

Increasing early presentation to ECU through improving care

Ebola Response Anthropology Platform

Briefing Note for Sub-SAGE meeting 30-10-2014

Key points

1. Improving care at the ECU is key to increase early presentation. When care is considered effective – from medical and social perspectives- people will seek it, and this will be an important incentive to presentation. Survivors and caretakers –mostly women- are at the centre of improving all care. They need to be recognized.
2. A significant proportion of the resources –material and immaterial- spent on ECUs need to be channelled to making ECUs more socially integrated.

Background:

Current Ebola epidemic control policy in Sierra Leone focuses on (a) triage and isolation in decentralised, ideally community-based Ebola Care Units (ECUs), leading to (b) transfer to Ebola treatment units (ETUs) for those diagnosed as positive.

Increasing early presentation to ECUs is essential for this strategy to be effective in reducing R_0 . This note outlines ways in which improved and socially-appropriate care – in ECUs, and at home – can assist this.

Authorship and Contributors

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This briefing notes represents the views of the Ebola Response Anthropology Platform. The above contributors do not necessarily agree with all of the briefing note's contents.

Care in ECUs

With the emphasis on epidemic control, ECUs are currently being framed largely as triage units through which people will ideally move quite rapidly.

However improving care at the ECU is key to increase early presentation. When care is considered effective – from medical and social perspectives- people will seek it, and this will be an important incentive to presentation.

Care can be medically poor (and at ECUs it will not be of the biomedical standards aspired to in ETUs) but socially still acceptable and valued and vice versa. Realistically, Ebola care at an ECU may amount to palliative care and be perceived as such, as people can see that most people die of Ebola. This may change if rapid transfer to more biomedically-effective ETUs can be assured. Meanwhile the personal medical incentives to present at an ECU are rather low. This means that making them socially welcoming places, where care (even if not treatment) is given, is particularly important.

A significant proportion of the resources spent on ECUs need to be channelled to making ECUs more socially integrated. Ideally each ECU should have two 'social managers', identified from amongst trusted local leadership structures (formal or informal), to develop and implement an ECU social action plan and institute community oversight committees with representatives from key social groups (women, youth, etc). The reason why there need to be two social managers for ECUs is to improve transparency and prevent (false) accusations as well as giving these managers moral and practical support. A concern is to promote the involvement of youth representatives on this committee.

These should include local religious leaders and respected members of men's/women's societies. They could be encouraged to visit ECUs, with appropriate transport costs reimbursed.

Such respected visitors from the community could also act as 'witnesses' to positive social and care practices there, and to the absence of feared activities (such as body part theft, killing of patients or that units are 'cash cows' for aid agencies and politicians) - reporting these back to others in their communities.

The ill like to be visited, and carers like people to visit. It is important to ensure that ECUs (and eventually ETUs) are set up to welcome visitors – with video links etc. Used if necessary at larger facilities with tighter isolation.

There has been much community worry and uncertainty about 'losing' family members into large ETUs of unknown location. Although this seems a lesser risk with community ECUs, these fears may remain. Each ECU therefore needs to have a system to identify its patients (eg. an arm band) which could follow patients from ECU to ETU. If a patient dies it could be disinfected and returned to the family (it will acquire significance) and provide continued information on burial locations etc.

Women are the main Ebola care providers to family members. Experience shows that mothers are very unlikely to abandon their children –especially sick children- to present at an ECU even if they know this will cost them their own life. The individual medical benefits of presenting at an ECU do not outweigh the social and personal costs. If we want women to go for testing and seek care it is important to make sure that their children are taken care of appropriately too, in ways that mothers perceive as good. Evidence from urban Liberia of 'community quarantining' of the small children of infected mothers who go to ECUs/ETUs – children who subsequently suffer physically and emotionally – underlines this need.

Management of discordant mothers/children is hugely problematic as it is difficult to find ways in which childcare can be assured. With mother isolated and baby in the community - there will be mechanisms for looking after children whose mothers are sick or dead e.g. with within wider kinship groups, however these are likely to be quickly overwhelmed and may not be as open to a potentially infectious baby who needs to be fed, cuddled and kept clean. If the baby is isolated, it's even harder to see how this is ever going to work. It is plausible that an uninfected baby has a better survival rate staying with their infected mother than the increased risk of non-Ebola death that comes with being removed from her.

Survivors and caretakers are at the centre of improving all care. When communities hear from survivors that the care to the dying is bad, that there is no medical staff and that there are no medicines to ease the pain they are likely to avoid ECU. The expertise of survivors has to be used to build better care –also for the dying. Being able to share personal experiences and being heard has individual psychological benefits –allowing people to heal- and can help to improve the care system based on concrete lived experiences. However, **if the survivors are going to be used to convey positive experiences, there will also need to be an appropriate mechanism for redress for negative experiences.**

Reports on the reintegration of survivors are –with some hopeful exceptions- rather bleak. Social stigma, loss of property and income and fear are commonly reported. When survivors are not treated properly it might encourage people with symptoms to deny and hide these. The life of survivors has to inspire people to go for treatment and become a survivor.

Free rapid testing of Ebola and other diseases and counselling is a key entry point for the provision of care. Without rapid testing to determine positive or negative Ebola status and other diseases – such as malaria- people will avoid the ECU as they will fear their symptoms might cause them to be locked up with Ebola patients. The only invasive test that is likely to be available and useful is malaria RDTs. There are barely any functioning labs for other tests. RDTs only require a drop of blood so it should be possible to take that drop at the same time as they take blood for the ebola test (which presumably everyone is getting) so this shouldn't represent any additional risk to the person taking the blood. However, if there is no care or if there is a fear for forced quarantine the motivations for people come for testing might be pretty low.

The provision of effective (preferably rapidly so) treatment for conditions other than Ebola needs more attention. We can't cure most people with Ebola, but we can cure the vast majority of people with pneumonia and malaria, two very common causes of fever in Sierra Leone. Providing caretakers at ECU with basic training on basic health training would probably save lives. If that is not feasible a stock of antibiotics for Ebola negative people with fever who are breathing fast, and a stock of ACT for Ebola negative but malaria RDT positive might go a long way to encouraging people to present.

Families are economic units within a broader kinship and community network with economic rights and duties of the members shaped by class, gender, age as well as other characteristics. These relations, rights and duties affect individual and familial health seeking behaviour. Potential loss of earning or labour (unpaid care) is a factor in presenting at an ECU –as not just the individual but his or whole family- is now at risk as being seen as potentially infected.

Care at home

Given the above, especially the poor medical outcomes of care and existing gender relations, home based care in a familial context is likely to be a preferred option for a significant part of the population. A realistic approach to ECUs for human rights and public health related reasons is therefore to see ECU as part of a network of care in which home-based care is an option. Individuals and families should make their choices for care based on informed consent taking both medical and social outcomes into consideration.

Home-based care is often framed as a 'desperate measure' only for those who cannot reach ECUs. However it is better framed as pre-ECU/ETU care, which not just fills the gap until or unless people can get to an ECU, but can actually assist early presentation.

Even with large numbers of small community care units, there will still be many challenges in getting symptomatic people to self-present within 3 days. Giving families and other community members stocks of PPE, and/or basic gloves, aprons, buckets and disinfectant, and basic training with how to use them when preparing for/during transport to an ECU/ETU, alongside appropriate dialogue about the need to do so is essential. Survivors can also play a very important role in home care, both in distributing materials and in counselling and supporting the care givers. Properly equipping families to provide safe care –including care during transport- will mean:

- a) Those living with, caring and transporting the patient have a small reduced risk of transmission, that could have a small but appreciable effect on the epidemic curve
- b) There would be a real and tangible way for anyone (if done well) to engage in the biomedical approach to managing the epidemic, should they choose to, even at home. Done well, this would go some way to avoid the current situation where there are conflicting messages about e.g. needing to get to care facilities, yet being unable and being given no assistance to do so, break down any barriers that are conversely caused by fear of transmission e.g. those transporting the patient refusing to do so, and be a very achievable first step along the pathway to getting the patient to an appropriate care facility.

Of course, some of this protective equipment might get used to treat people who continue to stay at home, or by other non-formal health staff who continue to see patients outside ECUs/ETUs. However this would create only a negligible additional cost, while availability of these protective materials would be unlikely to be a decisive factor in people's the decisions around whether or not to present to a formal health facility.

Caring at home should be valued, and carers treated as the heroes/heroines that they are. Home carers could be rewarded when they encourage their patients to come to ECUs. This could be a small financial reward, or the promise of care for themselves should they become sick.

Accommodation for home carers could be provided near ECUs or ETUs. Carers, after all, are more likely also to have become infected (and will be worried). They could be prioritised for early testing.