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Ebola to 2030, chronicling a threatening epidemic disease against the backdrop of patient-centred innovation

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The Ebola virus is the causative agent of two recent public health emergencies of international concern, the 2018-2020 epidemic in the northeastern provinces of the Democratic Republic of Congo (DRC) and the 2013-2016 epidemic in West Africa, which resulted in 28,616 reported cases and 1,310 deaths. The Ebola virus was first identified in 1976 in the DRC, and the vast central African country has now experienced fourteen outbreaks. The epidemics that preceded the West African epidemic (with its urban expansions) had emerged in remote environments. They were associated with an average output of less than 300 reported cases, with a very high case-fatality rate of over 70% and rapid die-off with response measures restricted to isolation procedures.

The massive epidemics of 2013-2016 and 2018-2020 produced several thousand people considered cured. These so-called Ebola 'winners' are likely to experience post-infectious sequelae or the burden of social stigma as a survivor's double whammy. As an example, the 2018-2020 epidemic in the Great Lakes region took place in a critical context of under-resourced health care, major social and political instability, reluctance and denial on the part of the affected population, and civil war. All of these elements contributed to the mistrust and even violence towards the teams of health professionals involved in the response. This extreme health situation nevertheless saw, on the one hand, the deployment of an experimental vaccine with the aim of interrupting the chains of transmission among contacts of excretory patients and, on the other hand, the implementation of a clinical trial to evaluate the effectiveness of specific promising treatments.

The emblematic framework of the response to Ebola is the infrastructure for individual patient care (treatment and isolation) implemented by humanitarian medicine teams and known as the Ebola Treatment Centre (ETC). In 2019 and despite the misfortunes inflicted by factious groups, the ETC has undergone a major evolution in terms of architectural innovation and resolute positioning closer to the communities at risk. These innovative measures not only allowed for a densification of supportive care, but also for access to family members as visitors to the patient, without derogating from the principles of safety with regard to viral risk. The CTE ceases to be an exclusive quarantine area, but becomes a space capable of restoring confidence by integrating the constraints of the emergency, and in which a visible care project is built up where i) the best level of care is proposed, ii) the information available for the hospitalised patient and his or her entourage is given, iii) and finally the best level of information is produced by clinical research for the benefit of future patients. This area of conciliation between individual benefit and public health obligation developed in the context of a major humanitarian emergency and war is in line with the concept of patient-centred medicine and access to information supporting medical decisions, developed at international level in the context of access to the right to health. The experience of Ebola by 2030 in terms of innovation in the design and organisation of care should be applied to the management of future expressions of threatening diseases with epidemic propensity in the North and South.