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Ebola in children: a personal perspective

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Abstract

This article documents reflections of a paediatrician working with the medical non-governmental organisation, Médecins Sans Frontières, in two Ebola Management Centres in Sierra Leone, in December 2014 and January 2015.

Keywords: Ebola, children

This article documents reflections of a paediatrician working with the medical non-governmental organisation, Médecins Sans Frontières, in two Ebola Management Centres in Sierra Leone, in December 2014 and January 2015. Patient names have been amended.

The 2014 Ebola virus outbreak in West Africa is unprecedented in terms of scale and international response. It is estimated that 3,922 children under 14 have had confirmed or probable Ebola virus disease (EVD) by 29 April 2015 [1]. As with previous outbreaks, children are under-represented in the epidemic, probably reflecting less exposure rather than reduced susceptibility to the virus [2]. The clinical consequences of EVD in paediatric patients have been sparsely documented but in the current epidemic, children aged under 4 years have the highest mortality [3]. They are likely to have different pathophysiological responses and may require different treatment approaches compared to adults [4–6].The impact of the outbreak on children includes high parent mortality and prolonged school closures, and reaches far beyond biomedical issues [7,8]. The following are personal reflections, based on caring for children and young persons with EVD and working alongside health workers in Sierra Leone.

From arrival to discharge in the Ebola management centre

Children and adolescents attended the Ebola management centres as suspected cases prior to test confirmation, as confirmed cases from holding centres or (rarely) as dependants of mothers, where there were no alternative care arrangements. The last scenario occurred when services were overwhelmed, patients were far from home and inevitably, children had already had significant exposure to the virus. The journeys were often long, uncomfortable, hot and sometimes spent next to those who had died en route. With this terrifying and debilitating backdrop, children arrived in management centres, to be greeted by staff wearing full personal protective equipment.

Counselling before and after giving the diagnosis of EVD reminded me of counselling for human immunodeficiency virus (HIV) in sub-Saharan Africa before the arrival of antiretroviral drugs. HIV was (and still can be) an infection that leads to people being insulted and rejected. In the 1990s and since, a lot of thought has been given to pre-test and post-test HIV counselling. In this outbreak, a diagnosis of EVD in the perception of many patients equated to suffering and death, but counselling was limited in the first instance. The child or young person who had a positive blood result had to be transferred quickly from the 'suspect' tent to the 'confirmed' area. This was to make space for new patients with suspected infections who, for reasons of infection control, could not be placed next to someone with confirmed EVD. This haste meant the counselling process was sympathetic, provided encouragement and advice, but could be as brief as five minutes.

If children with suspected or confirmed EVD had no infected family members, it was the norm to admit them to an Ebola management centre without a parent or familiar adult. Healthcare providers therefore became the temporary guardians of unaccompanied children. The duty of care extended beyond the medical needs to all needs, including the child's safeguarding – a unique responsibility, greater than in any other health intervention. Although there was concern for children for their isolation and vulnerability, guardianship was a new experience for us as health staff.

Medical care for children requires specific attention. Maintaining fluid balance in a sick child can be difficult even in a resource-rich setting, especially when there is an unquantified shift between the intravascular and extravascular compartments. In children who had less severe symptoms, we were encouraging frequent drinks of oral rehydration solution. This kept them hydrated and compensated for extra losses from diarrhoea, vomiting and fever. Making sure that children drink sufficient quantities of the solution is a difficult task even when they are held in their mothers' arms. It is far harder to achieve when an unaccompanied child is cared for by a stream of health workers, with timed interventions while in personal protective clothing. Intravenous fluids were delivered through precious cannulas, with no measure of electrolytes or renal function. We had good antibiotics and antimalarial medication, so important co-morbidities were treated, and we had anti-emetics and analgesics so symptoms could be alleviated. Survival seemed all about getting the fluid right until their bodies won the battle against Ebola. Ensuring early aggressive symptom relief or palliation was another critical intervention; however, some health workers hesitated to give fentanyl, morphine or diazepam to patients for fear of respiratory depression.

Musa, a 5-year-old boy, was admitted prostrate and febrile with diarrhoea. His grandmother was in the centre convalescing but she needed encouragement to care for him, as – despite our reassurance – she feared her own health would deteriorate as a result. He had intravenous fluids for four days before he showed an interest in his surroundings and started drinking more than just sips. Each improvement led to an excited handover from one shift to the next: 'his diarrhoea has stopped';'he can sit and ate some rice'; 'Musa is walking!' All we had done was maintain his hydration status and treat potential co-morbidities, but that was enough for him to recover and return to his family and village: a hero who beat Ebola. Others were not so fortunate. Sulayman, aged 14, arrived with cardiovascular compromise and a respiratory rate that felt disproportionately high. He died on the day of arrival, despite our efforts. In Sierra Leone, death from EVD is a more likely outcome than survival, with case fatality rates in

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children under 16 estimated at 56–86% [3]. How, in the present day, can we place so many children in body bags? The epidemic of injustice allows there to be minimal resources where there are the greatest needs. This fact continues to astound me; and I trust it astounds anyone else with a rational mind and a compassionate heart.

When children started to recover and began to comprehend their surroundings, they were often withdrawn. This was understandable, as they were isolated from their families, may have witnessed the death of a sibling or parent, and were recovering from an illness in a new, unusual environment where needles and oral rehydration fluid were compulsory. A paced, age-appropriate engagement with children was paramount but was not universally achieved in this 'outbreak' situation. Children became carers of their younger siblings and, because it was touching to witness this caring relationship, it was easy to overlook the fact that the carer was a young person too, with their own needs. Survivors were sometimes employed to care for children in the high-risk area. With supervision, this practice could improve hygiene, nutrition, fluid support as well as psychological well-being. In one centre, children were shown the process of dressing into protective clothing, so they could link a person to the friendly monsters in yellow suits.

Discharge, although an incredibly positive moment, was often filled with apprehension, as children may have lost parents and siblings. Ten-year-old Ibrahim was with his mother, and very excited about their discharge home; and so were we. His smile, not seen so often before, was irrepressible and he wanted to ride his bike again. On arrival in the village, however, Ibrahim and his mother brought the news that Ibrahim's elder sister had died in the treatment centre, so the celebration transformed to mourning, and his jubilation transformed to distress.

Not every child had a known relative; however, the duty to bring children back to a safe environment was critical. How do you find the correct aunt or uncle in a pre-verbal child who may have originally come from a different district far from the treatment centre? There were great examples of interim care before careful reunification, but there were also claims to children by strangers. Safeguarding was more challenging and at the same time more central to care than in other epidemics, when parents are with their children.

Beyond the Ebola management centre

Health workers were sometimes restricted, not only by crude medical tools, but also by where we could go. Some staff working in health centres that were not focused on Ebola were left for days and weeks without relevant knowledge or equipment with which to protect themselves. Meticulous contact tracing was attempted but was far from universal. Households were placed in strict quarantine but often lacked basic commodities and access to healthcare. The death toll owing to absent services and restricted movement meant many children died outside Ebola management centres, from EVD and other causes. In Bo District, during the last 4 months of 2014 more than 95% of pre-burial mouth swabs in children 5 years and under did not have evidence of Ebola. One could argue that there may have been some false-negative swabs and not all deaths were related to the Ebola epidemic but regardless, the toll from non-Ebola killers was high. Malaria, diarrhoea, pneumonia and neonatal deaths are all too prevalent in Sierra Leone and the pre-Ebola under-five mortality rate has been reported as a staggering 161/1000 live births [9].

The future

The ease of hindsight makes us realise we (everyone) did not act quickly enough to stop this fragile virus wreaking havoc in the lives of West Africans and beyond. We simply did not stop the chain of transmission. As well as the public health catastrophe, we also lost many precious opportunities to learn in real time, through prospective clinical and laboratory data and understanding social barriers, how to change behaviour.

Genomic and proteomic analysis of samples will continue to elucidate host responses and pathophysiological mechanisms. There has been rejuvenation of vaccine development and the start of the first vaccine trial in Liberia in February 2015. Monoclonal antibodies, convalescent serum and antiviral drugs all offer hope beyond supportive care [10]. The outbreak highlighted the lack of global frameworks to guide the use of unapproved interventions, on compassionate grounds, in the context of humanitarian emergencies. This shortcoming has led to a pledge by African authorities to establish a collaborative mechanism for fast tracking approvals for clinical trials and registration of Ebola-related products in affected countries [11]. This fast track, however, does not exclude interventions from controlled trials once emergencies are over.

It must now be impossible to walk away from the countries hit by Ebola. If there is a positive aspect for children in West Africa, it is the possibility for greater investment in their health, their countries' health workers and future epidemic control.

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