Prioritizing psychosocial support for people affected by Ebola in Sierra Leone

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Photo 1: Community drama organized by AJLC for Ebola affected families  (Photographer: Nicholas Bishop - IOM)

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I. Introduction

Humanitarian emergencies, including conflict and natural disasters, affect more people than ever before (148 million in 2013 alone),1 significantly impact mental health and psychosocial wellbeing of affected populations and undermine family and community relationships and support2. The ongoing Ebola crisis has impacted the psychosocial health of the population of Sierra Leone. Research highlights that women, men, girls and boys who have been directly affected by Ebola Virus Disease (survivors, multiply bereaved, orphans, unaccompanied and separated children) experience multiple barriers to social integration, including relational difficulties, complex grief and stress. Affected people adapt to adversity and bring about resilience through a wide range of coping mechanisms, resources and strategies in a culturally meaningful way. The provision of psychosocial support will facilitate this resilience by addressing their psychosocial needs.

focused, non-specialized supports, such as Psychosocial First Aid (PFA) and basic mental health care by primary health workers, comprise the pyramid’s third layer and are necessary for the still smaller number of people who require additional and more focused individual, family or group interventions by trained and supervised workers.

Global evidence indicates that 10% – 15% of affected people will require specialized services, the pyramid’s final layer, such as professional psychological or psychiatric support.

II. Methodology

Over three months from March – June 2015, University College Cork and Trocaire conducted participatory research in partnership with Access to Justice Law Centre, Centre for Democracy and Human Rights and Justice and Peace Commission - Freetown This research was guided by a pragmatic research design and sought to identify what works and directly bring about changes in practice. In Kambia, Port Loko, Bombali and Western Area Rural District, two person teams made up of staff trained in Psychosocial First Aid (who acted as a facilitator) and a local researcher (who recorded, translated and transcribed the material) engaged in service-based research with women, men, girls and boys directly affected by Ebola. Interviews and group sessions were conducted in Temne, Limba or Krio and later transcribed in detail into English. Children participated in at least three small group sessions over a period of six weeks and these groups were composed of similar aged children of the same sex. Three participatory methods – storytelling, timelines and social mapping - were used to facilitate participants in discussing their experience of social integration either after their bereavement or

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Figure 1. IASC Intervention Pyramid
when they returned to the community from the treatment centre and using resources to bring about processes of resilience. Grounded Theory Analysis was the analytic method used.

There were 52 Adult participants;

- 60% women, 40% men.
- 88% Bereaved (51% women, 49% men).
- 40% Survivors (53% women, 47% men).
- 33% guardians for children orphaned by Ebola (79% women, 21% men).

There were an additional 12 Key informants: 50% women, 50% men.

There were 69 Child participants (under 18)
- Average age: 11 years
- 52% girls (10 years 11 months), 48% boys (10 years 9 months).

How affected by EVD?

- 60% orphaned (43% double orphans)
- 20% survivors
- 30% quarantined.

Facilitators invited participants from their PSS case load in affected communities and so had existing relationships with participants and were in a position to provide ongoing support and referral where necessary. Written informed consent was obtained from all participants and in addition parents or guardians of child participants also gave their consent. Voluntariness, the right to withdraw at any time, data protection, risks of participation, confidentiality and the limits of confidentiality were discussed with participants and any questions or concerns were addressed. Psychosocial referral pathways were in place and used.

III. Why is psychosocial support needed in a post-Ebola context?

As of July 6, 2015, there are a total of 4,048 EVD survivors in Sierra Leone. 3,589 people have died leaving bereaved families, many of whom experienced multiple bereavements. Epidemiological calculations estimate that in Sierra Leone there are 3,300 orphans as a result of Ebola, with over 100 orphans having lost both parents.

A significant effort has been carried out over the past year to respond to Ebola with the goal of eradicating the disease. Psychosocial support is essential for the efforts to reach zero and helps ensure that the response is as effective as possible. However, while getting to zero, it is necessary for the Government of Sierra Leone, international donor community, INGOs/NGOs and medical practitioners to address the long-term health needs of those who have been impacted by Ebola, including distress, anxiety, loss, grief, shame and suffering.

The Ebola outbreak has resulted in a wide range of psychosocial protection concerns experienced at the individual, family, community and societal levels. Over the course of the outbreak, normally protective supports such as school, work, basic preventative health, community groups and daily routines have been disrupted while pre-existing problems of social injustice and inequality have been amplified.

The following barriers to social integration were identified:

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4 NERC. EVD Daily MoHS Update. Available at: http://www.nerc.sl/.
Pre-existing (pre-emergency) psychosocial difficulties:

Individuals or groups that are marginalized or experience extreme poverty often find these social problems are exacerbated by a crisis. People who are already socially marginalized are more susceptible to discrimination in times of economic and social stress. For example, when families experience extreme economic pressures, teenage girls are more likely to be expected to engage in transactional sex to support themselves and their families than boys. Children in informal foster care or ‘men pikin’ may be less likely to have their school fees paid than other children in the family. Underlying discrimination on the basis of gender, age, disability or social location can be heightened in the emergency context. As would be expected, well-developed social capital and social networks prior to the emergency operate as protective factors.

Emergency induced psychosocial difficulties:

Many of the people interviewed reported experiences of complex grief associated with multiple losses. The specific context of Ebola and the problems that come with it (such as the fear of infection, being unable to care for loved ones, the shock caused by transportation to treatment centers and witnessing deaths and culturally inappropriate burial practices) complicated and, in some cases, heightened people’s experiences of bereavement and loss.

Stigma and discrimination affecting adult survivors and bereaved family members varies. Rather than widespread stigma, most people reported complex relational difficulties in one or two relationships. Interpersonal conflicts tended to be rooted in distrust and blame associated with specific events during the emergency rather than a person’s general status as a ‘survivor.’ In a number of cases, a person or family may blame a friend or neighbor for bringing Ebola to the community, infecting a loved one or calling 117 to report a suspected Ebola case. This breakdown in relationships is more complex than the concept of ‘stigma’ would suggest and requires a different kind of response. Rather than community level sensitization on Ebola, more focused approaches are needed based on conflict resolution and mediation so that trust and relationships can be rebuilt.

While adults tended to report that children did not experience discrimination, children confirmed that they did. A considerable proportion of children who survived Ebola or lost parents felt isolated in their peer groups and tended to socialize with other children who had been affected by Ebola. In a number of communities children reported deterioration in their relationships once school started, which highlights the need for continued interventions in schools and peer group settings.

Orphaned children and their guardians also reported challenges in adapting to new family structures. As many of the interviewed people came from Ebola hotspot communities, many had been multiply bereaved. Guardians, 79% of whom were women, had often lost a number of children to Ebola. The day they bring these children to me I was thinking how will I be able to provide food and shelter for them but I pray to God to give the strength to provide the basic amenities for these children and as time goes by I have [gotten] used to these new responsibilities.

Fatmata, Guardian caring for 10 EVD affected children (AJLC/K/R/ FC).

Photo 2: Isatu, an Ebola survivor, is taking part in Trócaire’s project to strengthen her livelihoods and to cope with distress. (Photographer: Michael Solis – Trócaire)
family members to Ebola and were caring for between one and ten additional children. Some children and their guardians reported shortages of food, bedding and funds for school fees. Some orphaned children felt they were treated differently compared to biological children (for example, by receiving excessive house and farm work or not returning for school). Guardians expressed difficulties in providing for children economically and emotionally, particularly as children were grieving and in some cases were distressed, withdrawn or exhibiting mood or emotional difficulties. **Ongoing family-focused support is necessary, emphasizing guardians and orphans to support the development of health-sustaining relationships and improved psychosocial wellbeing.**

Relational difficulties vary over time. Some participants reported that their friends and neighbors were initially distant but that relationships gradually improved, while others felt they were welcomed warmly but experienced difficulties in some relationships as time went on. Needs change over time and even initially supportive environments can experience significant stress and tension when external support and attention decreases in the post-emergency phase. **This supports the need for long-term relational support, including family-focused community-based interventions.**

**Psychosocial difficulties associated with humanitarian aid and Ebola response:**

Distress induced as a result of the humanitarian response itself is a problem and must be prevented.

Health and social workers noted that explicitly targeting survivors for support causes resentment and can hinder reintegration. **Publically identified survivor specific services (i.e. “Survivors’ centers” or clinics) are not recommended.** Global evidence (see for example, IASC, 2007) supports **service provision on the basis of identified need rather than crude categories** such as “Ebola survivors” or “Ebola orphans.” **Specialized support should be provided for workers,** who can experience distress as a result of aiding people who have been affected by Ebola.

Severe distress has been experienced by families who remain unaware of the status or whereabouts of their loved ones. In a number of cases (over twenty in the Northern Region alone) parents have not received information regarding the whereabouts of their children who were taken by ambulance for treatment. Many of these cases originate in October, November and December 2014. Parents have in some cases received conflicting information from different service providers and do not know whether their children are still alive or have died. **People have a right to truth, information and acknowledgement in cases of failures made during the response. Information retrieval and investigations are required in cases of children who were taken for treatment and have not been accounted for and also in determining the location of burial sites of patients buried early in the response. Acknowledgement of harm, apology and symbolic reparation may be required.**

In Western Area, there were a small number of cases of children who were transported to Western Area for treatment from other districts and following their recovery were ‘reintegrated’ into local communities rather than returned to their home district. In one such case, the 14 year old girl involved reported that she was sexually exploited by an adult who had volunteered to care for her. Also in Western Area, researchers raised significant concerns about an independent, privately run orphanage caring for 19 children orphaned by Ebola where the sole staff member reported that she did not feel competent in caring for the children and would not permit the children’s families to visit them as she felt it was disruptive. The Ministry of Social Welfare, Gender and Children’s Affairs are conducting ongoing investigations into these cases, which raise significant protection concerns. **Family Tracing and Reunification processes require significant strengthening to ensure that all available options for care within the extended family and community of origin, with financial and psychosocial support if required, are exhausted before alternative care arrangements with vetted foster families are explored. Institutional care is not recommended and should only be used as a very short term measure while putting support structures in place to ensure safe and secure family placements.**
Another difficulty that has contributed to increased spiritual distress and harm is the fact that burials of Ebola victims did not follow culturally appropriate burial practices. This was particularly true during the first six months when people were buried in unmarked graves. **Appropriate memorials and remembrance ceremonies should be developed with individuals, families and communities in a way that is meaningful to them. Information retrieval regarding the location of appropriately marked burial is essential and should not be delayed any further. The Government of Sierra Leone should ensure that support is made available to families to design meaningful commemoration and remembrance ceremonies for their loved ones.**

**Resources and Strategies people use to build resilience:**

Children and adults talked about ways that they bring about a sense of safety, calming, self and community efficacy, connectedness and hope in their own lives. These five elements have been identified as key to effective emergency psychosocial programming. It is important for all stakeholders to learn how individuals, families and communities engage in these coping mechanisms so psychosocial interventions can be constructed based on the local context.

Adults and children attempted to bring about a sense of safety during the outbreak by practicing infection control measures, sharing stories, parables and songs about Ebola and listening to news about Ebola on the radio. Many participants made sense of the outbreak in spiritual terms, although they also accepted the medical and biological basis of EVD. Telling stories about the origin of the outbreak (for example, a curse, a witch plane crash and a prophecy) helped participants feel safe in some cases. However, the excessive focus on Ebola can lead to rumination and feeling worse about problems. A psychosocial lens should be used to design public information and social mobilization campaigns during EVD outbreaks, ensuring that governments, UN and humanitarian actors engage in dignified and open dialogue with affected communities. Confused, frightening and contradictory messages must be avoided.

Children and adults used a range of methods to try to calm themselves, including self-medicating with pills. There is clearly a locally expressed need for calming and relaxation that is not currently being adequately met. **Resources are required to fund programs, incorporating relaxation techniques (breathing exercises, traditional dance, music), sleep hygiene, practical skills and stress management for dealing with acute anxiety and stress. More targeted approaches such as grief and bereavement counseling or economic support will also be necessary in some cases.**

Participants promoted connectedness within their relationships, families and communities. There are numerous stories of people reaching out to support each other during quarantine, when family members were in treatment or when survivors returned to communities. Participants reached out to others to promote their own connectedness when they needed it.

While orphaned children and their guardians experienced difficulties negotiating new family structures, children also experienced problems in peer relationships. Safiatu, an 18 year old woman who lost her husband, three children, mother and father to Ebola, described how she attempts to provide a safe base for the children in her care.

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7 All names of beneficiaries quoted have been changed to protect their privacy.
For young women like Safiatu, short-term economic support is welcome but insufficient, as long-term, family-focused interventions either individually or ideally in a group setting are required. **Family-focused interventions that are supported by the government and/or donors through bilateral aid allocations can bring parents/guardians and children together to promote understanding and positive patterns of relating, reduce conflict and strengthen people's tools and strategies for coping with difficulties.** There are indications that interventions carried out to date to respond to people's psychosocial needs have had positive effects on their wellbeing. They are able to come to terms with the crises while forgiving those that they may have initially blamed.

**IV. What is needed for the development of successful psychosocial interventions?**

Long-term and appropriately resourced psychosocial service provision is required to respond to locally identified needs. Training, supervision and resourcing of national community-based staff is needed. Short-term project-based funding is not sufficient to meet the psychosocial needs identified. Without adequate support, follow-up and acknowledgment of the impact of the crisis on people’s lives, livelihoods and long-term wellbeing will be compromised. Appropriate, community-based programming will prevent escalation of problems and a resulting strain on clinical settings.

*Psychosocial interventions should draw on existing familial, social and cultural systems in facilitating psychosocial recovery.* Effective interventions will mimic naturally occurring supports and utilize local resources and strategies that foster wellbeing and bring about resilience at family and community levels. This can involve linking to existing family and community support, focused, non-specialized supports and specialized services. Strong referral mechanisms within and between intervention layers are essential. Further, this approach should be intersectoral, making sure healthcare workers, teachers and child protection workers are trained in psychosocial practices. The reasons for prioritizing long-term, psychosocial support programs include the following:

- They respond to a need that has not yet been prioritized as a necessary part of a humanitarian response
- They are cost effective. For instance, with $200,000 it is possible to implement a tailored family-focused intervention with 120 guardians and children in 6 severely affected communities over 18 months.  
- This is the ideal time to invest in these types of programs. Appropriate, community-based programming will prevent escalation of problems and strain on clinical settings. As is such, there is a strong case for encouraging international aid agencies and civil society organizations to work in tandem to respond to the psychosocial needs of Ebola-affected communities.

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8 This would include the creation of sustainable community systems, training community counselors, individual and group counseling sessions, partner operational costs, communications costs, and a PSS health line. Staff costs, supervision and training are essential.
Rigorous evaluations of socio-culturally adapted low cost, scaleable psychosocial interventions for girls, boys, women and men, families and communities are essential. A recent meta-analysis\(^9\) found that although the vast majority of mental health and psychosocial support programming in humanitarian settings focuses on strengthening family and community based supports, the available research evidence focuses almost exclusively on the top layer of specialised clinical mental health services, which are required only for a very small subset of a disaster affected population. The risk of causing harm by continuing to implement untested interventions is significant. The lack of a solid evidence base is one factor in the continued implementation of ineffective programming, for example psychological debriefing, which has been found to exacerbate symptoms of distress\(^10\). A recent systematic consultation of humanitarian practitioners and academics emphasised the urgent priority for “research that achieves tangible benefits for programming and gives emphasis to participation with and sensitivity to, the specific socio-cultural context of populations living in humanitarian settings.”\(^11\) This process generated a consensus based research agenda to guide the field from 2011 to 2021, where the highest rated research questions related to psychosocial interventions were “How best can we adapt existing mental health and psychosocial interventions to different socio-cultural settings?” and “What is the effectiveness of family based interventions to prevent mental disorders and protect and promote psychosocial wellbeing and mental health among children and adolescents in humanitarian settings?”

An inter-agency working group comprised of Trócaire, International Medical Corps, Plan International, Save the Children, Medicos del Mundo, CAPS Sierra Leone, International Organization for Migration, Mental Health Coalition, Enabling Access and UNICEF was established in June 2015 under the Child Protection and Psychosocial Support Pillar of the National Ebola Response Centre to implement the recommendations of the research by developing socio-culturally adapted, empirically informed tools and methodologies for psychosocial programming in Sierra Leone. This group of agencies is engaged in an ongoing process to identify, adapt and rigorously evaluate scaleable psychosocial interventions that can be delivered by lay practitioners to respond to current and future crises within Sierra Leone and support adaptive responses to adversity and resilience within families and communities.

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