Urgent call for a global enforcement of the public sharing of health emergencies data: lesson learned from serious arboviral disease epidemics in Sudan

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One crucial element of the timely detection and identification of the causative agent(s) of a health emergency is access to live and historical data about the health risks in the area of concern. Therefore, sharing data on health emergencies is essential to the early investigation and detection teams. Although, theoretically, there is a global agreement on sharing data rapidly, in practice this is not always the case, particularly in developing countries such as Sudan, where there is continuous failure in making epidemics-related data publicly available. An alternative model for information and data sharing is suggested.

Keywords: arboviral diseases, data sharing, epidemics, information sharing, health emergencies, publicly available data, Sudan

In this communication, the current situation of data sharing in Sudan will be explained, important limitations will be discussed and solutions for more efficient and timely data sharing will be offered.

When epidemics or other serious health emergencies develop, having access to up-to-date data is necessary to execute timely and informed decisions on how to implement a strategic containment response. Otherwise there will be an increased risk of spreading the epidemic to new areas and greater loss in life and resources. For an effective response, historical and updated information is essential to save lives, time and resources. Investigating the causative agent(s) of an epidemic requires accessing information on the health profile of the area, which helps to identify the potential source(s) of risk.\textsuperscript{1} Also, it will help the population at risk, visitors and travellers to take personal preventive measures, including vaccination.\textsuperscript{2} In particular, epidemic of zoonotic diseases are correlated with changes in the interactions of humans, pathogens and animals with the environment. These changes could be in the circulating pathogens (emergence/re-emergence), the hosts’ population immunity and the introduction of susceptible/infected hosts.\textsuperscript{3,4} Therefore, having the latest knowledge about the risk of an infection in the area is instrumental to preventing and controlling communicable disease epidemics. Particular attention is needed in dealing with vector-borne diseases, because their successful control requires following one health approach with timely coordination between different directorates, including vector control, epidemiology, animal resources and health, social affairs and metrology.\textsuperscript{4,5}

Unfortunately, in spite of the declaration in 2015, from the World Health Organization consultation about the global dissemination of epidemics and health emergencies data, and the international commitment to share health emergencies data in a timely and transparent manner,\textsuperscript{1,5} many countries, like Sudan, still fail to declare health emergencies and do not publicly share their data. This lack of data sharing consistently leads to deterioration of the situation, greater financial loss, increased human and livestock deaths and the spread of infection into initially unaffected areas.\textsuperscript{3}

In Sudan, this absence of communicating information and lack of publicly available data are common practice. Our intent is thus to explain the risk of this practice to the public health of people and animals in Sudan and the countries sharing borders and/or direct travel routes, as well as other low- and middle-income countries. We also attempt to offer an alternative model for the sharing of information and data.

Sudan is suffering from a severe and rapidly growing public health problem that is directly linked to deadly outbreaks of mosquito-transmitted diseases, particularly arboviruses such as yellow fever (YF)\textsuperscript{6} and dengue fever (DF).\textsuperscript{4} A recent
large-scale outbreak of chikungunya virus and DF in East Sudan was announced by the Mediterranean Office of the WHO on 30 September 2018. This epidemic had been growing since 31 May 2018, starting from the coastal area of the Red Sea and spreading to Kassala state. There was a complete lack of information and data sharing from May to September and the number of cases had grown exponentially to >13,000 infections. The complete absence of data and information sharing and the lack of official communication (or clarification about the disease) intensified public fear and panic, which further nurtured rumours and false information and caused wild speculations. Some of the rumours suggested that it was an Ebola epidemic, and people fleeing the disease helped export the virus to many other previously unaffected areas, including at least seven states in Sudan and the bordering country of Eritrea. It was estimated that at least 1000 Eritrean cases were imported from Sudan, while reported cases in Sudan had risen to around 47,000 by early March 2019 (personal communication, Ministry of Health).

A similar scenario occurred in October 2012 during a YF epidemic in the Darfur area of western Sudan. This epidemic was considered the worst YF outbreak in Africa in decades, with 849 cases and 171 related deaths. Although the first suspected cases of YF were reported on 2 September 2012, an health emergency announcement was not released. By mid-February 2013, the WHO reported two confirmed cases of YF from the neighbouring country Chad which were suggested to have been imported from Darfur. Apparently the delayed disease announcement (data dissemination) and consequent lag in response time caused YF to spread unchecked throughout the Darfur region and into neighbouring countries.

More recently, in 2014–2015, dengue emerged among refugees living in the humanitarian crisis area of North Darfur state. Unfortunately, the lack of information and data available to local communities, healthcare providers and health partners about this public health issue resulted in an outbreak of dengue across the five states of Darfur in 2015–2016.

The hierarchy of the Sudan Ministry of Health is designed to collect data but not to share it (Figure 1). The current political transition in Sudan is repatriating many Sudanese to help in the country’s recovery. Highlighting the issue of information and data sharing might draw their attention to consider reshaping public health policy to correspond with International Health Regulations, which is vital to achieve universal health coverage. A clear, well-established communication channel and content is a crucial pillar of response, and containment strategies for epidemics and health emergencies, need to be in place as a core component of early preparedness (Figure 1).

Previous experience has shown that increased international travel and trade facilitate the easy and rapid movement not only of humans, but also of animals, vectors and pathogens. This is particularly true in the case of arboviral diseases, where most of their emergence and re-emergence is strongly correlated with international travellers, visitors, refugees and migrants moving through endemic areas. The Ebola pandemic in West Africa showed how quickly a disease can be distributed when communication fails and data are not shared. When a better data sharing strategy was put in place, the disease was successfully contained. Many deaths could have been averted if data and information had been shared in a timely manner.

In conclusion, we desperately need to cultivate a transparent and contemporary data sharing culture to help address and control disease epidemics and health emergencies before they increase in magnitude. There should be a global commitment to resolve this issue and fill crucial gaps in sharing health information, particularly considering that the right to access instantaneous health information is one of the pillars of universal health coverage, a global development goal that needs to be achieved. In Sudan and similar settings, this might require capacity building, advocating and raising awareness and political commitment.
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