

Social Science Lessons Learned from Cholera Epidemics

In this 'Social Science in Epidemics' series, different aspects of past disease outbreaks are reviewed in order to identify social science 'entry points' for emergency interventions and preparedness activities. This evidence will come together to determine tangible ways to better address the social, political and economic dynamics of epidemics; and to ensure that interventions build on the social and cultural resources of the communities they aim to support. This SSHAP Lessons Learned Summary explores lessons about the social dimensions of past and recent Cholera epidemics, highlighting recommendations for future responses.



11-year-old Angeline uses the Save the Children handwashing station at the camp in Jacmel, Haiti.

PHOTO: SAVE THE CHILDREN/Flickr

1 Cholera is not principally defined by behaviours, indeed behaviours are a product of poverty and inequality linked to deficits in water, sanitation and hygiene (WASH) infrastructure.

The defining factor in the elimination of cholera in the Global North and wealthier segments of the population in developing countries has been investment in water and sewage systems that keep contaminated water away from drinking water and food. Populations that rely on surface water or other unsafe water sources, and that conduct open defecation due to inadequate sanitation facilities are

at risk of infection. Nevertheless, there are short-term response activities that have succeeded in containing (yet not eliminating) cholera: water treatment (filtering, purifying, chlorinating) and hygiene promotion (e.g. washing hands) activities, particularly when coupled with provision of hygiene kits (soap, ORS and purifying tablets) and basic WASH packages.

- Acknowledgement in hygiene promotion messaging that the cause of the outbreak is inadequate water and sanitation provision, rather than breaches in personal or community hygiene, is necessary. Making sure to emphasise that water treatment and hygiene practices are still effective activities to pursue during an outbreak, alongside strengthening the WASH system.
- Hygiene promotion messaging should occur even when there are no outbreaks, so people do not associate these messages with cholera or other diarrhoeal disease outbreaks.
- To avoid cholera persistence, even when hand washing and safe water is available, basic WASH packages must be delivered during the emergency.
- Link humanitarian emergency and development programmes to ensure sustainable WASH infrastructure is in place in the long-term.

2 Vulnerability is shaped by the likelihood of being in contact with contaminated food or water: differential access to adequate WASH infrastructure is shaped by socio-economic status and social norms and practices.

Exposure to the disease is shaped primarily by poverty and marginalisation, conflict, social position and gender roles, livelihoods and occupation. These factors shape access to adequate WASH infrastructure, with internally displaced people (IDPs) and slum dwellers being particularly at risk of infection. Other factors that shape infection are the immunological naivety of the population, physical proximity to cholera patients and biological factors such as gastric acidity and O-blood type. The severity of the disease and case fatality rates (deaths amongst confirmed cases) will be shaped by the immunocompetence of the population (with higher mortality rates amongst infants, elderly and people with HIV), levels of malnutrition, the strain of the *V.cholerae* and, most importantly, people's access to health services.

- Conduct ethnographic rapid surveys that identify differences in social roles and responsibilities to assess differential vulnerabilities in terms of gender, age, class, rural/urban, etc.
- Assess how different livelihood groups and/or occupations are likely to come into contact with contaminated water or food, and the factors that shape their vulnerability: mobility, access to safe WASH facilities, physical contact with coastal or lake waters, role in conflict, norms and practices, etc. Beware that this appraisal and its communication does not contribute to stigmatising at-risk populations.
- Prioritise the WASH needs of urban slums in urban planning, including infrastructure and hygiene promotion.
- Ensure provision of basic safe water and sanitation for IDP camps.
- In the rapid assessment indicated above, identify how social difference shapes access to health services.
- Encourage decentralisation of healthcare, with the provision of rehydration therapy (Oral Rehydration Solutions (ORS) or IV fluids) at the level of the household or the community whenever possible.

3 Cholera has the potential to be highly politicised and stigmatising because of negative associations with lack of personal hygiene and 'backwardness'.

Cholera has become a symbol of 'backwardness' and its emergence represents significant reputational damage to the elites of countries boasting modernity or development. It also carries the economic risk of lost trade, travel restriction and diminished tourist revenues. Some countries have underreported cases in the past, downplayed the outbreaks or blamed cholera victims for their plight. Affected communities are more likely to be poor and marginalised, and the response must beware of the risk of stigmatising them. In the past, the responses of some African and Latin American countries focused on individualised personal behaviour change rather than on structural causes, and poor people were 'othered' as dirty or filthy. It is worth noting that even well-intentioned response workers can play a role in this stigmatisation of particular groups by earmarking specific communities. People with stigma are less likely to seek treatment for themselves or their families.

- Conduct a rapid ethnographic review to compile the different narratives by different social groups of the cholera outbreak (i.e. what caused it, what mechanisms of transmission exist and what is to be done).
- Communication messages about transmission pathways should not single out particular social groups (slum dwellers, indigenous people, pastoralists, fishermen, petty food traders, etc.) to avoid stigma and scapegoating.
- As cholera control measures can be a way of singling out the poor and marginalised, ensure prevention measures are universal and apply to all economic classes and social groups.

4 Resistance, accusations and cholera rumours often build on existing social, political and economic differences.

Communities are more likely to resist and rumours more likely to emerge if their relationships with health providers and state institutions are poor. Adversarial theories about cholera not existing in the first place or being the result of neglect or purposeful contamination of the water supply are likely to emerge, when there is longstanding distrust of State authorities. Further to this, cholera narratives of blame can also serve to pit social groups against each other. The response can mitigate this by engaging with recognised social institutions, and establish communication channels with communities via trusted informal and formal public authorities and individuals.

- Understand the historical and political dynamics at different levels (national, provincial, local), through the different institutions in charge of different elements of WASH (e.g. water authority, municipality, electricity, engineering, health services, etc.).
- Engage with trusted and credible social institutions, formal and informal leaders and trusted individuals to mediate with the response and public authorities.

5 A focus on 'cholera hotspots' can be effective, but unintended consequences require mitigation.

There is an element of predictability of cholera emergence based on weather patterns (rainfall, air and water temperature and phytoplankton levels) combined with socioeconomic and political factors (WASH infrastructure, malnutrition, conflict, marginalisation, etc.). This has allowed for the identification of 'cholera hotspots'; areas at risk of cholera (re)emergence that can be as narrow as city neighbourhoods. This allows for targeted WASH investment, hygiene promotion campaigns, and preventative vaccination. However, there is potential for mistrust and resistance both by targeted communities for being 'singled out' and potentially

blamed for conditions beyond their control. Neglect can also be felt by nearby non-hotspot communities for not receiving WASH investment which they may feel entitled to. The response will additionally need to seek information about these social reactions and engage with communities accordingly.

- Incorporate rapid social analysis of the context when carrying out narrow geographical targeting of cholera interventions to avoid stigmatisations of those who are targeted and mitigate feelings of neglect by nearby communities that are not getting the WASH investment.

6 People's movement combined with poor WASH infrastructure allow for the geographical transmission of the disease.

6 Interventions in 'cholera hotspots' should better incorporate migration and displacement of people, a key factor in the expansion of cholera epidemics. There is a need to better triangulate with other surveillance mechanisms to map out population movements in endemic and at-risk areas. There are positive experiences of retroactive modelling of cholera outbreaks using mobile phone data. Additionally, an understanding of people's usual movements (pilgrimage, economic activities and so on) is useful information that can be acquired through simple qualitative or participatory research.

- Appraise and map population movements (through participatory mapping or mobile phone technology) and incorporate this more prominently into cholera hotspot targeting when necessary.

7 Cross-border collaboration in outbreak prevention and response is crucial, particularly when countries share bodies of water.

When the disease 'retreats' in endemic settings, it can settle in bodies of water such as rivers or lakes without interacting with humans. Often these water bodies are shared by different countries, so regional/international approaches to cholera response are recommended. Cross-border collaboration is also useful to 'follow' cross-border movements of people (as above).

- Enhance cross-border collaboration in preventing and tackling outbreaks, particularly so in countries that share bodies of water (e.g. the Democratic Republic of Congo (DRC) and East Africa. Also, the internationally shared lakes and river Nile).

8 A focus on food transmission is misleading and may deflect attention from water contamination.

Focusing on food contamination and its role in the epidemics may eclipse the fact that the main culprit is water and that seeking safe water and handwashing are the priority. In several outbreaks, street food vendors and fisherfolk have been scapegoated by the authorities. The banning of street food markets or sale and consumption of seafood can be counterproductive, and can generate resistance. Further to this, banning particular food stuffs can serve to stigmatise those social groups who are associated with their consumption (e.g. Warao indigenous people in Venezuela are associated with crab consumption). Whilst the implementation of basic food safety procedures is important, transmission of cholera via contaminated food should be put into perspective vis-à-vis other forms of transmission.

- Avoid banning the sale and consumption of seafood or other food items. Instead, advise consumers to follow hygiene procedures and cook food adequately.

- Instead of banning street food vending, engage with street vendors and roll out training on basic food safety procedures.
- Ensure communication campaigns do not focus unduly on food, but also on water quality and the importance of good hygiene practices and water treatment.

9 Hygiene promotion messaging can build on notions of 'dirt' and pollution as a form of transmission.

People are more likely to react to perceived visual risks (e.g. soiled waters, flies, dirt, etc.). These ideas of dirt and contamination are often used by WASH and cholera programmes to trigger emotional responses to promote hygiene practices and other forms of social mobilisation (e.g. community clearing of drainage, use of latrines, etc.). Messaging that highlights positive factors rather than condemning negative behaviours is most successful, particularly when it conveys a feeling of control. Hygiene promotion exercises are most successful when community leaders and health promoters participate: demonstrating, in person, how they use tablets, and drink purified water.

- Work with local understandings of hygiene, building on ideas of dirt and pollution to shape hygiene messaging.
- Use positive messages that convey a feeling of control, appealing to visual and emotional triggers.
- Work with community leaders and trusted individuals to mobilise the population in hygiene prevention measures and to demonstrate, in person, how they are participating in the changed behaviours (e.g. drinking purified water in workshops).

10 Alternative causal explanations of cholera are uncommon, and do not preclude biomedical care seeking or treatment.

Across several contexts, biomedical explanations of cholera diarrhoea and transmission have been found to be dominant in surveyed populations, with people identifying WASH-related factors and ingestion of contaminated water or food as the cause. Less frequently, non-natural narratives do coexist, with explanations of the outbreak being God's will, due to soil-eating, or caused by witchcraft or sorcery. Even if a non-natural explanation is articulated, recourse to clinical treatment and demanding vaccination is expressed in the majority of cases (although this may be complicated in some socio-political contexts, see point number 4. above, though here we separate conspiracy from other non-biomedical explanations).

- The response need not focus on countering alternative causal explanations, but rather emphasise the importance of rehydration and accessing services at health facilities as early as possible.

11 Cholera vaccination campaigns have a high acceptance rate, yet they require explanations about effectiveness and side-effects.

Oral cholera vaccines have high levels of acceptance across different contexts. Even if there are discrepancies in the causal explanations of cholera, this does not preclude those people seeking vaccination. Less than 100 per cent effectiveness is common amongst vaccines, and requires adequate explanation to the population, as they may witness first-hand people who are vaccinated but do get cholera, therefore this may lead people to mistrust the vaccine. Similarly, potential side effects need to be explained (e.g. vomiting, nausea), as witnessing people with negative side effects has allowed for stories of the vaccine causing the disease

to take hold in particular contexts. Those negatively affected by the cholera response on a social level (e.g. fishermen) were less likely to seek vaccination. Type of preferred provision will vary according to social factors (IDP or host, pastoralist or settled, and so on).

- Assess the populations' previous historical experience with vaccination, and clearly explain the side effects and efficacy rates. Tailor messaging to people affected by cholera stigma (e.g. fishermen) as they may have added reservations about the vaccine.
- Use knowledge, attitude and practices (KAP) survey to assess people's attitudes to the vaccine and different social groups' preferences in delivery (door-to-door, mobile clinics, centres, etc.). Use transboundary vaccination and link to other service provision (e.g. animal vaccination in the case of pastoralists) when appropriate.

12 Understanding the local typologies of diarrhoea and dehydration is helpful to understand health-seeking behaviours.

In many contexts (particularly those in which cholera is endemic), lay people have an understanding of the different types of diarrhoea (including cholera diarrhoea), and will react differently depending on the diarrhoea type, with different perceptions of risk or urgency, therefore seeking treatment from different providers. A complementary approach will be to identify how different social groups identify and describe dehydration symptoms and the causes they attribute to them. Identifying these 'local typologies' of diarrhoea and dehydration will help ORS promotion programmes. This knowledge can be achieved by means of a rapid ethnographic assessment.

- Define in each context the different taxonomies of diarrhoea and dehydration, how they relate to different models of health/disease, patterns of health-seeking and specific treatments.
- Use the local word for 'cholera' within messaging in an epidemic. If Acute Watery Diarrhoea is to be used, then it is important to convey the urgency of outbreak.

13 Cholera deaths are shaped by physical and economic access to health services.

The importance of access to quality healthcare is crucial to respond to cholera outbreaks. Once infected, a person is much more likely to die if they do not have access to adequate treatment (namely rehydration therapy and antibiotics). In many cases, the problem is the lack of provision in remote areas, poor transport infrastructure and conflict, with people dying before reaching the clinic. Access to biomedical clinics may be shaped by economic costs. Whilst often treatment is free in the cholera response, families factor in indirect costs (transport, accommodation for accompanying family members, lost revenue from work, etc.), which may be prohibitive. On occasion, rumours may spread that care has to be paid for. In specific contexts, decision-making mechanisms in the family (i.e. who needs to be consulted and who makes the decision of seeking treatment) may delay treatment seeking.

- Incorporate decentralised provision of care to households and communities, communicating where treatment is available, and emphasising that treatment is of a high standard and free. Ensure referral to health facilities occurs swiftly when patients are severely dehydrated.
- Identify and understand if there are any social (e.g. gender, age) factors that determine household and community health-seeking practices (in general and in the context of cholera) and address through messaging and community engagement.

14 There are often multiple health providers, who can be allies in the response.

Therapeutic options can range from home-remedies, herbalists, traditional health systems, private and public biomedical clinics, community health workers and drug sellers. These therapeutic options often coexist. People will resort to these different providers depending on the kind of diarrhoea and other symptomatology that they see, and the causal explanation that they attribute to it. Urban dwellers are more likely to seek treatment in biomedical centres than rural people, although that may vary across context.

- Identify and work with alternative health providers, helping them identify the symptoms of cholera, and work with them to refer severe cases to hospitals or cholera treatment centres, treating mild and moderate cases with ORS.

15 Rehydration therapy (oral and intravenous) is highly accepted, and on occasion it can be adapted to cures in traditional medicine.

Household ORS provision used for both prevention and during a cholera response have been very successful in treating mild and moderate cases of cholera. A majority of people across different contexts identify ORS and IV rehydration as the most adequate treatment for cholera. There are multiple experiences of alternative health providers incorporating ORS (purchased or homemade) into their work, and adapting traditional remedies (e.g. boiled roots in Mozambique) to incorporate rehydration properties.

- Provide ORS to households by trusted community workers.
- Work with alternative health providers to treat mild and moderate cases with purchased or homemade ORS.
- Refer severe cases to clinics, hospitals or specialised cholera units for IV rehydration therapy.

16 The decentralisation of care is well received and increases access, yet 'white tents' can lead to mistrust and suspicion.

Decentralised provision of care has been largely successful, although in some cases, the reach has varied regionally, and some people have still had problems accessing these treatment centres. People may have, however, an ambivalent feeling towards these decentralised health posts. They are satisfied to have easier access, but they may question if health staff are skilled enough, for example, to provide intravenous fluids and to prevent cholera infection between patients.

Cholera treatment units and centres can be a potent symbol of the response, and when there is community resistance, attacks can be directed at these premises, as was the case in Haiti or Mozambique. Similarly, in particular contexts, these treatment units can play a role in symbolically 'othering' the victims of cholera and contribute to their marginalisation.

- Ensure health volunteers are appropriately trained and then communicating this via messaging: explaining where treatment can be sought, and providing assurance of staff capabilities and available stocks of rehydration therapy solutions.
- Decentralise treatment to the household as much as possible in sensitive contexts, avoiding high visibility 'cholera tents' if necessary. Before setting up treatment centres, engage in dialogue with communities. When tracking transmission, prioritise private, face-to-face interactions.

17 Burial and funeral practices can be adapted in collaboration with communities to be safe whilst maintaining the symbolic and emotional elements.

Bodily fluids coming from the body of a deceased person with cholera are infectious. In public health terms this requires the disinfection of the body, and the safe disposal of the body in a site not connected to an aquifer. These objectives can contrast with needs of the mourners and communities, who may wish to wash the body and to follow customary funeral rites. There are positive experiences of the latter being adapted (e.g. family members washing the body with disinfectant and gloves with the ceremony led by the Imam) so they maintain their significance. Funeral feasts can lead to transmission if there are not appropriate hygiene measures in place for the provision of water, and the preparation and consumption of food.

- Engage with communities to seek burial sites that do not contaminate aquifers or other water sources.
- Work with community and faith leaders to incorporate public health activities (e.g. disinfection of the body with gloves) into rituals whilst maintaining their cultural and emotional significance.
- Work with key organisers of funeral feasts to ensure handwashing, with the provision of hygiene kits if necessary. Ensure those who wash bodies do not prepare food.

About

The Social Science in Humanitarian Action Platform (SSHAP) aims to establish networks of social scientists with regional and subject expertise to rapidly provide insight, analysis and advice, tailored to demand and in accessible forms, to better design and implement emergency responses. SSHAP is a partnership between the Institute of Development Studies (IDS), the London School of Hygiene and Tropical Medicine (LSHTM), Anthrologica and UNICEF Communication for Development (C4D).



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