaluate the PSS response of URCS to VHF, against the needs of beneficiaries and communities focused on the areas of most 'added value' of the URCS; community engagement mobilisation and support, documenting any unintended outcomes and best practice related to the operation.

The outbreaks in Kibaale and Luwero

As the response in Kibaale was considerably larger this report will mainly focus on describing the operations there but adding points where relevant for Luwero.

Kibaale

Kibaale is located approximately 219 kilometres by road, west of Kampala, Uganda's capital and largest city at an altitude between 680 metres and 1,500 metres above sea level. The climate is tropical with relatively reliable rainfall. Population of the district in 2010 was approximately 514,200, socially heterogeneous, with more than thirty two registered ethnic groups. About 60% of the population are Catholics, 30% belong to the Church of Uganda, and 3% are registered as Muslims with an average population density of around 145

persons per km². Only about 1% of the inhabitants live in urban settlements and agriculture is the mainstay of the district economy.

In July 2012, an outbreak of Ebola virus disease was reported in Kibaale district, and as of October 4th 2012, had infected 24 and killed 17, a 71% case fatality rate. It all started in early June of 2012 when a 16 year old girl in the Kibaale district fell ill. As she was living close to the Kyegegwa district she was first treated in a local health facility, Hapuyo Health centre but eventually in EMESCO health centre. After being discharged she returned to her family but when her illness continued to worsen and she developed bleedings from her nose and mouth she returned to the hospital one day later. She had no clear direct points of contact with the disease and the only thing which had been out of the ordinary in her life was the fact that she was engaged in opening up new forest land that was to harvest bats. As bats have been found to be a carrier of the virus this was considered the most likely point of infection.

The girl lost her life to the deadly virus and shortly thereafter her mother died as well as a priest who had come to pray for them. The family the girl visited when discharged from the hospital also fell ill with nine family members dying. As most deaths occurred in this one family it is hereafter referred to as the “Index family”.

By July 24th 12 people had lost their lives in the district but 22 were recognized to be affected. Alongside this a case was reported of a nurse from Kibaale district that had died from similar symptoms at the National referral hospital in Kampala. She had been in contact with one of the Ebola cases in Kibaale in the course of her duties.

On July 27th 2012 after receiving confirmation from the UVRI that more samples had tested positive for Ebola, the WHO together with the MoH and CDC formulated a National Task Force (NTF) to conduct proper investigation. It aimed to ensure coordination of the response activities and national emergency response plan was formulated. The plan aimed to reduce morbidity and mortality from Ebola through prompt identification and effective management of cases; effective social mobilization and coordination of the epidemic response activities. On the 28th of July the MoH officially declared an Ebola outbreak in Kibaale district and as a result most of the health care staff left the Kagaadi hospital (the main health facility on location). Following this response they encouraged the set up of a District Task Force –DTF with the necessary subcommittees to ensure a solid response. According to the WHO six weeks went by before there was an official outbreak declared. Outside of an outbreak period, due to non-specificity of symptoms, it is only when the patient starts developing severe haemorrhages about a week into the illness phase from multiple sites of the body, that people recognize it as Ebola. A weak surveillance system related to the health centre where the index cases reported to, could also have caused a delay as well as health seeking behaviours of the community in Kibaale. At first it was not seen as a physical illness since the index family was believed to have been bewitched by one of the co-wives in the family who apparently had been sent away from their home somewhat earlier by the husband.

Luweero

Luweero is located approximately 75 kilometres by road, north of Kampala. Luweero District was the site of a fierce insurgency by the rebel group National Resistance Army and a brutal counter-insurgency by the government of Milton Obote known as the Luweero war or the "Bush War", that left many thousands of civilians dead during the early to mid 1980s. It is estimated that the population of the district in 2010 was about 433,100 where 85% of the district population are engaged in agriculture. About 30% of the population are Catholics and 20% are registered as Muslims.

About a month after the outbreak in Kibaale was declared to be over, a new outbreak emerged in the district of Luweero, or on the 16th of November. The district Ebola epidemic response plan was finalized and submitted to the Ministry of Health the same day. As of 28 Nov 2012, seven cases (six confirmed, one probable), including four deaths (two from the same family), were reported in Luweero and Kampala. The first isolation unit was set up at Bombo Military Hospital but then MSF set up an isolation facility at Nyimbwa Health Care IV and it was completed on Saturday 17th November 2012. Uganda Red Cross responded with 20 volunteers to conduct door-to-door community sensitization, gave 20 sets of PPE's, 20 gum boots, 50 bottles of JIK, 10 mega phones, 1000 IEC materials on Ebola and 50 body bags. The volunteers provided support to about 100 households or about 580 individuals.

The Subcommittees and URCS volunteers role in those

The key activities of URCS in accordance with the DTF subcommittees included social mobilisation and communication of disease prevention messages to communities, support of surveillance and case tracing activities for suspected cases as well as support to affected families.

1. Surveillance

The objective of the surveillance was containment of disease spread by early identification of cases or reporting and referring suspected cases or contacts (by using a predefined criteria). A Regional Response Team - RRT was created by the DTF and mandated to respond to all possible alerts from community members and thus a hotline was established at Kagaadi hospital so members of the community could easily report any cases. URCS volunteers and Village health teams (VHT) doing disease surveillance would also report to the DTF (either directly or through Kibaale URCS Branch manager). For a suspected case pick up the RRT would first meet with the community leader and afterwards the team would be accompanied by a village member to the persons house. The RRT then notified the ambulance team in case of a suspected case or the burial team in case of death. The ambulance teams transported the suspected cases to the isolation units for further evaluation and screening. Specialized burial procedures were operationalized to ensure safe burials of infected bodies. A total of 407 contacts had been listed at the end of the outbreak.

Due to this active process the number of admissions rapidly increased and by the 1st of August there were a total of 30 patients in the isolation ward. Although the health workers were trained in infection control and management many of them choose to leave the facilities due to fear of catching the deadly virus. Thus health

workers with prior experience in Ebola management from e.g. Bundibugyo and Gulu districts (previously affected by Ebola) were immediately responded to Kagaadi hospital.

2. Case management

When the outbreak was declared most of the nurses from Kagaadi hospital including some doctors left the hospital in a hurry and refused to return. After a few days some returned when convinced there would be PPE available. However, this left the hospital understaffed for about 3 days until MoH responded some health workers from Hoima district and MSF arrived. The government and NGO's immediately responded with increased funds to Kibaale district as well as increased resources in terms of health workers, blankets and bed sheets, vehicles and medical supplies including 400 sets of PPE from WHO and additional 450 sets of PPE from CDC. These health workers as well as provision of PPE's and isolation units proved to be instrumental in addressing the epidemic. A team from MSF Netherlands gave support by setting up a clinical unit in Kagaadi hospital including an isolation facility. Although this was all well and good it took a few days to operationalize. Thus there was a gap of 3-4 days in the Kagaadi hospital that hindered operations. Before MSF had operationalized the isolation unit one of the wards was turned into an isolation ward and the emergency mode the hospital was now operating within, led to a suspension of normal operations. Patients had to be sent away and according to URCS volunteers left them feeling abandoned. The hospital suffered from lack of health care staff and logistic problems. Coupled with this was the problem of lack of running water and sewage system and lack of lighting that made the operation of the isolation a challenge. URCS played a key role in this where they stepped in as a valuable resource for Kabaadi hospital, helped with triage of patients, managed the gate as well as setting up the isolation facility with MSF. However, at this point even though being placed at the gate and in triage the volunteers only had basic PPE, mainly gloves.

As the patients who were identified as suspected cases were being taken rather rapidly to the health facilities they could be frightened and disoriented. Upon arrival at the local health facility the person was taken out of the car and sprayed down with disinfectant and its possessions burnt in front of their eyes (their mattress, their clothes etc.) to prevent any cross contamination. During the first days of the response the person was then left to stand naked out in the open and sprayed down again and then brought into the hospital and left on its own for several days (3-4 days) or until PPE and external health response (including isolation unit) was in place. The instructions were: Do not help. Minimize contact. This meant that the person with high fever was in a hospital bed without any clothes, vomiting and with diarrhea and little means to care for him/herself and no external assistance for about 3-4 days. Even food and water was unavailable to them until Infectious Disease Institute – IDI came in with food and water support on day 3. Some had to stay there with a deceased person in the next bed. This applied both to children and adults. The suspected cases were put in with the confirmed cases and some of the suspected cases tried to leave the ward/unit out of fear and disgust. When trying to leave the person would be naked. To control the epidemic it was found necessary to have armed police outside the hospital to prevent patients from leaving. No violent episode arose in Kibaale but in Luwero one suspected case was removed from a taxi by the police and taken to the isolation center.

When a person has been declared Ebola free they are allowed to return to their household. This could both be individuals that were suspected of having Ebola due to symptoms they were having or contact they had with an infected person or this could be a person that had recovered from Ebola.

The mental health professional from MoH together with Red Cross volunteer prepares the families for discharge and reintegration, visits the household and prepares the community for the returning person. The person receives a “Kit” upon departure that is supposed to supplement for most of the things they lost when they were being referred to the hospital and it was considered necessary to burn their possessions. The main contributors to the Kit were (different by region): URCS, World vision and WHO. The Kit typically contained: A mattress, blanket, kitchen set (jerry can, sauce pan, plate etc.), mosquito net, soap and JIK (for disinfecting) etc.

One challenge that arose later in the operation was that patients that got treated as suspected Ebola cases on the basis of symptoms (and had everything burnt) did not receive a kit as they proved to be carrying another disease.

3. Social mobilization

Even though URCS played a key role in surveillance and case management they became the lead agency in social mobilization and PSS in Kibaale. This was different in Luwero where their main task was social mobilization. Case management, surveillance and logistics were handled solely by the government and NGOs (MoH, MSF, AmRef, Plan Uganda). The volunteers provided psychosocial support and confidence to the community to ensure risk reduction and infection control interventions could be implemented quickly. This put to a halt the spread of the disease and limited mortality as well as contributed to the well-being of the community. They took on sensitisation measures such as giving out key messages on the radio and in co-operation with key medical personnel answering to open questions to dissolve any myths or misconceptions. They influenced behaviours and practices that might predispose the community to infection (such as abstain from hand shaking throughout the outbreak period) as well as providing psychosocial support to community members affected by the outbreak and had to be isolated in their households for 21 days. They distributed Information, Education and Communication (IEC) materials to various target groups and locations, making household visits to educate about Ebola etc. Furthermore, they handled distribution of non-food items to replace those that had been destroyed as part of the infection control and prevention activities.

The branches responded by calling for trainers in PSS to come and train the volunteers. Such a training was conducted in the first few days by staff from URCS HQ in Kampala followed by a training from Makerere University and in Kibaale also an additional one day training by MSF. After the first URCS training teams formed and assigned a team leader. All team leaders were selected by the volunteers and managed by the branch manager. The volunteers were mostly experienced volunteers with a few newly recruited as a result of the response. All volunteers were insured. Social mobilization teams comprising Red Cross volunteers and VHT reached most of the villages and households in the most affected sub-counties in Kibaale district. PSS was provided to 100 households in Kibaale district with about 585 people involved and approximately half of that

in Luwero. It was identified that the communities were largely ignorant of Ebola and as a result it was agreed to adopt and implement a health education approach and print Information, Education and Communication (IEC) materials for distribution. 48,000 posters were printed and distributed. Broadcast of health awareness messages was done every evening on the radio and by film vans and open calls were taken on radio shows and answered by health experts to clarify any myths or misconceptions. In addition to this the president himself Yoweri Museveni made a public televised announcement on the 30th of July where he assured the public about the government's ability to contain the outbreak and urged caution. This was all done to reduce fear and minimize panic in the country. To ensure coordination in information flow the chairman of the NTF and WHO representative were designated the official spokespersons on the outbreak as well as the District health officer. This information flow arrangement enhanced visibility and public confidence and trust in the response activities.

The URCS volunteers are oriented and trained to follow up on patients that return to their households and visit them regularly afterwards, or for a total of 21 days. The volunteers follow the people up in their homes, make sure that they are comfortable and safe and that they are in the possession of the kits. It has proven necessary to follow up on the use of the kit so that it is being used for the intended person. Suspected cases, cured and bereaved cases are followed up. Due to lack of transport or logistical resources the volunteers could only cover a very small area every day. As this was mainly a rural area this would sometimes mean that the volunteers would go on foot all up to 4 hour walk one way to visit a household. Thus, they might only reach a single household per day. With the limited resources some households would only be visited once during the 21 day time frame. The suspected case was not allowed to leave their premises for this time period and due to fear of witchcraft the normal social support elements in a rural community in Uganda were not operationalized where community members might bring food and water to the gate and the person under quarantine might be able to reach it. But the fear of witchcraft and getting associated with that kept community members away. This proposed a great risk for the person as there is no running water in the villages. Thus people, in some cases, people were starving for days.

To attend to psychosocial matters, MoH hired a professional mental health professional to work with the social mobilization and PSS committee. In Kibaale a facility (staff wellness clinic for mental health) was set up within the hospital and services provided to staff and patients Monday/Wednesday and Friday. That person guided the entire PSS intervention within the hospital and in the field e.g. they addressed the stigma and prepared the community with education about transmission routes, reduced fear through personal approach (visiting neighbours and the person's house and by doing that showing there is little risk of transmission) etc. The URCS volunteers worked in co-operation with this person and obviously their network amplified the impact of this work by multiplying the number of households to be reached. Within the health facility the isolation centre and hospital health care staff are attended to by this professional who gives them support and counsels them.

The centre mainly functioned as a sensitisation element, counselling patients and staff and resilience building. The URCS volunteers did not have any formal means of support but the branch managers tried to create a

supportive work environment by meeting with the volunteers in the morning before going to their tasks and in the afternoon at the end of their tasks. In Luwero this was mainly done in the morning of each day.

On the 4th of October 2012 when the outbreak was declared to be over a total of 24 cases had been confirmed as probable or confirmed cases with 17 resulting in death, making the CFR 71% for this epidemic. Three of the cases were health workers with one succumbing to the infection. This is considerably lower than in Gulu in 2007 where 15 health workers died in the outbreak.

The evaluation in February 2013

Methodology

Three independent evaluators representing Disaster Management, Health and Psychosocial support were sent to the affected areas to gather lessons learned of the response. None of them had been involved in the set up or creation of the response and are thus considered being unbiased in their reporting.

A field study was conducted by visiting two of the branches involved in the response, Kibaale and Luwero branch as well as various partners involved in the response (see Appendix 1). Time constraints inhibited us to visit the third one, Kabale branch which was at a considerable distance from Kampala the capital of Uganda. The participants joined on a voluntary basis understanding what was expected of them and informed of confidentiality.

Qualitative semi-structured interviews were conducted with key informants (branch managers and program managers of various NGO's) involved in the response (Appendix 1). The tool used as a framework (with questions nr.9-21 as added questions) is the participatory assessment: Perceptions by severely affected people^{xxxix} (see Appendix 4). The benefit of meeting key informants in this short timeframe was the possibility of examining topics in depth by asking them to clarify information and their ability to provide relatively easy access to a wealth of knowledge. Focus group discussion (FGD) were held on both locations with 25 volunteers participating in Kibaale and 12 in Luwero. These were around 25% of the volunteers involved in the response in Kibaale and 50% of the volunteers involved in the a Luwero response. Language of the FGD was English with no obvious problems. One volunteer in Luwero needed clarification/translation of language which was provided by the field officer accompanying the assessment team.

The questionnaire was tested with PSS programme manager at HQ in Kampala for relevance to the response. During the FGD, branch managers stuck around and kept coming in and out, which may have biased the replies of the volunteers. Later they were requested to keep a distance from the FGD and the volunteers were encouraged to speak honestly and openly for the purpose of learning from the response and improving future responses to epidemics.

Results and Discussion

Pre-response factors

Many volunteers mentioned lack of training in PSS and other sectors necessary for the response e.g. Community based health and first aid (CBHFA), including epidemic surveillance and control and the use of PPE. Some mentioned not having been aware about the importance of a PSS training until they received it and understood how much it added to their skills in community mobilization and support and their own sense of self-care and care for their fellow volunteers. They mentioned that this response had put forward the need for being trained in the basic elements of a response on a regular basis believing the response could have been activated quicker and more securely if they had previous training in those subjects as part of disaster preparedness. However, in spite of the IFRC responding to an average of 18 epidemics annually the IFRC training manual on psychosocial support does not address PSS in an epidemic response. The elements of fear and stigma do require a specific PSS approach. With more preparation it could have been possible to reduce fear and stigmatization sooner and possibly minimize the 3-4 day gap in the hospital or at least contribute more efficiently to the patients' well-being. With training on PPE (which could be integrated into the trainings) and pre-placement of even 20 kits of PPE would have helped and pointed out that the drivers and cleaners also need training in PPE as they are often points of contact for the patients.

Community surveillance is an area that can be strengthened by good training of URCS volunteers. Especially since many of the URCS also work as VHT who are always in the community and have their finger on the pulse like URCS volunteers. URCS branches could also function as a training resource for VHT. According to Dr. Christina W.Mwangi of the CDC in Kampala the humanitarian response was too slow as it tends to be according to her in epidemics. This is reflected in the approximately 4 day gap between declaration of outbreak and MSF set up of isolation unit in Kibaale.

When asked about motivation to volunteer in such a setting they mentioned that it was good to have the feeling that you were saving a life and keeping people safe by sensitizing the community who otherwise might have acted as far as killing the patients. That by volunteering they gained overview of location of confirmed and suspected cases, a knowledge that helped with self-protection. One volunteer said: "if you volunteer you know where all the sick people are and you know how to protect yourself and your family".

Peri-response factors

Having a seat on the DTF is a vital point for the URCS in terms of participating in the co-ordination process and having a voice in the decision making process. Representative from the MoH did mention that it was important for URCS to have a person with authority attend the meetings (not regular volunteers) so they could more efficiently participate in the decision making. This could also mean that the perception was that Branch Managers (if they were the one attending) did not have enough decision authority to participate actively in the planning. However, others complimented the URCS for efficient response and their capacity to link with the community and access key community representatives that could facilitate the distribution of health

messages. In Luwero, deputy resident district commissioner, did mention how quick, efficient and reliable URCS was in their response and how valuable the social mobilization efforts and PSS had been to the community and households. She mentioned not having known much about URCS before the response but being convinced that for future response URCS would need to be one of the key partners.

Once the response was in full action one of the volunteers greatest challenges were difficulties moving around for surveillance and follow up of patients. With no logistic support (not even bicycles) it was hard for those that were not in possession of any transport to move around. Due to stigma related to Ebola nobody wanted to drive the volunteers or let them use their means of transport. The traditional form of moving around to greater distances, Boda Boda, did not want to drive them to the households. This had not only to do with approaching Ebola infected households but fear of being associated with witchcraft and the volunteers themselves were seen as possible carriers of Ebola.

This called for another related challenge, which had to do with access of basic necessities. The volunteers reported being unable to enter shops or markets where they could be identified as URCS volunteers as people would shun them away in panic. Pedestrians would point to them and call out “Ebola” as to indicate that the person everyone should be aware of had just entered the area. Some volunteers considered it a potential security risk for them to enter the market as they feared being assaulted by the crowd. The volunteers if wearing any identification of the URCS e.g. a vest, would remove that before entering the market. As said earlier in the report, the formal means of community support cannot be expected in an epidemic outbreak of this level.

The volunteers talked about general lack of support for their concern. The family support element and community support element wasn't as understanding and tolerant as in other operations. Family in most cases preferred that the volunteer would not be involved in the Ebola work. The volunteers mentioned trying to sensitise their families and explaining the risk of Ebola and the means they were taking to protect themselves. The daily life's of the volunteers was highly affected during the outbreak. The challenges faced mostly had to do with families at home or participating in community activities. When returning from their daily visits to Ebola suspected cases or survivors they would be asked to take their clothes off at the door and wash them with JIK (a locally used disinfectant). Most of the volunteers mentioned not being able to sleep in their normal facilities but rather being asked to either sleep outside or in a separate room. They sensed a lot of fear in their own families and struggled with guilt about possibly bringing the deadly virus to their own households. In spite of extensive training and education on the subject the fear remained and the volunteers were highly alert to any symptoms they themselves might develop. This caused a few of them to become rather psychosomatic and one ended up in the isolation unit as a suspected case as a result. After the response they themselves counted 21 days so they would know that they were in the clear. Responding to an epidemic differs from the traditional disaster response of e.g. earthquakes or floodings due to its contagious nature. It puts volunteers at risk of being infected and has large consequences on their social and family networks.

What has been a challenge in some disaster operations is the difficulties volunteers face with returning home in the end of the evening. Community members, neighbours and relatives may pressure them for additional resources^{xi} For this response a handful of volunteers mentioned difficulties returning home and one volunteer ended up sleeping at a suspected case home during the response.

Their main source of support was the branch manager and the volunteer group. Thus the group meetings held every morning and every evening in Kibaale (and every morning in Luwero) were a great source of support for them. The volunteers were not using the Mental health services provided at the hospital. It seems that the service was directed to patients and staff. They mentioned the need to have a counsellor at a branch level that they could ventilate their concerns with and seek support from. Especially support regarding difficulties at home and challenges working within the households.

A short survey was conducted amongst the volunteers during the assessment where they were asked to rate their need for external support (in the form of a counsellor) during the response. They were instructed that giving it a 10 would indicate the greatest need they could imagine and 0 meant that they had no need for external support at all. The results are here below:

0(0), 1(1), 2(5), 3(3), 4(1), 5(2), 6(0), 7(0), 8(1), 9(1),10(1).

This tells us that most of the volunteers had some need and a few had great need for external support.

Post-response factors

Such a strong negative community reaction unavoidably leads to self-stigmatization both in the patients and the volunteers. There is a difference in self-stigma and world or community-stigma. Self-stigma is what you believe the world thinks of you. Your confidence of your self-image is one of the ways self-stigma begins to enter into your life. You can act a certain way because you believe people expect you to act a certain way. This can also cause you to believe that you are worse than you really are, which in turn makes you act accordingly (avoiding places, situations or people). In the mental health community, it is well-known that your self-stigma can be more disabling than a mental health diagnosis. However, gradually with time the community stigma and the self-stigma has worn off and the community has started to accept them back. Some community members are still rather sceptic towards them, especially those that still hold on to the belief of Ebola being related to witchcraft.

Apart from the stigma mentioned and the fears of returning home and carry the virus with them the volunteers mentioned the difficulties of arriving at a person's household without any material support. The people might be lacking food and water and expect some form of material support from the URCS. On occasion they would find people in very difficult emotional states, feeling abandoned by family and friends and their community and feeling unsafe. Fearing that their house might get burnt down or they themselves hurt or killed should they try to go and buy some necessities. The volunteers found it difficult to deal with these emotions and not being able to offer any material support. This highlights the need for food distribution in

epidemics and especially those that carry stigma or fear. World Food Program or the URCS should have been mandated to make sure the approx. 100 households in Kibaale and xx in Luwero had food and water.

When asked about improvement in response and what would have facilitated their work or improved their own well-being they mentioned the following:

Certificates for the training conducted and a training material to read further at home would have been useful and welcomed. The discussion about **logistical support** was always very prevalent and it is clear that increased logistical support would have facilitated the response for the volunteers especially in terms of household coverage and it would have facilitated transport of some resources .e.g food and water. When discussing logistical support they mentioned that even some bicycles would have been helpful. Furthermore, to keep in touch with each other, co-ordinate themselves, clarify instructions/information given or rumours and provide collegial support they had to use their own **airtime**. One important element, which also has to do with visibility and clarity of the URCS, is lack of **identification** for the volunteers. Although in this case it was better for them to go without t-shirts and vests due to danger of harassment, that doesn't always apply in disaster response. The volunteers mentioned the awkwardness of presenting themselves to a household and asking for their attention and trust without any form of identification. Simple ID cards are necessary for the volunteers so they can show they do in fact represent the URCS. This put additional stress on the volunteers when having to enter a household or present themselves to people for the first time. On top of this It has also been shown that acknowledgement, in particular social acknowledgement is important for a person's mental well-being after a critical incident^{xii} and for volunteers mental well-being after working in disasters (see Thormar et al., 2013)^{xiii} . Thus, being able to openly show that you work for a highly appreciated organisation is likely to facilitate resilience in the volunteers. It is encouraged that all volunteers, especially those that work in high strain circumstances, have access to t-shirts, vests or other form of visible identification. A part from contributing to resilience it is likely to provide safety to the volunteers.

Another important key element was lack of ceremony at the end of the response. The volunteers were missing a form of closure. It is important from a mental health perspective to provide some form of closure of the official response also to facilitate detachment from families they have been visiting. It was clear that the families had become quite attached and appreciative of the volunteers who often were their only form of human contact for the period of 21 days. This bond needs to be offered an exit strategy if it is burdening the volunteers. A final ceremony might also provide an opportunity to hand out certificates earned for training. It is clear that a form of celebration might be difficult to conduct when such a tragedy has struck but a respectful appreciation of their work in the form of a ceremony is needed.

To prevent outbreaks of this size occurring again, quick and effective communication to the affected communities is vital. In order to overcome the fear and mistrust, the Red Cross volunteers play a vital role between authorities and medical staff and the affected communities. The volunteers, as part of the effected community are in a unique position to pass key messages. They help identify possible cases and follow up with suspected contacts, but most importantly perhaps, they provide psychosocial support and confidence to the

community to ensure risk reduction and infection control interventions can be implemented quickly. This puts to a halt the spread of the disease and limits mortality as well as contributing to the well-being of the community.

Conclusions and recommendations

The overall PSS response was perceived to be very effective and it is clear that the URCS is highly appreciated and very professional in their work. Their impact could be fairly greater with increased resource support. However, the answer to effectiveness always lies in between perception and outcome. In order to design good programming assessment of the impact is essential. Very little work has been done in effort of translating psychosocial programmes into empirical models. The currently best frame of reference towards scientifically sound programming is a panel of experts that come together to recommend elements important for good programming. Recognizing the limitations of research to date and the heterogeneity of traumatic events and individual responses, they were not attempting to recommend specific intervention models for populations affected by mass trauma. Rather, this panel of experts, assembled to establish consensus on broad concepts of approach to intervention, identified a set of five guiding principles to inform future intervention and prevention efforts through synthesis and integration of empirical research from the fields of psychiatry, psychology, sociology, epidemiology, public health, and emergency and disaster medicine. Hobfoll and colleagues' synopsis of the research and experience to date supports that post-disaster practices should promote 1) a sense of safety, 2) calming, 3) self- and community efficacy, 4) social connectedness, and 5) hope. These elements appear critical to the establishment of a recovery environment that fosters adaptation and resilience amongst individuals and larger populations. They suggest that disaster response interventions at the individual, community, and public policy levels should incorporate these "five essential elements." Being guided by the 5 principles of Hobfoll the PSS program is likely to reach the goal of being supportive to the beneficiaries as well as volunteers and staff.

It is clear that time is an important variable when responding to epidemics. In this response it seems that the humanitarian response was somewhat lacking behind the national response. Any measures taken that reduce both response time and contribute to well-being of communities and patients should be supported. Well designed Community health interventions and BCC would benefit from working closer together with PSS programming especially with regards to reducing stigma and fear. Stigma and fear have a negative impact on disease prevention and control and can delay response time. They can also have a serious effect on social relationship both inside and outside of families, put patients and their relatives at risk for potential violence and affect livelihood for a considerable amount of time. However, the URCS is lacking trainers for the various topics, especially in PSS. A Training of Trainers (ToT) is recommended to take place no later than the fall of 2013 where two trainers per district should be strategically selected from high risk areas throughout Uganda to participate. These trainers should ideally function as team leaders during a district response and thus have the opportunity to retrain volunteers rapidly if needed. Thus an element of team leadership training should be

integrated into the PSS ToT. These district based trainers could be mandated to give a yearly training to the local branches as a form of disaster preparedness. Such a training should ideally be combined with a training on CBHFA, epidemic surveillance and control as well as use of PPE. A basic training should be 3 days of PSS, 2 days of CBHFA, 1 day of epidemic control and surveillance. In total this would come to a 6 day training. Refresher training could be done in 2-3 days if there is not much turnover of volunteers in the area. If the number of new volunteers reaches 10 per branch a new basic training should be conducted for them.

Logistic support should be agreed upon beforehand with a local NGO and/or by provision of bicycles to the branches. Food and water distribution should be organized into the response plan and operationalized as soon as suspected cases start returning back to their households and such support should also be provided to the hospital in the emergency face of the outbreak. On the basis of IDI providing food and water support for the isolation unit in Kabaadi hospital they might be the best point of contact to take on this role (possibly together with World Food Program). URCS volunteers might also act as wheels for this distribution to households or the distribution could be the logistical support needed for the volunteers in terms of follow up of patients. On the other hand with effective interventions to reduce fear and stigma it may be possible to re-activate the normal support structures in the community which would make food and water distribution unnecessary.

Burial and handling of bodies was clearly a challenge for the volunteers and the communities. A local NGO or WHO with knowledge and expertise on the topic should be brought on board during such an epidemic. Both for proper handling of bodies as well as consideration for different religion and burial habits (e.g. Muslim) that can cause distress in times of epidemic response.

The effects on livelihood needs to be explored further. Since these areas mainly support themselves with agriculture, a Ebola affected community member (whether recovered or previously suspected) that mainly supports his/her family by crops might not be able to sell them for a certain period of time after being associated or diagnosed with Ebola. This could have a great impact on these families. This is also an area that may be influenced through improved stigma and fear reduction.

The psychosocial aspects of such a life experience are many and impactful. Both on the volunteers themselves as on those suspected or diagnosed with Ebola and their families. It is the responsibility of humanitarian actors such as the IFRC to take care of the mental well being of their volunteers as well as the beneficiaries. It is thus recommended based on need identified with the volunteer that a local counsellor is made available to the volunteers during such a response. This is an effort made to keep the volunteers healthy and more able to support the beneficiaries. Such co-operation can be set up through the Counsellors Society of Uganda (pointed out by Nina Lugumba, clinical psychologist and a trainer of MoH). It is clear that suspected and confirmed cases will need support as a result of the hospital admission process. Respect, dignity, care and support comes in as a much needed element.

Last but not least although outside of the scope of this report it could be recommended to train hospital and clinic staff better in epidemic response and case management and provide the with PPE's on stock. Evacuation

of medical staff caused a great challenge at the beginning of the operation.

Appendices

Appendix 1

The following is a list of locations and respondents visited during the evaluation:

1. **URCS HQ** – Mr. Michael Nataka, Secretary General; Mr. Alex Ssimbwa, Assistant director of community development and responsible for PSS; Mr. Morris Anyikaying, Senior programme manager CBHFA.
2. **Kibaale branch** – Mr. Fred Othino, Regional manager for Hoima region; Sunday Issa, Branch manager Kibaale branch and 25 volunteers.
3. **Luwero branch** – Mr. Kasozi Micheal, Branch manager Luwero branch; Mr. Henry XXX, chairman branch governing board for Luwero branch and senior health educator of Luwero district; Ms. Princess Precious, deputy resident district commissioner; Ms. Margaret Mugisa, Program Manager for Central Region AmRef; Ms. Josephine Alidri, program manager Plan Uganda. Also 12 volunteers.
4. **Makarere hospital** – Dr. Janet Nakigudde, clinical psychologist, head of department at School of health sciences at Makarere University and acted as head of PSS team in Kibaale and Luwero during the response.
5. **Ministry of Health** – Dr. Esther xxxxx, epidemiologist and a member of the National Task Force for Ebola response and an active member of the Kibaale and Luwero hospital team; Ms. Nina Lugumba, clinical psychologist and a trainer of MoH in PSS and counseling and URCS main PSS trainer and professional mental health back up.
6. **WHO** – Dr. Solomon Fisseha XXXXX
7. **MSF** - The Netherlands as MSF on location had changed rotations and didn't feel informed enough about the response to meet with us.

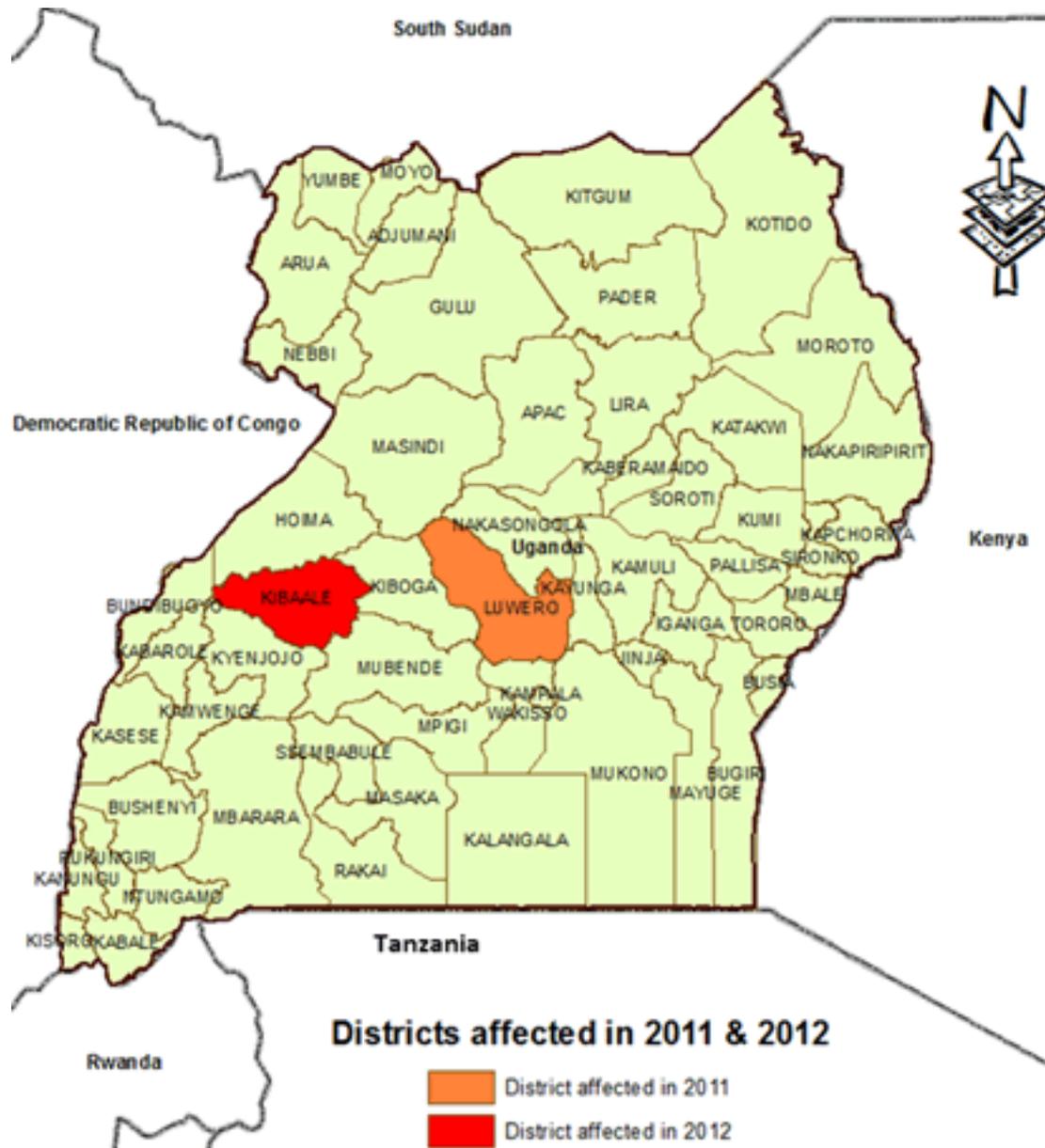
This should include detailed information referred to in other sections examples include: details of methods used, work plans etc.

Appendix 2



Appendix 3

This map shows the location of the outbreaks.



Appendix 4

I am especially interested in your experience of being a volunteer during the Ebola response

- 1. Could you tell me how being a volunteer on the Ebola response affects your daily life today?**
- 2. Could you tell me how being a volunteer on the Ebola response affected your daily life during the outbreak?**
- 3. Did you try to find support for the challenges you faced?**
- 4. Could you describe how you have tried to manage the challenges faced?**
- 5. Have you received support from other in dealing with these challenges? In particular the URCS?**
- 6. What kind of support did you get?**
- 7. To what extent did this help to deal with the challenges faced?**
- 8. Do you feel you needed (or need) additional support?**
9. Did you feel that you were trained enough to participate in this response?
10. If not, what did you feel you lacked training in?
11. What did you perceive as being the main benefit of your work?
12. Did you feel that the tasks given to you were always clear?
13. What motivated you to volunteer in such a high risk situation?
14. Was there anything you missed in the co-ordination of the URCS?
15. How were the external coordination mechanisms with regards to PSS and the engagement of RCRC in these?
16. How effective was the coordination and did PSS enhance communication between partners that resulted in improved response?
17. Do you think that including PSS facilitated the response?
18. Did PSS prove to be effective in social mobilization? If so how? If not, why not?
19. Did PSS prove to be effective with regards to behavior change? If so how? If not why not?
20. What is the added value of PSS for communities?
21. .How does PSS contribute to reducing mortality and morbidity?

References

- ⁱ Brymer M, Layne C, Pynoos R, Ruzek J, Steinberg A, Vernberg E, et al. *The Psychological First Aid Field Operations Guide*, Second ed. Terrorism and Disaster Branch, National Child Traumatic Stress Network, National Center for PTSD, 2006. Available online at: www.ncptsd.va.gov/ncmain/ncdocs/manuals/PFA_2ndEditionwithappendices.pdf (Accessed September 17, 2007).
- ⁱⁱ Prewitt Diaz, J.O., Murthy, R.S., & Lakshimanarayana,R.(2006). Advances in disaster mental health and psychological support. Voluntary Health Association of India Press, American Red Cross.
- ⁱⁱⁱ Alexander, D.A.(2005). Early mental health interventions after disasters. *Journal of Continuing professional development*, 11, page: 12-18. DOI: 10.1192/apt.11.1.12
- ^{iv} . Gray GM, Ropeik DP. Dealing with the dangers of fear: the role of risk communication. *Health Aff (Millwood)* 2002; 21:106–16.
- ^v Das V. Stigma, contagion, defect: issues in the anthropology of publichealth. *Stigma and Global Health: Developing a Research Agenda*; 2001 September 5–7; Bethesda, Maryland. [cited 2003 Aug 8]. Available from: <http://www.stigmaconference.nih.gov/FinalDas> Paper.htm.
- ^{vi} . Agency for Toxic Substances and Disease Registry. A primer on health risk communication principles and practices. The Agency. Available from: URL: <http://www.atsdr.cdc.gov/HEC/primer.html>
- ^{vii} . Chesney MA, Smith AW. Critical delays in HIV testing and care: the potential role of stigma. *Am Behav Sci* 1999;42:1162–74.
- ^{viii} Weiss MG, Ramakrishna J. Stigma interventions and research for international health. *Stigma and Global Health: Developing a Research Agenda*; 2001 September 5–7; Bethesda, Maryland. [cited 2003 Aug 1]. Available from: URL: <http://www.stigmaconference.nih.gov/FinalWeissPaper.htm>
- ^{ix} Centers for Disease Control and Prevention. Use of quarantine to prevent transmission of severe acute respiratory syndrome—Taiwan, 2003. *MMWR Morb Mortal Wkly Rep* 2003;52:680–3.

^x Weiss MG, Ramakrishna J. Stigma interventions and research for international health. *Stigma and Global Health: Developing a Research Agenda*; 2001 September 5–7; Bethesda, Maryland. [cited 2003 Aug 1]. Available from: URL: <http://www.stigmaconference.nih.gov/FinalWeissPaper.htm>

^{xi} Gray GM, Ropeik DP. Dealing with the dangers of fear: the role of risk communication. *Health Aff (Millwood)* 2002; 21:106–16.

xii

^{xiii} Maunder, R.G., Leszcz, M., Savage, D., Adam, M.A., Peladeau, N., Romano, D., Rose, M., & Schulman, B. (2008). Applying the lessons of SARS to pandemic influenza: An evidence-based approach to mitigating the stress experienced by healthcare workers. November/December 2008, Vol. 99, No. 6

^{xiv} Thormar, S.B., Gersons, B.P.R., Juen, B, Djakababa, N., Karlsson, T. & Olff, M. (2012). Organisational factors and mental health in community volunteers: the role of exposure, preparation, training and tasks assigned and support. *Anxiety, stress & Coping: An international Journal*, DOI:10.1080/10615806.2012.743021.

^{xv} Maunder R, Lancee WJ, Rourke SB, Hunter J, Goldbloom DS, Petryshen PM, et al. The experience of the 2003 SARS outbreak as a traumatic stress among frontline healthcare workers in Toronto: Lessons learned. In: McLean AR, May RM, Pattison J, Weiss RA (Eds.), *SARS: A Case Study in Emerging Infections*. Oxford: Oxford University Press, 2005;96-106.

^{xvi} Tam CW, Pang EP, Lam LC, Chiu HF. Severe acute respiratory syndrome (SARS) in Hong Kong in 2003: Stress and psychological impact among frontline healthcare workers. *Psychol Med* 2004;34(7):1197-204.

^{xvii} Chan AO, Huak CY. Psychological impact of the 2003 severe acute respiratory syndrome outbreak on health care workers in a medium size regional general hospital in Singapore. *Occup Med (Lond)* 2004;54(3):190-96.

^{xviii} Nickell LA, Crighton EJ, Tracy CS, Al Enazy H, Bolaji Y, Hanjrah S, et al. Psychosocial effects of SARS on hospital staff: Survey of a large tertiary care institution. *CMAJ* 2004;170(5):793-98.

^{xix} . Maunder RG, Lancee WJ, Rourke S, Hunter JJ, Goldbloom D, Balderson K, et al. Factors associated with the psychological impact of severe acute respiratory syndrome on nurses and other hospital workers in Toronto. *Psychosomatic Med* 2004;66(6):938-42.

^{xx} Birmes, P. J., Brunet, A., Coppin-Calmes, D., Arbus, C., Coppin, D., Charlet, J. P. et al. (2005). Symptoms of peritraumatic and acute traumatic stress among victims of an industrial disaster. *Psychiatric Services*, 56(1), 93-95. DOI: 10.1176/appi.ps.56.1.93.

^{xxi} Weiss MG, Ramakrishna J. Stigma interventions and research for international health. Stigma and Global Health: Developing a Research Agenda; 2001 September 5–7; Bethesda, Maryland. [cited 2003 Aug 1]. Available from: URL: <http://www.stigmaconference.nih.gov/FinalWeissPaper.htm>

^{xxii} Centers for Disease Control and Prevention. Use of quarantine to prevent transmission of severe acute respiratory syndrome—Taiwan, 2003. *MMWR Morb Mortal Wkly Rep* 2003;52:680–3.

^{xxiii} . Gray GM, Ropeik DP. Dealing with the dangers of fear: the role of risk communication. *Health Aff (Millwood)* 2002; 21:106–16.

^{xxiv} Das V. Stigma, contagion, defect: issues in the anthropology of publichealth. Stigma and Global Health: Developing a Research Agenda; 2001 September 5–7; Bethesda, Maryland. [cited 2003 Aug 8]. Available from: <http://www.stigmaconference.nih.gov/FinalDas Paper.htm>.

^{xxv} . Agency for Toxic Substances and Disease Registry. A primer on health risk communication principles and practices. The Agency. Available from: URL: <http://www.atsdr.cdc.gov/HEC/primer.html>

^{xxvi} . Chesney MA, Smith AW. Critical delays in HIV testing and care: the potential role of stigma. *Am Behav Sci* 1999;42:1162–74.

^{xxvii} Weiss MG, Ramakrishna J. Stigma interventions and research for international health. Stigma and Global Health: Developing a Research Agenda; 2001 September 5–7; Bethesda, Maryland. [cited 2003 Aug 1]. Available from: URL: <http://www.stigmaconference.nih.gov/FinalWeissPaper.htm>

^{xxviii} Centers for Disease Control and Prevention. Use of quarantine to prevent transmission of severe acute respiratory syndrome—Taiwan, 2003. *MMWR Morb Mortal Wkly Rep* 2003;52:680–3.

^{xxix} Weiss MG, Ramakrishna J. Stigma interventions and research for international health. *Stigma and Global Health: Developing a Research Agenda*; 2001 September 5–7; Bethesda, Maryland. [cited 2003 Aug 1]. Available from: URL: <http://www.stigmaconference.nih.gov/FinalWeissPaper.htm>

^{xxx} Gray GM, Ropeik DP. Dealing with the dangers of fear: the role of risk communication. *Health Aff (Millwood)* 2002; 21:106–16.

^{xxxi}

^{xxxii} Schulze B, Angermeyer MC. Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. *Soc Sci Med* 2003;56:299–312.

^{xxxiii} Herek GM. Thinking about AIDS and stigma: a psychologist's perspective. *J Law Med Ethics* 2002;30:594–607.

^{xxxiv} Lancee WJ, Maunder RG, Goldbloom DS, The co-authors of the Impact of SARS Study. The prevalence of mental disorders in Toronto hospital workers one to two years after SARS. *Psychiatric Services* 2008;59:91-95.

^{xxxv} Toronto Academic Health Sciences Network. *Pandemic Influenza Planning Guidelines*, 2006. Available online at: <http://portal.sw.ca/tahsn/default.aspx> (Accessed October 6, 2006).

^{xxxvi} National Strategy for Pandemic Influenza. Washington, DC: Homeland Security Council, Government of the United States, 2005.

^{xxxvii} Maunder RG, Lancee WJ, Balderson KE, Bennett JP, Borgundvaag B, Evans S, et al. Longterm psychological and occupational effects of providing hospital healthcare during SARS outbreak. *Emerg Infect Dis* 2006;12:1924-32.

^{xxxviii} . Maunder R, Hunter J, Vincent L, Bennett J, Peladeau N, Leszcz M, et al. The immediate psychological and occupational impact of the 2003 SARS outbreak in a teaching hospital. *CMAJ* 2003;168(10):1245-51.

^{xxxix} World Health Organisation & United Nations High Commissioner for Refugees. Participatory Assessment III: Perceptions by severely affected persons themselves. In: Toolkit for the Assessment of Mental Health and Psychosocial Needs and Resources in Major Humanitarian Settings. Geneva: WHO.

^{xl} Thormar, S.B., Gersons, B.P.R., Juen, B, Djakababa, N., Karlsson, T. & Olf, M.(2012). Organisational factors and mental health in community volunteers: the role of exposure, preparation, training and tasks assigned and support. . *Anxiety, stress & Coping: An international Journal*, DOI:10.1080/10615806.2012.743021.

^{xli} MAERCKER ETC

^{xlii} JAMA ARTICLE